

AN ETHNOGRAPHIC STUDY OF A CARE CENTRE FOR HIV-POSITIVE PATIENTS

By

LAUREN MICHELLE HINCKLEY

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SUPERVISOR: PROF S HERSELMAN

CO-SUPERVISOR: PROF M DE JONGH

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SUMMARY

This ethnography was undertaken in an AIDS hospice with the objective of understanding the functioning of the Centre holistically, including the experiences of the patients and the role of the Centre in the fight against HIV/AIDS. Organisational anthropology in a clinical setting involved gaining entry and rapport with the staff and patients. The methodology included interviewing and observation. The personnel structure and leadership of the Centre were explored, revealing communication, power and management relations that shape the organisational culture. The staff's attitude towards their jobs and their commitment to assisting those suffering from AIDS revealed the underpinnings of the organisation. The care that patients receive at the Centre was examined along with adoption of the children and the effects of stigmatisation surrounding HIV/AIDS and its impact on patients and their families. The meaning of illness for patients and their sick role as well as the impact of death from HIV/AIDS are exposed.

KEY TERMS

Care centre, HIV/AIDS, anthropology of organisations, ethnography of organisations, organisational culture, stigmatisation, meaning of illness, counselling, outreach programme, antiretroviral treatment.

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I declare that 'An ethnographic study of a care centre for HIV-positive patients' is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Lauren Hinckley

Date

1. INTRODUCTION

1.1 The problem

HIV AND AIDS is a global phenomenon rapidly killing people without discrimination in terms of race, sexual preference, age or socio-economic background. Fairly recently HIV AND AIDS was perceived to be an exotic disease in far-away places, now many people have first-hand experience of AIDS or they know someone with HIV AND AIDS. When HIV AND AIDS was first identified there seemed to be a slow response to and lack of prevention education concerning this disease, since HIV AND AIDS was associated with stigmatised groups i.e. homosexuals, drug addicts and prostitutes, and seen as 'unnatural' and self-inflicted, but it cost many lives, particularly amongst the poor (Perrow & Guillen 1990:6). It supposedly did not affect the affluent, hence the slow response. In 1989, 91% of HIV AND AIDS patients worldwide were either male homosexual or male drug users and almost all were economically active. Sixty percent of the HIV AND AIDS carriers in sub-Saharan Africa are women (Joint United Nations Programme on HIV AND AIDS 2008:33). Currently, HIV AND AIDS affects mainly heterosexual people and is known to be more easily transmitted from male to female, placing women at a disadvantage and in a vulnerable position with their life-spans being shortened by the advent of HIV AND AIDS. A recent Joint United Nations Programme on HIV AND AIDS (2008:175) indicated that 11.5% of the health careworkers in the public sector in South Africa and 14% of the nurses were HIV-positive, creating dire circumstances for the industry and for those requiring care.

The United Nations listed lack of education about HIV AND AIDS as the leading cause for its spread, causing uneven distribution in its incidence and making many poorer communities, such as those living in informal settlements and without proper access to education, more vulnerable

to HIV AND AIDS. Disturbingly, according to the Gauteng Department of Health less than 2% of people in South Africa know their HIV status and most do not make any attempt to discover it (Joint United Nations Programme on HIV AND AIDS 2008:36-47). Some misconceptions about the methods of HIV AND AIDS transmission still exist in Africa, for instance, sharing clothes, seats, combs, toilets, kissing, sharing bath water and mosquito bites (Allen 2007:368).

In 2007, 33 million people were living with HIV AND AIDS worldwide and 2 million people died from HIV AND AIDS-related conditions. Sub-Saharan Africa accounts for 67% of all people infected with HIV AND AIDS and for 75% of HIV AND AIDS deaths during 2007. In South Africa specifically, over 15% of the population was living with HIV AND AIDS in 2007 (Joint United Nations Programme on HIV AND AIDS 2008:39), more than half of whom were women. More than 340 000 people died from HIV AND AIDS in that year. It is however, difficult to ascertain the exact number of HIV AND AIDS-related deaths since these deaths are seldom documented as HIV AND AIDS but rather as the consequences of secondary infections. South Africa has the largest population of people living with HIV AND AIDS in the world. From 1997 to 2005, deaths tripled for women between the ages of twenty and thirty-nine while deaths for men from thirty to forty-four years of age have more than doubled, with at least forty percent of these deaths being attributable to AIDS. In 2008 only forty-five thousand people were receiving antiretroviral drugs. During the same year approximately 30% of pregnant women using public clinics were diagnosed as HIV-positive (Joint United Nations Programme on HIV AND AIDS 2008:30-45). Based on HIV AND AIDS statistics, life expectancy in South Africa has dropped below fifty years of age (Das & Poole 2004:144). Worldwide the 15-24 year-old population group is the most affected, accounting for an estimated 45% of all new HIV AND AIDS infections worldwide, with devastating consequences for the economy of a country (Joint United Nations Programme on HIV AND AIDS 2008:32-33).

However, positive trends started to emerge in 2007 with the decrease in the number of 15 – 19 year olds having become sexually active before their 15th birthday, and the decrease in the frequency with which members of this group have more than one sexual partner. An increase in condom usage among this group has also been reported, suggesting a possible trend towards less risky sexual behaviour. In the absence of treatment, i.e. antiretroviral drugs, the average survival time for someone with HIV AND AIDS is 11 years (Joint United Nations Programme on HIV AND AIDS 2008:30–45, 170).

The real tragedy of HIV AND AIDS is the estimated 2.9 million HIV-positive children, under 15 years of age, who live in sub-Saharan Africa, and approximately 12 million children who have lost either one or both parents to HIV AND AIDS, one million of whom are in South Africa (Joint United Nations Programme on HIV AND AIDS 2008:163). Ninety percent of children with HIV AND AIDS contracted the virus from their mothers. This number of orphans has increased by more than 50% in the last 20 years in Africa due to the elevated death toll of parents from AIDS-related conditions. Children who are orphaned by AIDS are normally younger than those orphaned by any other cause because mothers are mostly young women. They become ravaged quickly by the disease while pregnant and giving birth, and if they die their children are much more vulnerable and susceptible to emotional problems and exploitation than other children. AIDS orphans from low-income groups are more vulnerable to the consequences of poverty because the community is less able to support them because of already strained budgets. If the current trend continues, there will be an estimated 14 million AIDS orphans in Sub-Saharan Africa by 2015. HIV AND AIDS increases the economic and emotional burden on poor households which in turn, creates inequality in societies which may result in members of such households being increasingly vulnerable to HIV AND AIDS. HIV AND AIDS causes a decline in household income which places further strain on it. A further implication is the

additional expense that accompanies HIV infection such as transport costs to clinics to collect treatment, extra fruit and vegetables for a balanced diet, and funeral costs after the death of those infected with HIV AND AIDS (Joint United Nations Programme on HIV AND AIDS 2008:162, 170).

In South Africa approximately 67% of children who are HIV-positive as well as children who have lost parents to HIV AND AIDS are supported financially by either state-funded programmes or by NGOs (Non-government organisations), leaving an estimated 33% of such children unaided (Joint United Nations Programme on HIV AND AIDS 2008:164-168). Some of them, if known to the Department of Social Welfare, are supported by private institutions but the rest are unassisted. My study aims to understand the situation of both adults and children afflicted with HIV and AIDS and more specifically those that are confined to an institution caring for those living with HIV and AIDS. The circumstances that led to them being infected with HIV and AIDS as well as their beliefs, needs and behaviour within the institution is the central focus of my study.

Currently the number of AIDS orphans in South Africa account for more than one orphan per two economically active women and countrywide, 67% of households include at least one child orphaned by HIV AND AIDS. According to Joint United Nations Programme on HIV AND AIDS 2008, women are the care givers to two thirds of HIV patients in Africa, increasing their household and community responsibilities (Joint United Nations Programme on HIV AND AIDS 2008:168). Zelda is the Department of Social Welfare's representative at the Centre where this study was focused, and she ensures that the children with HIV AND AIDS who are placed at the Centre receive the best possible treatment and care. According to Zelda, children of mothers with HIV AND AIDS are often split between careworkers when the mother dies. In the past the vast majority of AIDS orphans were cared for by extended families but this is no longer the case

and according to the Department of Social Welfare, the majority of children orphaned by HIV AND AIDS are no longer cared for by extended families but rather by the state or NGOs. 'Mixed households' are those where orphans and non-orphans live together. They too are increasing in number.

This situation poses a number of challenges, especially for the orphans (Joint United Nations Programme on HIV AND AIDS 2008:166). According to Zelda, orphans are generally unhappy due to the discrimination, isolation, neglect and lack of care and attention given to their health problems. She also noted that some of these children are perceived as a burden and may be physically beaten and even exploited by their careworkers such as by forcing them to work at very young ages. In most of the cases where Zelda has been involved, she noticed that the biological children of the parents are given preference over the orphans, who come from the extended family, due to financial constraints and this has a physical and emotional toll on the children, resulting in them being very quiet and careful. Unfortunately within these poor communities, the community networks are strained to the limit with having to care for growing numbers of HIV AND AIDS orphans. Social workers attempt to monitor such situations if they are aware of the orphans and if there are adequate numbers of social workers to carry out home visits, but unfortunately this is often not the case in South Africa due to the large numbers of AIDS orphans and the limited numbers of social workers (Joint United Nations Programme on HIV AND AIDS 2008:164, 166, 168, 177).

Ideally, orphans should be cared for by someone of the same generation as their parents because they need someone to whom they can relate and with whom they are comfortable. Yet most orphans receive care from female family members, usually older sisters who give up school and find jobs to care for younger siblings, or from grandmothers. Siblings are forced to take on responsibilities far beyond those they should be required to. Many say that they must

keep their situation a secret, which in turn affects them negatively by isolating them from their friends and support systems (Macklin 1989:103; Joint United Nations Programme on HIV AND AIDS 2008:164).

Due to a lack of resources, namely school fees and uniforms and parental supervision to ensure school attendance, the fact that AIDS orphans are singled out because of their lack of parents and resources, and the stigma attached to HIV AND AIDS, AIDS orphans have a lower rate of school attendance than HIV-negative children and children from households not affected by HIV AND AIDS. In 2007 in South Africa, orphans were found, on average, to be 12% less likely to attend school than non-orphans (Joint United Nations Programme on HIV AND AIDS 2008:166). Girls are more likely than boys to leave school and assume burdens such as becoming the household head. This reduces their chances of employment after school and a reduction in the human resources for future growth of the country, consequently perpetuating a cycle of poverty. When parents take antiretroviral drugs, it has a positive effect on their children in that they are able to work and the children have more time to be at school since they do not have to look after ailing parents and perform household chores. The improved access to anti-retroviral drugs increases the life spans of users, creating the effect of fewer young children being orphaned due to HIV AND AIDS. This means that such children could have grown to be adults when their parents eventually die from HIV AND AIDS (Joint United Nations Programme on HIV AND AIDS 2008:163, 164, 166, 167-168).

Many babies with HIV AND AIDS remain in hospital after their births because their families cannot afford to care for them since caring for these babies is costly and emotionally demanding. Consequently, they are forced to find sanctuary in organisations and institutions that care for those with HIV AND AIDS (Macklin 1989:103-104).

The large numbers of people afflicted with HIV AND AIDS and orphaned children will thus have to be cared for. If families cannot cope, sufferers and victims must find sanctuary in organisations and institutions. This has already happened and the question arises, how organisations deal with large numbers of patients suffering from what amounts to an incurable disease.

Furthermore, what type of organisation caters for such patients? Who is involved in it and why? How is it positioned within the broader social context? What are its norms and values, or its culture, and how does its culture influence its performance and pursuance of its purpose of caring for HIV AND AIDS sufferers? Answers to these and similar questions will be sought in this study.

1.2. Rationale and aims of the study

The rationale for this study included the fact that HIV AND AIDS is a contemporary epidemic and as far as could be determined, there appears to be a lack of research on institutions that deal with HIV AND AIDS sufferers and their experiences, specifically from an anthropological perspective. I wished to expose the difficult circumstances in which an institution operates and the way in which it overcomes daily challenges in caring for its patients. My prior knowledge of the care Centre that was selected for this study also generated the desire to honour the founder and staff for their dedication and tireless work, and for achieving the mission of the Centre.

This ethnographic study is intended to examine all aspects of a care Centre dealing with HIV-positive patients. The need to investigate the complicated care required by hospitalised HIV-positive patients, the emotional toll that staff experience, the impact of the death of a patient on other patients, staff and family members and their reaction to a death, as well as the vital role that an organisation such as this has in the contemporary South African situation, all contributed

to the decision to embark on this project. As far as the patients are concerned, it was also deemed important to determine their views on the multiple factors affecting HIV AND AIDS sufferers, such as stigmatisation, fear of contagion and status change of patients from healthy to sick, as well as the meanings they attached to the disease and to include them in this holistic study.

The objectives of this study made it necessary to identify a health care centre that cares for HIV AND AIDS patients and where I could undertake the proposed ethnographic research. Against this background, the main aims of my research are firstly, to holistically explore the nature and functioning of an AIDS hospice caring for patients in the last stages of the disease, as well as assisting patients in earlier stages with treatment to enable them to regain their health to function outside the Centre. I will focus on the patients and their position as HIV AND AIDS patients in the Centre. Secondly, this study aims to investigate the importance of the concept of organisational culture in relation to the Centre, the relationships of power between people in authority and how the Centre's value system contributes to its role of providing care for HIV-positive patients.

1.3. The anthropological study of organisations

1.3.1 History of organisational anthropology

Organisational anthropology originated in the 1930s, but until fairly recently (after the 1960s) minimal research was done in companies and where it was done, it focused on organisational behaviour via studying the goals of managers, specifically in large companies. From 1924 to 1933 Chicago was the site of one of the most famous human relations studies. It involved a number of organisations, notably Western Electric, the National Academy of Sciences and the Harvard School of Business Administration. The study was conducted at Western Electric's Hawthorne Works and involved the first qualitative examination of the informal social

organisation within a workplace. The Hawthorne studies helped to establish the notion of organisational behaviour and this fostered the understanding that human relations could be used to comprehend organisations and worker productivity, resulting in the creation of industrial anthropology. Lloyd Warner helped teams to apply anthropological fieldwork methods, such as direct observation, to the workplace; he proposed perceiving each workplace as a small society possessing an inter-connected social system. The 'observer' attempted to be unobtrusive while the interviewer was seen as an 'outsider' aiming to understand the informal aspects of the workplace as opposed to only studying its formal aspects. After this, few anthropological studies were conducted in organisations, although organisational research was revived during the Second World War (Jordan 2003:9–13; Wright 1994:5–7).

During the 1940s anthropologists trained by the Harvard and Chicago groups conducted various studies using functionalism as the key paradigm. Gardner, Warner and Henry formed Social Research Incorporated which was the first management consultancy run by anthropologists and to use anthropological methods to assess and mitigate organisational problems. The predominant data gathering method used during this era was by means of case studies (Bate 1997:1-2; Jordan 2003:9–13).

During the 1960s studies included the role of the organisation's value system in its success or failure, and later also the importance of culture in organisations and the relationship between culture and power. The term 'organisational culture' was first used in the 1960s as a 'catch all' phrase for describing the 'climate' at work. An organisational culture distinguishes members of one organisation from the members of another. The term 'corporate culture' followed in the 1970s to describe all elements that affect the behaviour of people at work (Bate 1997:1-2; Jordan 2003:9–13).

In the 1980s the concept of 'corporate culture' was initially accepted, even though it was associated with management, after which 'organisational culture' became popular since this was associated more with the employees, advancing the idea that an organisation's success is based on the shared ways members think about, feel about and act on issues. Many anthropologists became involved in addressing issues of how to improve work processes and make the workplace more efficient and effective. The client's interest centred mainly on methodology. This was especially crucial during corporate mergers and the introduction of large numbers of new staff. It has eventually become important to understand what people experience at work and the symbolism of everyday experiences at work. The various fields that anthropologists worked in ranged from international business consulting to inter-cultural training, in-house research and consulting on market and consumer behaviour (Bate 1997:1-2; Jordan 2003:16–19).

1.3.2 Defining the organisation and the notions of culture and organisational culture

An organisation is a group of people who are intentionally grouped to accomplish an overall, common goal or multiple goals (Hawkins 1988:351). These goals might be implicit, i.e. unrecognised, or explicit, i.e. overt. Organisations range in size, type and purpose, with some operating to amass profits while others, such as non-governmental organisations, operate on a non-profit basis. An organisation can be seen as an organic whole that controls employees' performance. An organisation operates in the context of a specific environment from which it cannot be isolated.

Organisations are essentially social systems that control the way in which staff interact with each other and with stakeholders outside the organisation. Differentiation must be drawn between the formal aspects of the organisation, i.e. tasks which have to be accomplished for the organisation to function, and informal elements that involve relationships between staff

members, gossiping and interpersonal tensions amongst others. An organisation is influenced by internal and external pressures, and involves inputs, processes, outputs and outcomes that are linked together to accomplish an overall goal (Anthony 1994:28–32; 37; Jordan 2003:45–52, 86-88; Wright 1994:17).

Exploring the policies of an organisation facilitates understanding of the type of organisation it is because policies assign meaning to much of the organisation's job-related behaviour displayed by staff. Familiarity with staff roles and purposes aids in understanding the reasons for the staff's behaviour and the beliefs behind such behaviours. Understanding the structure of the organisation leads to insights into the beliefs and practices of the key role players. The social roles of people in an organisation are defined by the organisation. The roles determine with whom people associate within the organisation. Examining the organisation as a social community and exploring how it is related to the larger community are important to understand its specific nature (Wright 1994:17; Jordan 2003:21–22).

Culture, in the conventional anthropological sense, can be defined in various ways, but the most useful definition, as is most appropriate for my study, is the Boasian version, namely, that culture is a system of shared knowledge, beliefs, values, customs, behaviours and artefacts that the members of society accept, usually without thinking about them, and use to cope with their world and with one another, and which are transmitted from generation to generation through learning, communication and imitation (Anthony 1994:28–32). Culture provides stable relationships between people, based on assumptions and agreements about values and meanings. Culture is the medium which helps members of a particular society to make sense of their world. Culture involves patterns of economic and social cooperation and networks of interdependence and reciprocity. It involves communication of myths, stories and symbols such as group skills, knowledge, attitudes, values and even motives from one member to another.

The meaning of the symbols are learnt and deliberately transmitted to each member of the group (Anthony 1994:28–29; Jordan 2003:40-48).

Culture is influenced by historical factors and is constantly contested and remade with the power struggles that exist within groups (De Jongh 2007:83). Culture as a concept will be used to interrogate why the people at the Centre where this study took place employ certain behaviour in particular situations (cf. De Jongh 2007:82). The key for anthropologists now is to strike a balance between reporting with sweeping universality and being too narrowly particularistic (Knauff 2006:420). Furthermore, contemporary ethnography must seek to incorporate historical influences with more temporality than previously.

Recent debates in anthropology suggest that culture as a concept should no longer be utilised in the discipline, based on four key objections. The first objection is that culture is a concept that divides groups and makes them different from each other, rather than having a unifying effect. The second objection involves the political use of the concept of culture, i.e. that culture can be used to promote the interests of a particular group to discriminate against others and encourage the 'us' versus 'them' attitude. In situations where there is advocacy on behalf of local people this could cause the people to be misrepresented and their rights and interests to be compromised (Borofsky et al. 2001:438, Knauff 2006:414). A further objection is that culture focuses on identifying the differences between groups yet there are differences within groups that may be overlooked, creating the illusion that cultural groups are homogenous and that meaning within these groups is not constantly renegotiated. The final critique is that culture as a concept is vague and general and is used to explain wide-ranging issues, not necessarily what anthropologists define as culture (Borofsky et al. 2001:432). This universalisation of culture is increasingly being criticised and there is a move towards research regarding specific agencies and NGOs including medical institutions as a means of explaining the relationships internally

that are influenced by external forces, but at the same time, acknowledging the uniqueness of the culture existing within such institutions. What precisely is constituted by a culture is increasingly seen as problematic because culture can be concrete and diffuse, local and global. Despite these objections, when used more precisely, culture remains a valuable anthropological conceptual tool of analysis (Borofsky 2001:434) and is meaningful for my study which seeks to understand the beliefs and behaviours of a group of staff and patients in a clinical setting.

Organisational culture is the 'personality' of the organisation and is comprised of assumptions, shared values, norms and tangible signs or artefacts of organisation members and their behaviours. It involves the same elements comprising culture in the conventional anthropological sense, e.g. expectations for member behaviour, technology, customs, rituals, stories, myths, jargon and symbols, and shared behaviours to which are attached specific group-sanctioned meanings. According to Anthony (1994:28), culture is something that an organisation is, i.e. it is embedded in the organisation. Organisational culture embraces formal aspects such as hierarchy, goals, policies, communication, finances, vision and mission statements, and informal aspects, which have the most meaning attached to them, such as friendship networks, issues of diversity and the ways in which individuals and groups interact (Wright 1994:17). In addition, organisational culture has components that mirror universal cultural components, for example, economic systems in organisations include reward systems, and organisational artefacts can be seen as art. These similarities make investigating organisational culture easier.

Organisational culture is based on traditions that are passed to new employees by current employees as the correct way to perceive, think and behave within it. Like culture in the conventional sense, organisational culture is not static and is constantly re-negotiated. Accordingly in the Centre culture is constantly changing, requiring members to adapt to change,

solve problems emerging from the need for external adaptation, and to ensure internal integration (cf. Schein 1993:373-374). Some organisational cultures are linked to the organisation's founders and grew from the company's history (Anthony 1994:37), which as will be shown, is the case with the Centre, while others emerged over time in reaction to the need to adapt to internal and external forces (Jordan 2003:45; Wright 1994:17).

Organisational culture defines the boundaries, structure and purpose of the organisation and acts as an instrument that ensures that interaction and meaning do not have to be interpreted on every occasion (Anthony 1994:32). Organisations may even create training programmes or induction processes to transmit this culture overtly to employees seeing that, unlike conventional culture into which one is enculturated from birth, this culture is obtained through secondary enculturation (Jordan 2003:45). Organisational culture is an invisible but powerful force driving the organisation. It cannot be created or imposed but can be guided, shaped and adjusted to benefit the members as it evolves over time. Organisational culture enables employees to achieve their personal goals while simultaneously attaining the organisation's objectives (Anthony 1994:18). Shared values and norms, appreciation, job security and other factors play a role in whether employees identify with, accept or reject the organisation's culture. All organisations are unique and therefore practices and policies that are successful in one organisation may not be successful in another (Anthony 1994:28–32; 37; Jordan 2003:45–52).

1.3.3 The ethnography of organisations: approaches to and methods used in organisational anthropology and the role of the anthropologist

Anthropologists, as 'outsiders', are well-suited to studying organisations, employing specific tools and techniques to make their cultures 'visible'. Anthropologists work in organisations to comprehend cultural groupings because organisations consist of multiple, complex and special-interest groups. An action-orientated approach in terms of getting involved in the human

experience of patients at the Centre, is fundamental to ethnographic studies in the field and will be used for my study. Anthropologists employ multivocality; they ensure that the voices of the informants are represented to avoid the pitfall of misrepresentation of the informants that may occur when the researcher examines a culture other than his/her own. It is easy to consider one's own culture as 'natural' (Jordan 2003:50). Another crucial consideration is the ethicality of the research and ensuring that the informants are 'heard' and not harmed or manipulated by the researcher or managers commissioning the study. Anonymity of the informants needs to be ensured and in some cases the anonymity of the organisation must be maintained to ensure it is not easily identified since the privacy of the informants is a priority and informants may be identified if the organisation is identified (Jordan 2003:54–61). In this study the voices of patients, staff and external influencers will be considered to ensure that everyone is fairly represented and that the true issues are uncovered. The research question will be reflexive to allow challenges, concerns and themes emerging from the research to be accommodated and explored.

Anthropologists in organisations are often problem-solvers since they understand that there is a shared value system that underpins the organisational culture. They also investigate the structure, policies, processes, changes, and decision-making by authorities by using anthropological methods. Observation, interviews, questionnaires, documentary analysis, analysing communication and spatial dimensions etc. are all procedures that help the anthropologist to gain understanding of employees' attitudes towards their colleagues and the organisation. Observation helps to place data received from respondents in context (Jordan 2003:20–37). Anthropologists see the holistic view by placing actions and beliefs in context, by establishing patterns in individual components and by critically analysing what is often taken for granted (Jordan 2003:20–37).

Anthropologists investigate organisational issues that may be apparent or obscured in order to understand and respect the perspectives of all employees in the organisation. To understand meaning, anthropologists holistically consider both internal and external influences on the culture of the organisation e.g. the economic, political and social contexts. They examine verbal and non-verbal communication, and the distribution of power (Hamada 1999:1-3). The historical context of the country and the influence of the history of the disease on the organisation are considered to ensure that the organisation is studied in context and not as an isolated unit. Qualitative methods, such as interviewing, uncover issues that the employees identify as important, with employees defining the problem, rather than the anthropologist assuming what the problems are. Anthropologists notice symbols such as logos, layout of furniture, how people are dressed, types of food staff eat, and even the pictures on the office walls since each element indicates something about the organisational culture.

Anthropologists critically question assumptions about the beliefs and behaviour of informants using ethnographic fieldwork. Consequently, what is usually taken for granted by members of the organisation is questioned by anthropologists to understand this 'micro society' and to explain the culture from the members' or insiders' point of view. The 'insider perspective' required of the anthropologist can be achieved when the researcher and the organisation's members become comfortable with each other. Trust is gained when the researcher shows interest in the respondents' lives and their perspectives, and also shows respect for them and their opinions. Evaluating the organisational culture from a variety of perspectives and understanding the meanings attached to various beliefs and behaviours within the organisation require detachment from one's own culture. Some elements of organisational culture can be observed while others must be explored in interviews with staff (Anthony 1994:28–32; Jordan 2003:20–37, 46-50; Wright 1994:23).

Anthropologists focus on the organisation as a whole, considering the link between the individual and the wider group in order to make sense of the sociocultural context. A pattern of linkages, which can be obtained by studying the relationships and interactions between groups and individuals, could be used to explain behaviour in the organisation. Anthropologists consider work activities and leisure activities among staff members which are advocated by the organisation to fully grasp how they influence the culture within the organisation.

Comprehending the social structure of the organisation, i.e. the roles and relationships between people, is the foundation for understanding how the organisation actually functions and why people identify with and are satisfied with it (Anthony 1994:28–32; Bate 1997:5-6, Jordan 2003:5–7, 84–88).

When conducting ethnographic research in an organisation, one should start with flexible research questions and methods to grasp processes of the organisation, i.e. the functions, roles and reasons for behaviour styles. Research is done by studying the staff with little stature and authority before researching the management, thus getting to know the political climate, tensions and personal biases in the organisation in order to know which questions to ask management and thus elicit valuable information. The lower level employees often contribute more about the organisation (personal and professional information), whereas managers are usually more guarded in their responses to questions (Bate 1997:5-8; Jordan 2003:20–38).

A constant presence to observe relevant incidents and behaviour and attend meetings wherever possible, is needed to fully understand the organisation and the way in which each player fits into it. Semi-structured and unstructured interviews may be more viable as research instruments than structured interviews since the latter may be postponed and interrupted due to emergencies and heavy workloads. Information such as varying frames of reference is gleaned from ordinary employees and management and through observation, and conclusions.

Generalisations can be drawn from this data, from which patterns pertinent to the organisation can be identified (Bate 1997:9-10).

2. RESEARCH METHODOLOGY

2.1 Introductory remarks

My research design centred on the fundamental elements of an ethnographic study.

Ethnography is both a field method used to study people's ways of life and is also a method of writing about and documenting such ways of life. Interviewing was used as a fundamental technique to gain information, and included in-depth interviewing and informal interviewing which occurred during observation, where staff and patients were questioned about organisational practices, amongst other matters. Data collected from in-depth interviews with patients, outpatients and staff were subjected to content analysis in order to identify themes and patterns relating to the experiences of patients and their health beliefs, the relationships between staff and patients, and the meanings of and explanations for HIV AND AIDS. Pertinent information was obtained through interviews with patients and authorities at the Centre such as the Matron, Sister Claretta; the Director of the Centre, Tilly; Father Stan, the Founder, the Psychologist, Social Worker, and the nursing staff. Each participant offered particular insights into the Centre's operations and missions, as well as the plight of the AIDS patients and the available options to help patients and outpatients. Tilly had expert knowledge of running institutions because she had been a director of Child Welfare, while Father Stan had conducted extensive research on HIV AND AIDS prior to establishing the Centre. I used observation to focus on tensions, alliances and other unspoken phenomena within the Centre (discussion to follow, see 2.7). The flexibility of ethnographic research is one of its key strengths and allows one to adapt one's strategies as the research progresses (De Villiers 1995:22).

In a clinical setting, one has access to patients and their family members and often their communities which helps to place the patient's situation in the proper context, making understanding their beliefs and behaviour easier. Nurses provide information about the patients'

conditions, their backgrounds, their health beliefs and the treatment being used. Employees provide information on their work conditions, tensions, alliances and their home life.

Before the actual selection of informants, the nature and purpose of the research as well as how the data would be utilised were explained to the Board and key staff members and following this, patients and staff who would be comfortable being observed and interviewed were identified. As far as the patients were concerned, their case histories provided by the social worker and psychologist were also taken into account in the selection process. My research findings are specific to this care Centre and cannot be used to generalise for other such institutions.

I arranged appointments with staff during their lunch breaks or occasionally after their shifts. This was done with the Matron's and Director's permission. Staff interviews were conducted mainly during their working hours to clarify the roles and functions of staff members as well as to observe the relationships between staff and patients.

2.2 Literature study

The aim of the literature study was to obtain relevant information that would constitute essential background for the proposed study as well as to contextualise it.

- **AIDS, inequality, and discrimination against women**

Publications by Fox (2001), Hepworth and Shernoff (1989) Perrow and Guillen (1990) were consulted as a foundation to inform the study about possible issues and areas of concern around inequality and discrimination relating to AIDS sufferers.

The social context of South Africa is one of vast unemployment, limited education, poverty and limited access to education (Hepworth & Sheroff 1989:68), and the social context of HIV AND AIDS, being unequally focussed in poorer communities, and the stigma attached to it are vital in understanding how the HIV AND AIDS epidemic spread and why it spread so disproportionately. Such information formed important background to interviewing patients at the Centre. Furthermore, the impact of diet and the lack of resources constraining those with HIV from seeking medication, counselling and assistance constituted important information to understand why so many patients are seemingly reluctant to treat their disease.

The plight of women with HIV AND AIDS is emphasised in Fox's work which helped to explain the greater pressure placed on women as careworkers relative to their male counterparts, necessitating an exploration of women's role in managing HIV AND AIDS while considering how culture factors fit into this equation (Fox 2001:65).

Sexual behaviour and the reasons behind the behaviour are highlighted by Perrow and Guillen (1990:86). This reading provided insight into the cultural and social positioning of women in relation to sexual practices and norms (Perrow & Guillen 1990:86) as well as condom usage. This information together with details from Hepworth and Shernoff (1989:54) helped to contextualise the background to the rapid spread of HIV AND AIDS.

- **Stigmatisation**

To acquire information on stigmatisation and its effects, I consulted publications by Brouhard (1993), Goldin (1994) and Macklin (1989). Stigmatisation is a key concept to understand since it is a side-effect of HIV AND AIDS and sometimes prevents households from accessing disability grants and other forms of support that the government furnishes AIDS sufferers. Stigmatisation may prevent orphans from acknowledging that they have HIV AND AIDS or that their parents have HIV AND AIDS and therefore, from seeking help (Macklin 1989:129). Consequently this explanation must be considered in order to contextualise the current epidemic of HIV AND AIDS in South Africa and the reason for so many with AIDS lacking subsistence and being disenfranchised. Brouhard (1993:17) explains one of the many ways in which those suffering from HIV AND AIDS are stigmatised, i.e. for 'contravening' values seen to be associated with the church, adding to the pressure placed on those who are HIV-positive. Goldin's work alerted me to the role of society in stereotyping those with HIV AND AIDS, which leads to stigmatisation of those with the disease and consequently a struggle for those with the disease to get help (Goldin 1994:1359-1366). Stigma is a common and debilitating consequence of HIV AND AIDS that needs to be examined from the patient's perspective and from an institutional point of view.

- **Sociocultural phenomena related to HIV AND AIDS**

Publications by Perrow and Guillen (1990) and Rieder and Rupelt (1988) were used to obtain an understanding of the influence of sociocultural factors on HIV AND AIDS and consequences of the disease for people's lives. Ten Brummelhuis and Herdt's (1995) focus on cultural practices that may contribute to the spread of HIV AND AIDS, as well as on the social context of HIV AND AIDS also informed my understanding of the HIV AND AIDS epidemic. They emphasise the connection between poverty, gender and HIV AND AIDS and the realisation that poorer women are at greater risk of contracting HIV due to the cultural construction of sexual practices (Ten Brummelhuis & Herdt 1995:29-53,79-97). Altman emphasises the inequalities associated with HIV AND AIDS, i.e. that this disease is linked to those in the lower economic classes and how a consequence of this phenomenon is that the inequality between richer and poorer people is increasing (Altman 1994:3). McCombie (1989:59) and Leukefeld and Fimbres (1987:41-43) helped me to comprehend how misconceptions such as casual contact and the spread of HIV AND AIDS could lead to the fear of contamination and how organisations can address such misconceptions. Rieder and Rupelt (1988:206-209) stress the difficulties involved in successfully changing people's behaviour, especially when it pertains to sexual behaviour such as safer sexual practices and the need for condom usage. Perrow and Guillen (1990:6,15,62) provided insight into the nature of the stigmatisation experienced by those infected with HIV, i.e. that many sufferers are 'blamed' for their condition due to the lifestyle choices that they made in the past. Those who were openly gay were seen to have inflicted the disease upon themselves and this analysis of the situation that many HIV-positive people find themselves in proved invaluable in understanding their mindset and their reluctance to admit their HIV-positive status and to find help.

Das and Poole (2004:155) provided background information about how death is perceived by many in South Africa, the way bodies should be treated under normal circumstances, and the way bodies are treated when death has resulted from AIDS.

- **The sick role, meaning of illness and death**

As a foundation for comprehending the sick role and status change experienced by patients, I consulted Macklin (1989). I used Das and Poole (2004) to acquaint myself with an understanding of death from terminal illnesses such as HIV AND AIDS since it occurs from time to time in the institution, to know how to address the subject of death, and how various cultures view death. Macklin clarifies the stages associated with HIV AND AIDS from diagnosis till death. This assists in understanding patients' mindset and provides some insight into what AIDS sufferers are experiencing and to sensitise me, as an interviewer, to dealing with them in an appropriate manner (Macklin 1989:105-125). Das and Poole consider AIDS in the South African context where some equate AIDS with witchcraft. The similarities between the symptoms of HIV AND AIDS and witchcraft are explored, alerting me to the possible differences in health beliefs and meanings assigned to illness that I might encounter in my study (Das & Poole 2004:141-154).

- **Children and AIDS Orphans**

Fox (2001) and the Joint United Nations Programme on HIV AND AIDS (2008) provided fundamental insights into the impact of HIV AND AIDS on children and the resultant plight of those who are orphaned or become heads of households. Fox documented the reality for girls, i.e. that many girls are taken out of school to care for sick relatives, leaving them unable to secure employment later on, disallowing them the opportunity to live a 'normal' life, and burdening them with adult responsibilities (Fox 2001:65-66).

Fox's exploration of issues facing children with AIDS acted as a platform from which I could focus on the specialised physical and psychological care that such children need and the role of the institution in their lives. The Joint United Nations Programme on HIV AND AIDS (2008) provided recent information about children with HIV AND AIDS and AIDS orphans, as well as some of their circumstances such as standard of living and school attendance.

- **Methodological issues**

In preparation for this research, various references dealing with qualitative research methods were consulted. Bate (1997:3-4), De Villiers (1995), Hamada (1999) and Jordan (2003) collectively provided me with the tools and techniques to approach ethnography in the Centre and to identify various risks to watch out for while conducting research in an organisational context. Hamada was instrumental in providing clarity about how anthropologists could marry ethnography with organisational practices to make sense of the culture within an organisation (Hamada 1999:3). Jordan's work provided a framework depicting techniques that could be utilised to conduct fieldwork in a business environment and thereby to elicit meaningful information for my study (cf. Jordan 2003:20-38). In addition, the ethical considerations inherent in conducting studies in an organisational context are addressed by Jordan, providing guidance for undertaking my study (cf. Jordan 2003:54-62).

- **Organisational anthropology**

Anthony (1994), Bate (1997), De Villiers (1995), Jordan (2003), Weisfeld (1991), and Wright (1994), were consulted as a basis to understanding the field of organisational anthropology, to acquaint me with the history of organisational anthropology, and the approaches and procedures involved in conducting ethnographic research in an organisation. They also served to define the concepts of organisation, organisational anthropology and organisational culture.

Bate's (1997:2-5) review of organisational anthropology was basic to my orientation of the field of organisational behaviour from an anthropological perspective. Bate familiarised me with various methods for conducting ethnography in an organisation as well as the possible challenges and pitfalls of the process, and the manner in which ethnographers write (Bate 1997:2-5). De Villiers (1995) was fundamental in providing insight into doing research in a clinical setting, and for providing guidelines on patient selection, possible problems with interviewing, and how to ensure a holistic approach. De Villiers, in addition, offered practical guidelines on how to start the study, i.e. with supporting data and how to choose the most appropriate method and design for the study as well as a framework for conducting the fieldwork (De Villiers 1995:22-23).

To acquaint myself with hospices, health professionals and careworkers at such institutions, I consulted Weisfeld (1991). This source also drew my attention to the challenges of dealing with an epidemic within an institution and in a broader sociocultural context. Weisfeld (1991:1-3,41) offered information about HIV AND AIDS care centres in the United States of America, which provided a basis for comparison with which to evaluate the services offered by the Centre where the research was conducted. Weisfeld (1991:50), furthermore, provided information concerning the challenge of staff burn-out due to the extreme stress associated with working in an institution for patients suffering from a terminal disease.

Anthony (1994) and Jordan (2003) were pivotal in highlighting the role of the anthropologist in organisational environments and as problem-solvers in organisational contexts. They emphasised the importance of understanding the meanings of organisational culture for the members of an organisation in terms of how it influences their functioning and behaviour within a corporate system. Their contribution provided essential background information that helped

me to make sense of the healthcare setting. Wright (1994) and Jordan (2003) were instrumental in contributing towards my understanding of the history of organisational anthropology and how to engage organisational anthropology. Jordan's work chronicles the history of organisational anthropology, which provided clarity for me about how anthropologists have gone about fieldwork within organisations as well as the challenges and obstacles that they faced (Jordan 2003:9-19). In addition, Jordan explores the study of organisations on three levels i.e. individual, group and on an organisational level as a whole. The study of the various cultural components in relation to each other provided me with a structure for exploring the hospice environment (Jordan 2003:84-93). Anthony provided parameters within which the concept of culture and organisational culture can be defined and understood so that I was aware of the various subtleties to pay attention to in my study (cf. Anthony 1994:28-31). Wright focuses specifically on the Hawthorne Experiments and their impact on the evolution of organisational anthropology (Wright 1994:5-8). In addition, these sources offered a comprehensive platform for the study in that the complexities of organisational anthropology and ethnography could be understood, as could the specific role that the anthropologist plays in organisational settings. Wright suggests that organisations are "sites for constructing meaning", denoting that each organisation's culture differs and can only be understood by studying it from the 'inside' and getting to grips with the meaning that each symbol and ritual holds in that context (Wright 1994:3).

2.3 Identifying the research locale and gaining entry

The objectives of this study made it necessary to identify a health centre that cares for HIV AND AIDS patients and where I could undertake the proposed ethnographic research. The company that I worked for as a project manager in the early 2000s, had been successful in its tender to renovate an HIV AND AIDS hospice and construct necessary facilities such as a mortuary, teenage ward and patients' dining room. When considering where to conduct my ethnography, Father Stan, the Founder, suggested to me that his care centre would be suitable for fieldwork.

Because I was familiar with many of the staff members and patients and because I knew the history of the Centre, this seemed to be a feasible option. It meant that I would not have to start with investigating the background of the organisation or spend much time becoming familiar with the staff.

Nonetheless, before fieldwork began, I inspected the site to determine its viability as a research setting. It proved to be suitable because patients were available constantly; I had access to medical personnel, and could perform follow-up interviews at any stage. It is essential to have easy access to participants to answer questions about observed phenomena or to ask follow-up questions, but it is often difficult to trace patients once they have been discharged because patients come from all of South Africa's provinces. None were discharged during the research and I was able to do follow-up interviews with all patients. Another reason for the suitability of the institution was the heterogeneous nature of the patients: males and females, adults and children, of various racial, religious and ethnic backgrounds. This made it possible to interview people from most of these categories to contrast their beliefs, experiences and treatment expectations.

Father Stan allowed me to proceed with the research until formal permission could be obtained. A Board meeting was called where I explained the purpose and methodology of the research, as well as the usage of the data that I would collect. The Board members voted on whether or not the study could be undertaken. One member had reservations about how much information could be shared with me, stressing in particular the financial position of the Centre and emphasising that this should not become an issue for public scrutiny. I assured her that financial matters were not my primary concern and that I would focus on behavioural issues; relationships and interaction between staff and patients of the Centre, and the extent to which it achieves its objectives. Another member was anxious about confidentiality, but I informed her

that pseudonyms would be used, and anonymity would be ensured for all the informants (pseudonyms were used for all participants to ensure that the participants could not be identified and discriminated against). I assured her that I would ask each participant's permission to interview him or her and that the patients had the right to refuse to be interviewed.

Father Stan had explained to the Board and the senior staff that my research would not interfere with the operations of the Centre nor would I force patients or staff to participate in the study. Nonetheless, access to this site was difficult due to the sensitive nature of the disease and fragile state of mind of the patients. Entry was facilitated by placing the Board members' minds at ease through an agreement between myself and the Centre's management that was primarily aimed at ensuring anonymity for the patients and their families.

After some hesitancy the Board agreed to allow the research to take place and the secretary provided me with statistics and reports that had been submitted to funders and the government. Details included the total number of children and adults that could be accommodated at the Centre, the nature and source of funding, home-based care services, and the number of outpatients treated at the antiretroviral clinics associated with the Centre. The number of deaths, admissions and transfers per year are recorded in these documents, together with notes about all the deaths, the funerals and when families had been notified. I used these documents to assess and analyse the practices and policies of the Centre.

I was granted almost complete autonomy in my research, provided that Father Stan would have access to a copy of the final draft of my research report. This autonomy included access to all staff, patients and even certain funders for interviewing. I was also permitted to have access to patients' records that contained information on their physical and psychological conditions, as well as background information from the Department of Social Welfare and I was allowed to

actively observe and ask questions if necessary. Furthermore, I was given permission to attend institutional activities such as meetings, parties and fund-raising events. Zelda, the Social Worker, played a key role in my investigation since through her I gained access to the children and learned to understand the link between the Centre and the Department of Social Welfare. The cooperation between the Centre and the Department of Social Welfare is fundamental in ensuring that following placement at the Centre, the patients get the best care possible. Zelda and the psychologist at the Centre provided me with the case histories of all the children so that I could acquaint myself with their circumstances and sensitive issues concerning their condition, determine how to approach them, and to decide on the type of questions that I would ask them.

2.4 Establishing rapport and gaining trust

The importance of having a presence at the Centre helped to make my face a familiar one which helped me to become familiar with the staff and patients and to gain their trust (cf. Bate 1997:9). Once permission had been granted to conduct the research at the Centre, I spent a great deal of time with the children until they saw me as 'part of the team' and viewed me as a confidante, sharing their secrets and their feelings with me. The children trusted and accepted the psychologist, so that when she introduced me to them as a friend who was there to ask them some questions and to get to know them, they more readily accepted me.

Acceptance by the adult patients took longer since trust was an issue for them and they needed to become familiar with my presence. Some older patients saw me as an 'outsider' and viewed me with some suspicion. Eventually most no longer even noticed me. To be seen as part of the team by the staff took much longer and depended largely on their developing respect for me, as well as a greater comprehension of the purpose and scope of my research. In time, I was able to overcome most of the suspicion by explaining the type and purpose of the research.

I averted management's scepticism by discussing my research with them on a monthly basis. After a few weeks I was generally considered to be one of the team which helped me to make accurate observations, and to follow the gist of conversations and comments. Of primary interest to me were the daily experiences of terminally-ill patients; the seeming lack of control they have over their lives, and their perceptions of their health problems within the institutional context of the Centre. I began as a passive observer and graduated to a relatively fully participating member of the team as I gained knowledge about the Centre and the patients, and grew in confidence.

My fieldwork started in early 2004. I visited the Centre on a bi-weekly basis, spending an average of 14 hours per week at the institution. This continued for the first six months during which the initial interviews were held. During the following nine months I spent one day per week at the Centre and attended meetings and functions. Following this stage, I continued to visit the Centre at least twice per month for the purpose of follow-up interviews, to gain clarity on issues and questions, and to document changes that had occurred between my visits. To date I still visit the Centre on a monthly basis for updates on the patients, progress at the antiretroviral clinic, and to spend time with the children.

2.5 Research participants: selection and categories

When selecting patients to interview and to assess the quality and reliability of the information that they would provide me, I had to consider their physical and mental fitness, their medication type and frequency of taking it, as well as their stage of illness (cf. De Villiers 1995:24). I selected patients who had been assessed by the social worker and psychologist and identified as mentally fit and able to answer questions competently.

They identified the most articulate and suitable candidates based on their backgrounds and histories to ensure that I had a representative sample of the patient population at the Centre. I also selected patients based on questions I asked during my early visits to the Centre to assess their willingness to participate in the research.

There were 48 adults and 30 minor patients in the institution at the time of the research. This was due to the fact that the new adult wing had not yet been completed; three patients had died, and the Centre was awaiting new admissions from state institutions. The patient racial composition was as follows: 73 or 93.6% Black, 2 or 2.56% White, and the remaining 3, or 3.84%, included 3 Asian/ Coloured. There were 29 adult male patients (60% of the adult patient composition) and 19 adult female patients (40% of the adult patient population). The children displayed similar figures, with boys in the majority, i.e. 18 boys and 12 girls. Of the children resident at the Centre, 96% were Black and 4% Asian/Coloured. According to clinic records, more than 85% of the antiretroviral clinic users are Black; Asian/Coloured people make up 9% and the remaining 6% is Whites. Of the 30 people I spoke to at the clinic, 25 were Black, 3 were Asian/Coloured and 2 were White. I thus had a proportionate sample of outpatients frequenting the clinic. The patient numbers in the Centre itself remain constant until there is a death or a new admission. Each patient remains at the Centre for a minimum of four months. Those who stay longer sometimes remain for years before death claims them. Family and friends were used as additional informants wherever possible e.g. family of deceased patients were interviewed to understand their community's views on death from HIV AND AIDS and the stigma attached to such a disease. I interviewed nine children and twenty adult patients in the Centre. Each child was interviewed in two to three sessions of half an hour to one hour each, after which they had a break to paint and play. Longer periods could be spent interviewing adults due to their longer concentration spans. They also had more experiences about which they could talk, however, the children's experiences and feelings were included wherever possible and coherent

and could be validated by records. Most patients enjoyed the company to break the monotony of the day.

2.6 Interviewing

I started the interviews by explaining that according to the ethical anthropological principles, I would only use their first names to protect their anonymity. Sensitive issues that they discussed with me would be held in the strictest of confidence and only revealed in ways where the participants could not be identified. In a few cases, where participants were not comfortable revealing their first name, a pseudonym was used. Above all else the welfare of the participants was considered and any beliefs or behaviour that could cause them harm by the details being revealed was either eliminated or used in a more generalised format. Few patients were willing to have their interviews tape-recorded and therefore copious notes were taken. Most patients were willing to conduct follow-up interviews but some withheld personal information apparently for fear that it may be used against them. Consequently other informants were chosen to replace them. The bed-ridden patients were concerned that they had no privacy when revealing information to me so other patients in the room were temporarily relocated before an interview.

Being mindful of the clinical setting and the rigid schedules of nursing staff, interviewing schedules needed to be carefully considered (cf. De Villiers 1995:23). Interviews varied in nature from impromptu and informal questioning to scheduled formal interviews. Within this medical institution, more specifically a care centre for those needing to be nursed back to a degree of health so that they can be discharged and live as outpatients, and for terminal patients suffering from an incurable disease, the nurses were extremely busy with their daily functions as well as coping with crisis situations. Hence scheduled interviews were regularly postponed. I interviewed nurses whenever their schedules allowed; normally between shifts or even by obtaining permission to interview them while they were measuring blood pressure or

injecting patients. More frequent were the informal interviews held after the initial formal interviews since people seemed to reveal more information after a few sessions when they felt safe and comfortable and the encounters were informal. The structured interviews provided factual and historical information about patients, their medical condition and information about the Centre. Mainly open-ended questions were asked during the informal interviews to solicit ideas, views, feelings and more intimate or confidential information which I used when I compared management's version of the functioning of the organisation with that of the patients and staff (cf. Hamada 1999:3). The many open-ended questions generated a vast amount of information and I realised that I could decide at a later stage what was useable and what could be discarded. My questions in the initial interviews were structured but they also allowed leeway for possible open-ended answers, thereby allowing maximum data collection. I observed body language and reactions during interviewing and based questions on what I observed, for example, people rolling their eyes or showing agitation when asked about certain people or events. I used such reactions to probe the apparent tensions further.

Adult patients were asked personal questions to facilitate understanding of their history or background, circumstances that caused them to be at the Centre, their health beliefs and expectations, daily experiences at the Centre, their medication and its effects, their plans for the future and for their families. I used questions such as: "Tell me about your family", "How do you feel about the institution?", "Do you believe they are treating your illness and have they listened to your beliefs on how your illness is caused and how you think it should be treated?" Then, after a few interviews and having gained their trust, I asked them how they had become HIV-positive. Most informants were comfortable with answering this question; the few who were uncomfortable were not forced to answer it. All the informants except one spoke English hence generally communication between interviewer and interviewee was not a problem, although all the patients were offered the assistance of interpreters. One patient spoke little English and

hence I arranged for nurses to translate our discussions, although I was concerned that some of the meaning may have been lost during the translation. There was no way of verifying most verbal responses by the patients to my questions. Interviews and observations happened on a daily basis to identify patterns, trends and norms, and to place data in context (cf. Hamada 1999:3).

I interviewed as many staff members as possible, including the Centre Director, Housekeeper, Founder, Matron, Training Manager, Finance Manager, Social Worker, Psychologist, Doctor, Secretary and the nursing staff. Each participant provided information on the Centre from a different perspective, depending on his/her function within it. Interviews with these authorities were utilised to gain insight into the skills and knowledge base underpinning the institution, and the roles of each person in the structure and functioning of the Centre. They provided 'insider' information on events at the Centre and information on other staff members and patients that facilitated understanding of the functioning of the Centre (cf. Bate 1997:3). They also provided information of a more personal nature regarding the traumatised setting in which they work and the resources provided by the Centre. In addition, they gave me details about the antiretroviral clinic and home-based patient care, and the importance of all services provided by the Centre in the lives of the patients and their families and the community in general. I worked around the constraints of limited time in terms of availability of staff. The nurses worked shifts and office staff had to juggle their responsibilities with sessions during which they could provide me with information and answer my questions.

I interviewed the resident doctor and approximately 28 of the nursing staff, composed of nurses, sisters and nurse aides; all were amenable to being interviewed. The nurses are classed as permanent staff although most work on a shift basis, working a certain number of shifts per month at the Centre and then shifts at other medical institutions in the area. In this way the

Centre avoids staff burnout (cf. Weisfeld 1991:48-49). Some nurses may only work a few shifts per month. The large sample provided a great deal of data that I could also use to corroborate the participants' testimony and thereby ensure reliability.

I conducted interviews with home-based care staff or volunteers while they were in the communities performing home visits. In this way I was able to witness the services offered by these workers and observe the beliefs and practices of AIDS sufferers in the community. Many of the outpatients I visited realised that they were sick but attributed the disease to the ancestors being angry with them or to some form of witchcraft. Only two of the eighteen patients that the volunteers and I visited held biomedical views of their disease.

Interviews with patients gave me insight into the life of someone living with HIV AND AIDS, the available options for care and the emotions generated by their condition. The meanings they attach to their disease were explored to establish how these influenced their decisions, treatment expectations and plans (cf. Hamada 1999:3). These interviews provided information on the patients' experience at the Centre, helping me to comprehend its structure and to obtain a holistic view of it. The information gained from the patients was useful to obtain insight into the conduct of staff members before interviewing them.

Thirty people visiting the antiretroviral clinic were interviewed over a period of one month, with interviews being conducted intermittently, on varying days. The interviews with outpatients at the antiretroviral clinic were held on an informal basis in the waiting area when it was relatively empty, in vacant offices or even outside on the bench. On busier days I was allocated one of the examination areas where patients were waiting to be examined and to receive their medication. Each interview varied in length from 15 minutes to an hour, depending on the amount of information a patient was willing to provide. I explained the type and purpose of the research to

the outpatients, giving them a choice whether or not to participate. Questions were structured to ensure data that could establish the socio-economic status of outpatients, their source of AIDS transmission, knowledge of AIDS, type of treatment expected, treatment being received, as well as their health beliefs which helped me to assess the functioning of the clinic and how patients perceived their treatment. In some cases I struggled to gain sensitive information such as the cause of transmission, but as trust developed, mostly during the second interview, they were more forthcoming with such information (cf. De Villiers 1995:25).

I also interviewed a traditional healer consulted by clients who visit him to be cured of HIV AND AIDS, amongst other conditions. The interview was to understand the perception of HIV AND AIDS from the traditional healer's perspective and to gain insights into the perceptions and behaviour of people who visit a traditional healer. This interview provided useful information on misconceptions and varying health beliefs and practices of patients infected with HIV AND AIDS.

2.7 Observation

Observation was a primary method used to view alliances and tensions among the staff, the interactions between staff and patients and between patients, and to observe body language that might indicate alliances or tensions in staff and patient relationships (cf. De Villiers 1995:27). Observation also took place during doctor-patient consultations such as weigh-ins and blood pressure monitoring sessions. These were a vital source of information about the Centre's operations and provided insights into the most common concerns and challenges that patients with HIV AND AIDS have (cf. De Villiers 1995:26). These conversations provided a foundation from which I could work by drawing my attention to matters which I could formulate into questions for the patients.

I investigated the Centre from an operations perspective, including meetings, counselling sessions and hearings in order to facilitate a holistic ethnography. Observation was also possible during staff meetings, observing friendship alliances and observing staff interaction. When necessary, uncertainties arising from the observations were clarified through interviewing or by perusing supporting data such as documentation obtained from the Centre records.

Because most patients do not leave the Centre at any stage, they are readily available (cf. De Villiers 1995:22). This sustained, regular contact was vital to facilitate accurate recording of behaviour, and events as they happened, and it allowed me to record and analyse the changes that occurred over time. I also observed the daily casual interaction between patients and doctor. I had almost unlimited access to staff, patients, outpatients and families which allowed for the social context of patients to be included as a critical element in studying the existence of patients in this institutionalised environment. Observation was facilitated by there being few barriers in this environment and by me being able to participate in their daily activities.

The Psychologist ensured that the children were not exploited in any way by my questioning and in fact, at the commencement of my research, a copy of my questions had to be submitted for approval by the Social Worker and Psychologist to ensure that the rights of the children in terms of confidentiality and anonymity as well as their right not to participate if they so wished were protected. For many of the child informants, articulation was difficult because of their age and the trauma suffered in their young lives. As mentioned in 2.3 above, the background information on all the children included information on their families and issues that followed their arrival at the Centre and was provided by the Department of Social Welfare and the state hospitals where many of the babies were born and their mothers treated. The Psychologist expounded upon their state of mind, and their level of comprehension about their disease. If a child was uncomfortable speaking to me alone, she was present to mediate and put the child at ease. I

began by asking them questions about their teachers and their friends at the Centre to put them at ease, and once I felt they were more comfortable with me, I began asking questions about their nurses and the care they received in terms of the food they were given, the number of nurses present at various times of the day, and the type of stimulation presented at the school. I also addressed issues of understanding such as whether or not they actually understood their illness and what they knew about their families. These interviews allowed much latitude, i.e. I asked specific questions but many of the children chose to provide me with unrelated information, much of which was also useful. Usually after rephrasing the same question in a few ways, I was able to elicit the required information. Any questions raised that created discomfort for the children or questions that they said they did not want to answer were abandoned. The questions were all open-ended to allow the children to speak about what they wanted to tell me. The interviews were very informal to ease the sense of pressure on the children and create a friendly atmosphere.

The chapter that follows lays the foundation for comprehending the Centre as an institution caring for terminally ill patients. The structure and functioning of this organisation forms the basis of the exploration of more specific elements of its culture.

3. THE RESEARCH ORGANISATION AND THE RESEARCH PARTICIPANTS

3.1 Setting the scene: first impressions and description of the Centre

Understanding the spatial plan and layout of the Centre provides cues for determining the organisational hierarchy, importance of various activities within it and the functionality of its design.

In the early 1990s, some residents of Boksburg were alarmed about a house on a main arterial road becoming an HIV AND AIDS hospice. The then mayor, Beyers De Klerk, forced the Centre to choose between moving and closing down. As a result, Father Stan, the Founder, moved it to a plot of land in Everleigh in Ekurhuleni, Gauteng. This was typical of the general attitude towards HIV AND AIDS sufferers at the time and sadly this attitude to some degree persists today.

Father Stan opened the Centre in 1992 and in 2004 the antiretroviral clinic was added and became operational. This Centre can cater for a total of 75 adults and 40 children with HIV AND AIDS but at the time of my research it was not functioning to its full capacity (see 2.5 above) because the new adult ward was still under construction, three deaths had recently occurred and the Centre was awaiting patients that were to be transferred there from state institutions.

The mission of the Centre is to: "Provide a haven for terminally ill adults and children where they will be nursed in a professional and comfortable environment, whilst their physical and social needs are catered for with care and dedication". The Centre also strives to provide antiretroviral treatment to patients in the community as well as staff training in order to reach out to the wider

community through education, care and counselling. The Centre provides love, care, entertainment and acceptance.

My first impression of the Centre was the apparent agony on the faces of adult patients, which seemed to reflect their physical (sores, emaciated bodies and frailty) and emotional suffering. The lawn was lined with 'skeletons' shrouded in thin layers of skin. The sight was shocking and made one mournful for the pain and suffering the patients endure. The resident doctor informed me that many, especially women, suffer from dementia in the final stages of the disease, verbally abusing staff and fellow patients with vulgarities. They also try to convince the naïve, especially the volunteers, to give them a lift to their families or friends in an attempt to escape from the Centre.

Because patients referred to the Centre from state hospitals are in the final stages of the disease and hence are unable to do much, if anything, to take care of themselves, they suffer an immense loss of self-respect and dignity. General pride and morale are very low among many of the patients because they are embarrassed by their condition as well as regretful of the fact that they have contracted HIV.

One must develop a specific mindset when working with terminally-ill patients. In interaction with the children I tried to remain slightly emotionally detached because I knew that their existence is transient. Often when I arrived to spend time with them, I was told that another of the children had passed away, leaving me hurt and dismayed.

My first encounter with the children was vastly different in comparison with my first impression of the experience of the adult patients. Sounds of laughter and singing filled the warm summer breeze as a group of children, all well-dressed in brightly coloured clothes and leather shoes,

skipped up the driveway in an orderly row towards me. Sister Claretta, the Matron, introduced me. The children smiled and waved to me and had many questions such as Why was I taking photographs? Why did I ask so many questions? Would they be famous and on television because of the photographs? There were some difficulties explaining my purpose, but most of them knew that I was writing some type of book that would talk about them, their lives and their feelings. I told them that I was going to spend time with them over the coming months and that I would like to get to know them all.

Large black steel gates lead to a car park, flanked by a wooden guardhouse at the entrance where visitors sign a visitor's book for security purposes. The secretary's office is the first one on the right side and displays photographs of deceased patients and crayon drawings made by children. When I first arrived, I noticed baby blankets and knitted booties lying scattered in washing powder boxes on the floor and on the chairs, and outside the office were donations such as nappies and baby clothes.

Outside the laundry were further donations such as washing powders and fabric softeners, and outside the kitchen was piled food sponsored by a local supermarket. A bronze plaque honouring those who had helped found and support the Centre is mounted on the wall outside the administration offices. Behind the secretary's office is the office of Tilly, the Director, and alongside that is the office of the Matron, Sister Claretta. The patients' dining room is across from the administration offices and is equipped with a wooden veneered wall-unit with a television and homely ceramic figurines to make patients feel at home. The semi-open-plan kitchen has hygienic stainless steel appliances.

Off the dining room is the office of Denise, the Housekeeper, a nurse's station and a supply room. The supply room consists of floor-to-ceiling galvanised shelving packed with white bed

linen, towels and cleaning products to meet the demand for clean linen, the result of patients soiling their bedding daily. The sunny nurse's station is small and furnished with a few chairs, a log-book, an emergency buzzer board linked to each patient's room, and a small over-used kettle for the long nights on duty.

Upstairs, beyond the dining room, are the wards where completely bed-ridden adult patients spend the last 90 days or so of their lives. Rooms have brightly coloured duvets and curtains, and walls with paintings depicting seaside and forest scenes. The floors all have lino covering rather than tiles to prevent germs sticking in crevices which could cause secondary infections among the patients. Between the patients' rooms are the bathrooms equipped with a shower, a toilet and a basin. The shower has safety handles for the patients to hold onto and a shower seat so the exceptionally weak can sit while the nurses wash them.

Next to these patients' rooms is the office of Marinda, the Finance Manager. At the bottom of the staircase leads a passage that ends in the main ward for adult patients, with a reception desk and nurse's station manned by Solly, the adult ward receptionist, and a group of nurses and sisters. The ward was funded by Japan which invests heavily in projects at this Centre. Father Nicholas, one of the resident priests, is Japanese and has contacts in his home country to arrange for such donations. Photographs of loved ones and souvenirs of home appear throughout the ward since many patients come from far away and therefore friends and family do not visit often. The ward is equipped with multiple machines to measure blood pressure, temperature, etc., for use in emergencies and oxygen tanks which are readily accessible because most patients have difficulty breathing. Patients have portable buzzers in case they need to call for help. There are nurses on duty twenty-four hours a day and the doctor, Dr Ngumbe, is on call twenty-four hours per day, seven days a week.

Immediately outside the ward is a generator house where back-up electricity is generated in case of power failures. Beyond this is the mortuary which can house a maximum of eight bodies. Sadly, this number was adequate when the Centre was smaller, but with the addition of the new wards, an eight-body mortuary is often inadequate, especially in winter when many patients die as a result of secondary infections such as colds and influenza. The mortuary is composed of a walk-in freezer section and a small altar for prayers and short services for the departed.

Opposite the adult ward is the warm and sunny children's and teenager's ward. Swings, slides and jungle gyms abound on a stretch of lawn outside. The majority of children are under five years of age and as a result the most prevalent form of bed is a white cot adorned with Disney characters. The walls are painted with stencilled cartoon characters in exotic colours. The floors are lino covered and are sterilised twice a day with industrial strength bleach to ensure the health and well-being of the children. Their playroom is large and filled with brightly coloured medicine balls, teddy bears and all types of toys and games. The emphasis is not only on educational toys, but ones that encourage proper physical development which is essential for such sick children to prevent extreme physical deterioration. From birth they must receive a balanced, nutritious diet, exercise and be exposed to sunlight and proper stimuli.

Behind the playroom are the bathrooms with miniature toilets, basins and showers. The tiles are 'anti-skid', with miniature handles in the showers to help the children maintain their balance while in the shower. The children choose their towels and toothbrushes, and in order to teach independence and responsibility, each child is responsible for looking after his or her belongings.

Adjacent to the bathroom is the teenage ward where two female and two male patients can be accommodated. Few children with AIDS survive to teenagehood and those that do, need immense care since their bodies are extremely frail. Their only means of getting about is a wheelchair.

Directly behind the playroom is a nurse's station with a one-way glass panel for nurses to spot any incident that might occur and must be resolved immediately. A fundamental indicator of an organisation's culture can be found in the layout and furnishings of the workplace (see 1.3.2 above). The open-plan layout of the nurse's station and their office show an environment conducive to a team-orientated culture which is brightly decorated in yellows, with biblical messages on the walls, giving the impression of shared faith, hope and mutual help. The furnishings are cheap and old in comparison with the furnishings of the managers' offices, and there is no window. Nurses sit on low-back minimally-padded chairs. The nurses explained that this is due to budgetary constraints but also because, they have been told, "management spends more time in their offices and need to impress donors". This open-plan office must be used by all the nurses to complete their paperwork and as a lounging area when they are not doing their rounds. It forces a large group of people into a small space. I experienced camaraderie among the nurses as they helped each other with paperwork, while many off-duty nurses accompanied their fellow nurses on their rounds, helping with the patients. There are no partitions between the desks, indicative of the team spirit that is obviously present.

The management offices on the other hand, are the antithesis of the nurses' station. Most members of management have their own offices with expensive, new furnishings. There are few signs of team-work in these offices because each person works independently. Little sharing of information can be observed. Managers have relatively large offices with a desk, cabinets, several chairs for visitors, a high-back armed chair and accessories such as heaters, fans, and

plants. The managers' offices are carpeted, unlike the nurses' station where rugs are used to stem the cold in winter. Managers' offices are located in strategic places such as upstairs or in quiet areas of the buildings. Names mounted outside each office identify the staff members who occupy the offices which seems to indicate that managers are afforded greater importance than the nursing staff who are treated more as resources.

Further up the driveway is the conference and training facility operated by a private training company, and run by ex-university lecturers and retired teachers. The training centre, which seats 40 people, is equipped with an overhead projector, data projector, white boards and all other conveniences to facilitate training.

In a small piece of ground, surrounded by a palisade fence is the friary. The friary looks onto a humble garden with small shrubs and flowers.

The library is filled with old leather-bound books, wall hangings portraying Irish scenery, and many plush red chairs. Immediately off the library is a guestroom normally used for visiting priests. The dining room is adorned with photographs of Father Stan with Nelson Mandela, Bishop Tutu, Cardinal Napier, Joe Slovo, and the Irish ambassador, amongst others.

Photographs of Father Stan's family abound, as do Irish crosses carved in wood, paintings of Ireland and many scrap books with newspaper clippings of Father Stan's awards for his achievements.

Further up the driveway is the pharmacy where drugs such as ARVs and morphine are kept under tight security. Here too, Heather, the manager of the second-hand store, can be found. This store is where all donated goods, many of them unused, are sorted, cleaned and sold to bargain-hunters. Next to the second-hand shop is the function diningroom filled with octagonal

tables. There is also a fully functional rotisserie and bain marie. On the opposite side of the driveway is an industrial laundry facility with six washing machines and six industrial tumble driers for washing the bed linen and towels daily.

In the middle of the patch of grass is a chapel which can accommodate forty people and is used mainly for services for the patients who have passed away. A bowl of Holy Water is attached to the wall at the entrance. At the front of the chapel with its stained glass windows is a beautifully decorated altar and a candle-shaped light on the wall that burns constantly. The chapel is open to all on a Sunday, and occasionally those who visit the clinic attend a Sunday mass.

A huge steel structure with a roof and a concrete floor but no walls functions as an open-air church. For guest-speakers there is a stage alongside and a grandstand for seating guests who attend services or functions at the open-air church. Opposite this is the school which consists of two classrooms and where the children spend a few hours per day. The classrooms are decorated with brightly coloured pictures and posters to stimulate their imaginations and encourage learning and development.

Beyond the open-air church is the boardroom where conferences on issues pertaining to Father Stan's projects, conferences of the local Franciscan priests, and the Annual General Meetings of the Centre are held. A mahogany table and twenty-six chairs grace the main room which is flanked by toilets, a kitchen and two small conference rooms. To teach the children about farm animals, Father Stan started his own petting zoo which houses sheep, goats, chickens, tortoises, ducks, geese, donkeys and even small pigs.

The structure of the buildings is almost circular, like the Centre itself, since the patients and staff form a miniature community with priests and teachers, nurses and children.

The antiretroviral clinic is located across the road from the Centre at the rehabilitation centre. It is a very secluded building, surrounded by high walls to ensure privacy for those who fetch their drugs that are dispensed by the resident physician.

Staff composition at the Centre is relatively stable. What follows is a detailed description of the staff at the Centre.

Eve, the Centre's Secretary, is authoritative but has great affection for the patients. She works for the first half of the day at the Centre and for the second half of the day at the antiretroviral clinic. She creates the monthly newsletter that is sent to the benefactors, the parish, the schools that support the Centre, and the community in general. She takes minutes at all meetings, manages the switchboard and deals with general issues such as handling the petty cash.

At the time of the research, there were 28 nurses ranging in age from their early twenties to their mid-fifties at the Centre. All the nurses had nursing diplomas and were registered with their professional council. The nurses include qualified nurses and sisters. In addition, the 10 nurse aides have some training and experience with the care of patients. Home-based careworkers are home executives or retired women who have been touched by the plight of those affected by and infected with HIV AND AIDS. They range in age from twenty-five to sixty-eight years of age.

More than two thirds of the nurses were married with children and admitted to feeling relatively despondent occasionally about the growing number of HIV AND AIDS patients in South Africa, although they also felt that much was being done to help them. A few of the nurses complained about 'long shifts' but did explain that they were remunerated for working overtime and that they often received December bonuses as a gesture of appreciation. Patients that I spoke to said that the nurses were kind and gentle and gave them respect and care. Many who had previously been hospitalised in State institutions said that the care provided by the two types of facilities could not be compared, with State facilities being poor and understaffed and not properly maintained. Clearly they were satisfied with the care they received at the Centre.

Zelda, the social worker, deals with both adult and paediatric cases. She said that at times the job is almost overwhelming; she has high levels of stress but says she would not leave since she believes that she was placed at the Centre for a purpose. Zelda admitted that she becomes very emotionally involved with all the patients with whom she deals but said that this is an occupational hazard and felt that if she was not emotionally involved she would not be doing her job properly. She has the utmost respect for her colleagues. Zelda believes that the Centre is at the forefront of HIV testing and drug technology, and of psychological treatment for the emotional side-effects of the disease. Zelda has tried to place as many of the children as possible in foster homes or to get them adopted, but she said this is extremely difficult since most couples seek to adopt healthy children.

Dr Ngumbe, the Centre's Doctor, was born and raised in the former Zaire, but left when the political situation became intolerable. He has been in South Africa for over 10 years. He was extensively involved in the care of AIDS patients in his home country and hence when he came to South Africa, he was asked by Father Stan to become the consulting physician for the Centre. Dr Ngumbe, who is a devout Catholic, runs his own practice and volunteers at a state hospital

where there is a shortage of qualified medical staff. He said that he is highly pressurised at times but on the other hand he finds his job extremely fulfilling. Many patients confide in him. Dr Ngumbe examines the patients daily to monitor their progress and for early detection of secondary infections that could easily kill patients suffering from HIV AND AIDS. He was even asked by one patient to help him to commit suicide, which he refused, having to watch the man grow weaker and more frustrated until he eventually died. He treats all staff members equally: with respect and dignity. He is an integral, irreplaceable member of the team and staff are happy with his presence.

Tilly, the Director, is a firm leader, often securing donations from the private sector due to her no-nonsense approach and commitment to the institution. Tilly oversees the Centre's functioning in all aspects. She obtained a degree in industrial psychology and an MBA in the United Kingdom and, having worked at several similar institutions, she possesses the necessary qualifications and skills to run the hospice. She visits the wards daily, spending time with each patient to give them the personal touch. The patients need this since many receive no visits from family or friends who have abandoned them for fear of the stigma that knowledge of having a relative suffering from AIDS would bring to their family in the community.

Father Stan Brennan, the Founder and priest, champions the rights of those on the fringe of society. Father Stan was born in Ireland seventy-six years ago. He came to South Africa as a young priest and upon seeing the desperate circumstances of some groups of people, he embarked on a quest to uplift the lifestyle of suffering people and to care for those in need. Father Stan has always been associated with powerful, influential people who lend support to his projects. Father Stan says Mass daily at the Centre and at various community churches. He visits the patients and tries to keep up their morale. He even counsels families on how to 'forgive' the patient and give them the love and acceptance they deserve. He conducts the

funerals of patients who die at the Centre. Father Stan returns to Ireland bi-annually, where he campaigns for the HIV AND AIDS cause, never failing to net millions of Rand for further projects.

Denise is the Housekeeper and is in charge of her staff who provide daily meals, cleaning and general maintenance. She is Afrikaans-speaking and grew up in Kwazulu-Natal. She speaks fluent Zulu and acts as interpreter for patients and staff when the need arises. Denise and her team cater for each patient's dietary requirements and preferences and take meals to those who are bed-ridden. She has a staff of ten who assist her.

Sister Claretta, the Matron, is a very positive and patient person. She is a nursing sister and a qualified Catholic Franciscan sister and therefore her interests span both the spiritual and physical implications of HIV AND AIDS for the people living with the disease. She takes her role as Matron very seriously.

3.2 Primary functions of the Centre

An organisation's functions and how, if at all, it achieves its aims form the basis for understanding the organisation as a whole in terms of goals and values and arrangements for achieving them. In line with the discussion in the first chapter on organisational anthropology (see 1.3.2 above), my research focused on understanding of how the Centre functions and on links between its objectives and its culture. The Centre is a formal institution specialising in the care of AIDS sufferers, dedicating all its resources to their special needs. The way the Centre operates, including the use of technology and the ethical dimensions of decisions taken, are indicators of its culture. The Centre operates on a foundation of Christian principles, ensuring that each patient is treated with the dignity and respect that he/she deserves. Each staff

member has a specific purpose and role to play in the Centre and by investigating these roles one can obtain insight into the organisation's nature and how it operates.

The Centre operates to treat patients suffering from AIDS holistically, i.e. it does not only care for the AIDS sufferers but also the families affected by the disease and the entire community. The main functions of the Centre include caring for those dying from AIDS-related conditions, while the antiretroviral clinic offers free testing, consultations and ARV drugs to HIV-positive people and also to those at risk of being infected with HIV AND AIDS. The Centre also offers outreach programmes, including in-home care for patients who cannot be accommodated in the Centre and for their families.

In the course of 2007, the Centre admitted 492 patients, of whom 379 eventually died. One hundred and thirteen patients were nursed back to health through the use of antiretroviral drugs and proper nutrition. Since most patients are severely undernourished on arrival, nutrition is vitally important. The Centre's two food gardens provide much of the fresh vegetables and herbs for meals.

The Centre also cared for 30 children (aged between birth and 7 years of age) in 2007, all of whom were given antiretroviral drugs. From 2006 to 2008, 15 children were sufficiently healthy to start Grade 1, while 11 children were placed in foster care and 4 were adopted. The Centre uses loving care, medication and nutritional food to nurse the children back to some degree of health.

From what I observed, the nursing staff internalised values and practices inherent to the Centre, namely respect, kindness and dignity which in turn, are apparent in their attitudes and activities. The nurses are extremely polite to the patients, greeting each one by name, respecting them,

insisting that they do not constitute just a number, and enquiring after their health each day. The nurses have a gentle way when dealing with patients, both physically and emotionally, creating an atmosphere of love, safety and compassion. When patients raise concerns about pain or medication, a note is made on their charts for the doctor to investigate and explain when he does his rounds. The nurses check blood pressure and temperature and bring the patients their medication for the day. They ask the patients questions about when their families and friends are coming to visit, change their soiled 'adult nappies' and place them in their wheelchairs for time outside.

The nurses were observed spending time, often after their shifts had ended, listening to patients talk about their condition, their fears, their post-death arrangements for their children, and trying to offer advice, comfort and support to put their minds at ease. Welma, one of the nurses, said "this is not just a job, this is a calling", the Centre's beliefs truly resonate with the nurses. Some of the nurses, like Boitumelo, were offered positions overseas for a much higher salary but they chose to stay, Boitumelo said "I believe that my contribution is making a difference in the lives of the patients and in the fight against HIV AND AIDS so I am not leaving". Boitumelo gives public talks on the reality of AIDS, as well as at schools explaining to learners how HIV is spread and prevention methods that are important. With many of the Centre's nurses having had experiences with HIV AND AIDS in their own families, they understand the turmoil caused by this disease.

The threat of secondary infections are a daily reality for the patients at the Centre. Unfortunately for children who are HIV-positive, even a simple cold could mean a death sentence since their immune systems are weak and they cannot fight off secondary infections. Thus children with a secondary infection are isolated from the other children and given fast-acting child-friendly medication that complements their antiretroviral medication. When Sipho fell ill with a cold he

had to be separated from the other children which, for him was difficult to understand because he was five years old and he asked me “Did I make a boo-boo?” For Siphon, being isolated was especially traumatic since he had always been afraid of doing something wrong because he had been scolded relentlessly by his mother before he came to the Centre. His mother had threatened to send him to live with his Nigerian father if he behaved ‘badly’, creating a deep-seated fear in Siphon. The counsellor has to explain to the children in the simplest manner why they are isolated and that they will soon be reunited with the other children if they take the additional medication and fight off the infection. Pharmacists are careful to use medication with minimal side effects and prefer medication that will act quickly and prevent the spread of germs to the other children.

The threat of such infection, especially in winter months when influenza and colds abound, is taken very seriously, with weekly meetings about the measures that are in place to curb rapid infections, as well as daily updates about sick patients’ conditions and any symptoms shown by other patients. These meetings are chaired by the Matron and attended by the chief sister for each ward, the pharmacists and the Centre Director, Tilly. For the children, sickness is not uncommon so a few additional tablets are not seen as daunting. They are accustomed to being in a clinical environment and being examined by Dr Ngumbe weekly.

3.3 Secondary functions of the Centre

Besides its primary function of caring for terminally ill AIDS patients, the Centre also functions as an ‘extended family’ by providing shelter, care and counselling to people who are infected with HIV AND AIDS. This custom of caring is based on the values of the Centre’s founder and its mission, and is manifest in the provision of support in the form of AIDS education and food parcels for family members and children affected by HIV AND AIDS. For example, after Lennox was admitted to the Centre, his 10 year-old daughter was left without a breadwinner because

his ex-wife was unemployed. As a result, the Centre sent the psychologist to counsel the child, while Father Nicholas went to the informal settlement where mother and daughter lived to provide them with non-perishable goods. He arranged for them to become members of the Centre's monthly out-reach programme that provides financial and food support to families of patients.

The team works to educate family members and patients about how to deal with AIDS, identify the needs of a patient's family at each stage of the disease, and about the progression of the disease so they know what to expect. All patients are protected by doctor-patient confidentiality which gives patients peace of mind. The patients and families are involved in decision-making involving the care of the patient since this is a family-focused environment. Nutritional plans, vitamins and information about knowing one's rights are supplied to patients and their families, as well as contact details for HIV AND AIDS support groups.

From my observation, I discerned that the organisation's culture embraces and promotes empowerment of AIDS sufferers and their families by providing them with the necessary tools to cope with the consequences of the disease. The Centre empowers families of HIV AND AIDS sufferers with coping skills that prepare them for the progression of the disease and the loss of their loved ones. Lennox's daughter and ex-wife were counselled on what to expect when they visited him and how to handle their grief and sadness should he die. The Centre provides emergency shelter and counselling for child-headed household members until they can be placed in foster care. Princess, for instance was originally admitted to the Centre as a child household head along with her brothers. Further testing revealed that she was HIV-positive but that her brothers were not. They were subsequently counselled and placed in foster care, while Princess was admitted as a patient to the Centre.

Bereaved families are visited by the psychologist and one of the resident priests to help them cope with death. Where circumstances do not allow home visits, literature on bereavement is sent to the family to help them cope with their loss. Home-based careworkers or volunteers visit the communities of origin of the patients to inform them about the causes of HIV AND AIDS to lessen the stigma for the family left behind. The Centre also provides free funerals for those who cannot afford to bury their dead. The families are allowed a 'safe place' to vent their emotions, where they are also counselled as a means of support. When Lennox died, his ex-wife could not raise funds for a funeral and the Centre paid for it, inviting family and friends for emotional counselling before and after the funeral. The families of patients are asked to provide feedback on the quality of the care their relatives received in order to reinforce positive aspects of the care and to identify areas that might need attention.

When a patient dies, counselling sessions to reduce the possibility of stress-related illnesses are mandatory for careworkers who were directly responsible for the patient concerned. In attempts to ensure that they are more effective in performing their roles, careworkers are taught to ask for help when they are under pressure. This system allows careworkers to gain greater understanding of the patients' fears and be of the utmost benefit to them. Reports about the success of these sessions are scrutinised by the Centre Director, Tilly, and the Department of Social Welfare to guarantee accountability of the staff towards their patients. The system is effective and functions to the benefit of the patients and the careworkers. Miranda, one of the nurses showed signs of burnout after a patient that she had been emotionally connected to died. She had tried to continue in her job as though nothing had happened, without allowing herself to grieve. One of her colleagues reported that "she isn't concentrating and her eyes fill with tears when she looks at the bed where he used to sleep". The counselling sessions allowed Miranda

to speak about her feelings of grief and loss and following three weeks of sessions, she had achieved closure and was behaving the way she had prior to the death.

3.4 Outreach work

Volunteers embody the Centre's spirit of generosity and sharing, and in keeping with these values, they give of their time for the benefit of those less fortunate. There are 40 volunteer home-based careworkers who assist the patients with recreational activities and simple exercises. They also operate in 3 large informal settlements weekly, visiting HIV AND AIDS patients who cannot be accommodated at the institution. Over 1000 people have been cared for in their homes, while over 70 food parcels, at a cost of R200 each, are supplied to needy families on a monthly basis. The food parcels consist of nutritional supplements and appropriate portions of food to balance protein, carbohydrates and fats that help a patient's immune system to fight secondary infections. Volunteers deliver antiretroviral drugs to these people, and in winter supply them with clothes and blankets.

The volunteers help to bath and feed HIV AND AIDS sufferers, clean their houses and provide them with much-needed company for a few hours. They also read from the scriptures, while priests accompany the volunteers to pray for patients when they are close to death. The volunteers also make funeral plans for such patients before they die.

Advice and counselling may be provided telephonically to patients, while the Centre's volunteers visit the person responsible for caring for a particular patient, also to educate them on caring for an HIV AND AIDS sufferer. I observed the Centre's culture to be one of treating people as individuals, aiming to provide personalised care to each patient. Each outpatient has one volunteer home-based caregiver assigned to him/her to ensure that they get to know and trust the caregiver, the advice they give, and to help them follow the regime designed for them. This

means that each patient only has to deal with one caregiver, while each caregiver ultimately is responsible for several patients. "Sally-Ann made me to know what happens to Lennox and what I must do for me and the child" said Lennox's ex-wife who also explained that Sally-Ann acted as a source of information about the disease and what to expect in each stage as well as lending both emotional and material support to herself and her daughter.

Volunteers work very closely with their fellow volunteers, and because they share such meaningful, emotional experiences in assisting patients and the community, they form a close bond with each other. This allows them to view each other as 'family', assist each other and share vital information, and have a greater focus on human resources than on policies and procedures of the Centre. The volunteers are responsible for facilitating 'fun' activities with the children such as painting, making dress-up paper clothes and playing games such as hop scotch and jumping on the trampoline. They also help the adult patients to get dressed, read to them from books, and help them to write letters to their families. For them rules are less important than encouraging the children to think 'outside the box', be creative and have fun. Helping the adults to put their affairs in order and get some joy out of literature and music are essential to help them cope with their circumstances.

Thus the staff are more focused on being functionally-orientated with the patients in terms of managing their disease, whereas the volunteers show them how to have fun. For this reason the volunteers are popular with the children in particular, who say that they look forward to their sessions with the volunteers. The volunteers are less popular with the staff since they are more involved with providing the patients with fun and less instrumental in enforcing rules and structure, they bring a lively element to the Centre. Each child is treated as an individual and given the freedom to express himself/herself while being praised and cherished for their

accomplishments during these times. These sessions are a break from the often mundane routine of the day because they give the children a chance to express themselves.

The liaison officer, Granny Swelinkomo, conducts workshops to educate the community about the dangers of HIV AND AIDS, thereby demonstrating the values and beliefs that are intrinsic to the Centre. Two-hour school workshops have been undertaken in primary and high schools in Boksburg, Daveyton, Vosloorus and Reiger Park. Workshop themes include: home-based care training for staff and relatives of people with HIV AND AIDS; HIV AND AIDS as a disease – causes and treatment, condom usage and safe sexual practices; coping with rape; TB and AIDS; pregnancy and HIV AND AIDS, especially for expectant mothers at the antiretroviral clinic and in the informal settlements; post-HIV exposure prophylaxis for those infected with HIV AND AIDS, such as antiretroviral frequenters; opportunistic infections, and the use of antiretroviral drugs and their side-effects.

3.5 The antiretroviral clinic

In keeping with the Centre's caring values and practices, the antiretroviral clinic was devised to extend help to the community to include not only the patients but also the broader outpatient group. The antiretroviral clinic staff share the core values of the Centre, apparent from an abundance of cooperation and reciprocity evident among them. The clinic was built on the property opposite the Centre to serve the HIV-positive patients housed at the Centre and outpatients who visit/attend the clinic for their anti-retroviral medication (see 3.1 above). There is also a mobile clinic in Reiger Park that travels to informal settlements to conduct HIV tests, counsel patients and dispense ARVs. The clinic does not work by appointment but rather on a 'walk-in' basis since the idea is that people should feel at ease and unpressurised. The clinic is open from Monday to Saturday (07:30 to 19:00) and is closed on Sundays.

The antiretroviral clinic has helped more than 3000 people with HIV testing and counselling and to date 924 patients have been placed on antiretroviral treatment. More than 70 children visit the paediatric section of the clinic as outpatients; many have been referred by doctors and others are children of patients. The social worker aids the patients and their children to gain access to government welfare grants. She does this by helping the patients to access and complete the necessary documentation, and expedites the process for those who desperately lack resources. Many of the patients are unaware that they are entitled to a grant. Some use this money to help support their families.

After observing the clinic and speaking to 30 outpatients, it became apparent that the range of patients varies from white teenage former drug addicts to middle-aged black women who have been infected by husbands who sleep with infected women. Queues start early in the morning, with some people hiding their faces, while others unashamedly strut into the clinic. The outpatients come once every three months to fetch their three-month supply of medication, to be examined and the success of the drug regimen assessed, while nutritional supplements and advice are also dispensed at this time. Since the clinic opened, it has gained great local media coverage to make people aware of its existence and to assist as many people with HIV AND AIDS as possible.

The clinic's large waiting room is sunny and warm and has numerous chairs that are padded and have armrests for comfort. The colours are inviting pastel shades. A rack holds an extensive range of magazines. A heating and cooling unit keeps the room at an even temperature. The clinic's reception area and doctor's office display pamphlets in all of South Africa's official languages. The reception area is separated from the waiting room by a dry-walling partition to give the patients some privacy. The receptionist uses a high back boardroom

type chair and the patients sit on easy chairs while talking to the receptionist. The space between the receptionist and patients indicates that there is a comfortable, relaxed atmosphere as they sit relatively close together.

The floor plan of the antiretroviral clinic is indicative of the principles of respect for patients and their privacy, with the doctor's office and examination areas being completely private. The doctor's office is large enough for his desk, four chairs and a separate examination area. The counselling offices are large and light, with a plethora of nutritional and other health posters adorning the walls. As elsewhere in the Centre, I observed an environment that treats people as individuals. Each person is tested to see which drug cocktail will be the most effective for his/her needs since this differs from person to person. Patients receive holistic treatment in that they are given nutritional advice and an exercise programme, psychiatric counselling, physical examinations and welfare planning for their families and loved ones. The whole family is encouraged to come for counselling in an attempt to dispel myths surrounding HIV AND AIDS and to help the family to understand how vital their love, support and acceptance are to ensure the well-being of the patient. Coping strategies and plans are developed for each patient and their families but only if the families choose to be involved. Counselling is available during working hours for anyone who wishes it and Father Stan is available twenty-four hours per day.

The clinic is manned by three counsellors, one doctor, two nurses, one administrator and a receptionist. The counsellors administer counselling to the patients, after which they are examined by Dr Ngumbe, and then medication is prescribed. In the spirit of the team-work displayed by the Centre, the nurses help the doctor by taking blood pressure readings, weighing patients and aiding them to complete the forms. The receptionist and administrator ensure all records are up to date and accurate. The staff are all relatively young, averaging from 28 – 40 years, with the exception of Eve, the Secretary, who is older. Clinic management is also

pyramidal in structure with Father Stan being the head, Dr Ngumbe is next in authority, followed by the receptionist and administrator.

The clinic has an atmosphere of sensitivity, anonymity and confidentiality, with patients referred to by first names only or even by pseudonyms. Patients say little to each other to protect their anonymity. Staff are representative of the Centre's culture, displaying professional and non-judgmental behaviour, and avoiding discussing patients with each other to protect their confidentiality and to avoid stereotyping and discrimination.

In accordance with the organisation's values of sensitivity and compassion, nurses can often be seen comforting distraught patients and their families in the corridors and the waiting room because being diagnosed as HIV-positive is highly traumatic and signals a shift from being healthy to being sick. Observing the patients and staff reveals that there is good rapport between them and that patients are at ease at the clinic. The level of involvement with the well-being of the patients by the staff is clear from the fact that many of them attend funerals of patients. This also reveals their compassion and the deeper level of the relationship between nurses and patients.

While observing the arrival of outpatients, I noticed a man who appeared lost. He asked me whether he was in the correct place to be tested for HIV and I proceeded to question him to ascertain how much he, as a probable average outpatient, knew about the clinic and about HIV AND AIDS. Here is the conversation with this outpatient:

- John (patient): "Hello madam"
- Lauren: "Hello, how can I help?"
- John: "I think I'm sick, is this the medicine place?"
- Lauren: "Yes, the doctor will examine you and let you know if you're sick. If you are sick he will give you medicine to help."
- Lauren: "Do you know how you got sick?"
- John: "I sleep with hooker."
- Lauren: "Have you ever had an HIV test?"
- John: "No."
- Lauren: "So you know much about AIDS?"
- John: "I know you die with AIDS."
- Lauren: "If you are HIV-positive and you get drugs here, you can live much longer and you can live without getting AIDS for much longer."
- John: "Dankie Sus."

3.6 Organisational structure, leadership and human resources

The organisational structure is as follows:

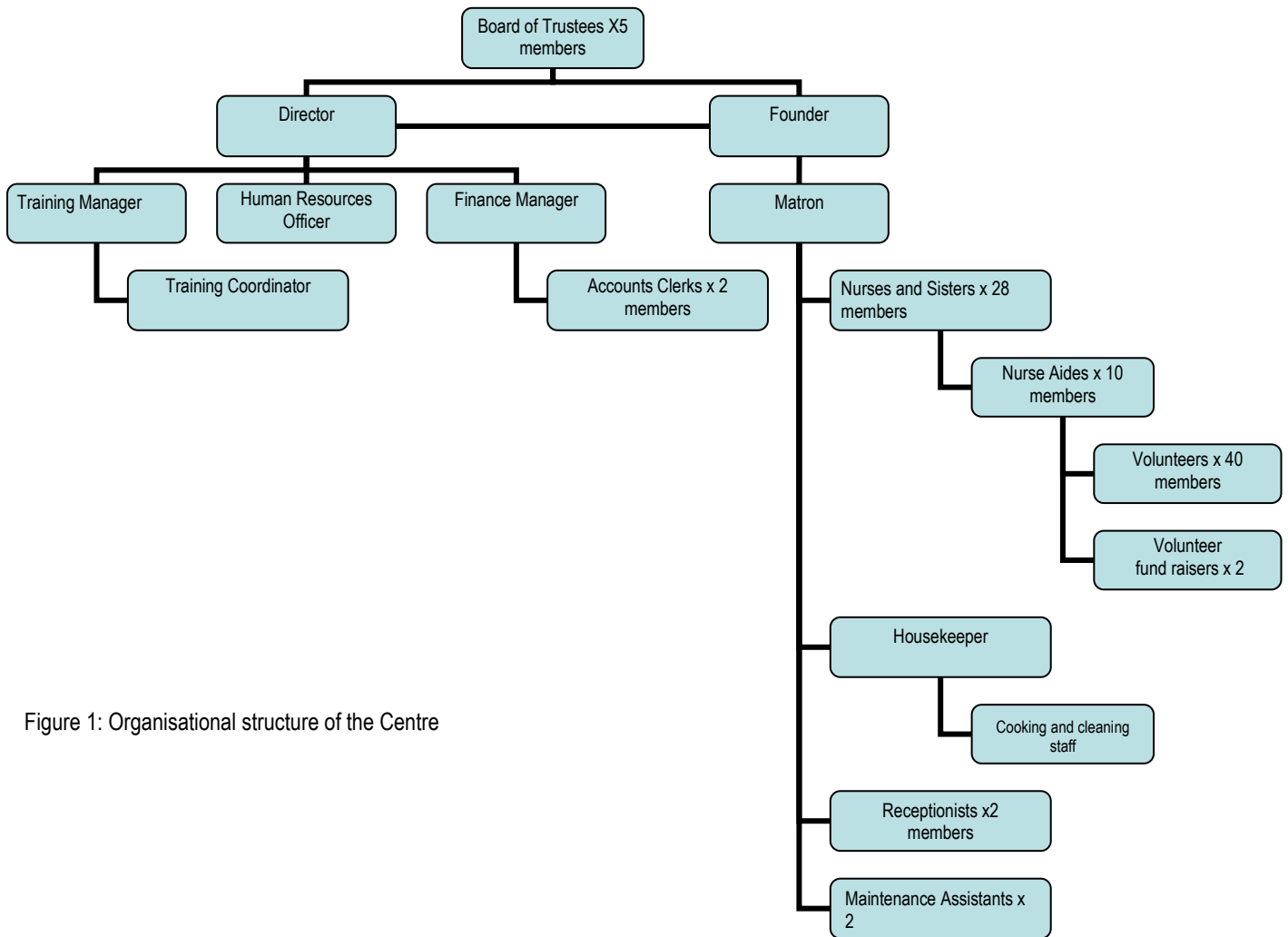


Figure 1: Organisational structure of the Centre

The organisational structure and leadership patterns provide a framework for understanding the Centre’s culture and specifically its political system that impacts on activities, relations and decisions, amongst others. Jordan (2003, also see 1.3.2 above) has noted the importance of such exploration of the organisation as a whole. There are one hundred and nine ‘staff’ members, sixty-seven of whom are employed by the Centre as salaried employees and forty-two who are unpaid volunteers (see Figure 1, above). This excludes Zelda, the Social Worker and volunteers (with Sally-Ann as the team leader) who work for the emotional reward of providing companionship, assistance and compassion to the terminally ill. An element of the organisation’s culture is represented by the diversity component which includes a multitude of

racess, gender, ethnicities, languages, and religious groups. The gender split revealed an interesting phenomenon at the time of the research: there were fifty-nine females in contrast with eight males among the salaried staff which reveals a female bias. This reflects the gender split within the nursing profession in general which attracts more women than men.

The Centre is under the authority of the Board of Trustees, while the Director (Tilly) and Father Stan are next in charge and of equal status, having equal authority over the other employees. Father Stan is generally respected as the unofficial authority figure with the greatest importance and most decisions are brought for his approval since he is influential with the Board of Trustees and because of his role as founder of the Centre. When Father Stan suffered a heart attack and was unable to make decisions on behalf of the Centre, the Board of Trustees assumed full authority and, due to Father Stan's ailing health, the Board was voted as the controlling authority of the Centre from that point onwards. The Finance Manager, Training Manager, Matron and Human Resources Officer are co-workers with equal status, with the first three each managing his or her own team. The Finance Manager oversees the activities of the accounts clerks, while the Matron has authority over the nurses, nurse aides, volunteers, the housekeeper, the receptionist and the maintenance staff. The Training Manager has authority over the training coordinator. The housekeeper has authority over the cooking and cleaning staff. Independent auditors assess the financial records annually.

The Centre has strong leadership, with the most leaders' goals and agendas readily being adopted by the organisation. This reflects the sharing of values and norms by the staff, which in turn indicates a cultural environment where the majority of employees identify with the organisation and its aims. To some extent management is not included since managers are more individualistic and work less cohesively as a team. Presently management styles in the different sections are participatory with all views being considered, but ultimately the final say is

reserved for the head of the section concerned. All medical decisions are made by Sr Claretta, the Matron and Dr Ngumbe, the Doctor. All staff with a lower status than that of the Finance and Training Managers and the Matron have little autonomy or few decision-making powers because decision making is fairly centralised in the senior managers.

Nurses work in shifts. There are three shifts of 8 hours each per day, from Monday to Sunday. All other staff work from 08h00 to 17h00 from Monday to Friday. The Human Resources department is very small. It is run by Lydia, the Human Resources Officer, who deals with disputes, employment issues, hiring and firing, remuneration, payroll issues and teambuilding amongst others.

The antiretroviral Centre is generally under Father Stan's authority (his 'pet project'). He makes the final decisions about staff acquisitions, operating hours, and policies and practices pertaining to its operations.

3.7 Issues of management in the Centre

3.7.1 Aspects of daily management

Smooth-running operations imply an organisation that is effectively managed and staff that identify with the organisational values and goals. Consequently operations are vital in a study of an organisation's culture and this section focuses on the links between organisational values and functioning.

The current ratio of patients to nursing staff is almost eight patients per nurse or nurse aide, with eight nurses and two nurse aides per shift for both the adult and children's wards. A nursing sister is in charge of the nurses during each shift. Nurse aides, of whom there are 10, perform duties such as bed-pan cleaning and lifting patients into wheelchairs for transport.

The Centre has many policies and procedures in place to ensure that it functions effectively. The policies dictate rules about appropriate levels of patient care, overtime worked by staff, involvement with patients in terms of physical relationships, leave, chains of authority, incident reporting, finances, fund-raising, pharmaceutical storing and dispensing, policies set by the Department of Health and the Department of Social Welfare and policies on the necessary qualifications of staff to deal with patients. The Departments of Health and Social Welfare require regular reports to ensure that policies applicable to the Centre are adhered to and that patients receive the desired levels of care.

Of all the nurses, only Maggie objected to Dr Ngumbe's presence, saying that the Centre needed a South African doctor who would understand the beliefs of the patients. All the other nurses felt he was filling a vital position and that his track record with them and the patients as a caring and knowledgeable professional was more important than the fact that he is a foreigner. The nursing staff seem to work together harmoniously with few complaints about each other, with the exception of Boitumelo, whom the other nurses felt was too attached to a patient named Karabo and that this was unhealthy, creating confusion for the child. These nurses confided that Boitumelo spent excessive amounts of time with Karabo because of her resemblance to Boitumelo's late daughter and that she should behave more professionally and show less favouritism. The nurses generally felt that Heather interfered excessively in the medical activities of the Centre and that she should allow Sr. Claretta and Father Stan to make the vital decisions affecting the medical staff. The general consensus among the nurses was that Father Stan treated them well and that none of them considered leaving the Centre.

The Centre attempts to ensure that the staff get help where help is needed so that the patients receive appropriate care from emotionally healthy staff. The long hours and emotionally-draining nature of caring for terminally-ill patients and having to cope with death as a constant element of the job causes extreme stress which may cause staff to resign or endure emotional scars, which in turn, affect patient care. Although the nurses experience their jobs as extremely stressful and many have made use of a counselling session at some point, they maintain that their job is rewarding and fulfilling. The counselling sessions are popular usually after the passing of a patient. The counselling sessions, provided by the psychologist, ease the nurses' stress, give them constructive ways in which to deal with it, and especially help them to deal with the loss of a patient and the associated grief. Sessions can be booked on any day or time of the week, depending on the workload of the nurse involved and the psychologist. Burnout is a very real possibility for staff in these circumstances and as such, the counselling sessions also help to prevent burnout (cf. Weisfeld 1991:48-50). "We get more emotional about the death of one of the kids than when an adult patient dies because lots of us have kids so it's harder to imagine that kid suffering and dying without its mother". The nurses said that while nursing is a draining and self-sacrificing career, they felt a sense of achievement from the work, and that this was much more valuable to them than any monetary reward. Nonetheless, there are occasions when a nurse is overwhelmed by the circumstances of her work. Sihle, a nurse who had been working long hours during the December holiday period, had to face the fact that a patient to whom she had become attached passed away. The pressure of the situation resulted in Sihle making a call to God, and driving her car into a tree. While she recovered physically, the Centre realised that Sihle was suffering from burnout and needed urgent attention.

Volunteers work with the patients to stimulate them both mentally and physically and help the nurses wherever possible to care for the patients. As mentioned in 3.4 above, volunteers help the patients to do simple exercises to keep their muscles in working condition and aid the patients mentally by conversing with them and reading to them. This means individualised care for patients unlike in state institutions where nurses have to care for many patients and hence do not have the capacity to provide patients with individualised care and attention.

Zelda, the Social Worker, ensures that the children she places at the Centre are adequately cared for. In this way she complies with the objectives of the Department of Social Welfare. With the proper policies in place, the smooth running of the organisation is ensured since one always has a policy to refer to in order to provide guidance to staff when incidents occur. In this way it is possible to guarantee the procedures followed are in line with organisational policies. The policies provide order in what otherwise seems like a chaotic environment.

The pharmacist dispenses medication, does stock-taking and completes the necessary paperwork for the Department of Health. She also provides information about how the drugs will help patients as well as the possible side effects that they might experience as a result of the drugs. The Matron functions as the pharmacist during emergency situations that may be experienced by the patients in order to alleviate the pressure on the pharmacist and to ensure that she can complete the scheduled tasks set for the day. The nurses ensure that the patients take their medications or 'meds'. It is more difficult with the children as some experience side-effects such as nausea and dizziness. The children are so used to this part of their day that they already line up waiting for the 'meds' before the pharmacist has started to distribute the medication. They know that the drugs will help them to feel stronger and fight the illness in their bodies.

Meetings involving operational and nursing staff are held to ensure the efficient running of the Centre. This offers them the opportunities to communicate their concerns and requirements to each other.

The prescription itself, i.e. instructions for taking the medication and how to fill the prescription is explained to the outpatients and their families (cf. Weisfeld 1991:81) since not everyone understands a prescription or has used one before. These explanations help patients to adhere to medical regimes. Staff at the Centre and the antiretroviral clinic explain the details to the patients and their families in their home languages, thereby making them aware of the importance of the medication for extension of their lifespan and improvement of the quality of their lives. Benjamin, one of the adult patients at the Centre, shared that “At that other clinic the doc gave me a paper to get pills but no-one said where I must take it and what must I do with the pills”. The need for clear instructions about what to do with the prescription and why the pills are necessary cannot be understated and hence the Centre and clinic provide clear guidance on both.

3.7.2 Crisis management

Crisis management or contingency plans employed by the Centre that I witnessed reflected well-developed organising skills and a cohesive institution. Crisis management measures are in place. For instance, on a cold day in June the Centre experienced a power failure and with almost immediate effect, the back-up generators started and the patients that were connected to respirators did not experience a break in their care. The generator also powers the lights because many of the children are terrified of the dark and the last time the power failed, some children screamed and Doctor, one of the child patients, hid under his bed because “the monsters are going to get me”. The housekeeping staff panicked about how to prepare the evening meal; one looked for the paraffin stove and the others tried to make salads to ensure

that the patients did not deviate from their nutritional plan. Fortunately, the kitchen is also connected to the generator but this section took longer to get power from the generator. Patients are negatively affected by the cold because their bodies are so frail and thin and because of this, the generator also powers the heaters and the day the power went out, the nurses rushed to give the patients extra blankets until the heaters came back on. Spare oxygen tanks outside the ward ensure that oxygen is available to ventilate patients in need of oxygen. At the back of the property is a reservoir that can be used if a water shortage occurs. There is always a stockpile of antiretroviral drugs to ensure that drugs are available between deliveries of consignments.

In the event of there being more bodies than can be accommodated in the mortuary, a contract is in place with Avbob, the funeral undertakers, which ensures that excess bodies are taken to a private mortuary and kept there until the funeral takes place. During the winter months there was a time when there were more than eight bodies that needed to be accommodated and the Director had to instruct Avbob to remove a few of the bodies but the local branch of Avbob was already inundated with bodies waiting for burial because there had been a particularly dangerous strain of influenza that had taken many lives. It took Avbob two days to remove the excess bodies so a fellow AIDS hospice had to be contacted to assist in the storage of the excess bodies.

A private medical staff recruitment agency has commissioned trained contingency staff who, in the event of strike action or unforeseen incidents, take care of the patients. A full-time psychologist is on call 24 hours per day to deal with crises that involve emotional and psychological issues for patients or their families. Families of sufferers can be accommodated in the friary if necessary, alleviating some of their stress.

3.7.3 Disciplinary measures

Disciplinary measures are in place to ensure that all the staff, including the nursing staff, behave in accordance with required procedure, failing which, disciplinary hearings are held. Disciplinary hearings are held by the Human Resources Officer, Lydia. Less serious offences such as insubordination are dealt with informally and may result in verbal warnings. Serious offences such as gross misconduct, negligence, sexual offences or stealing warrant a disciplinary hearing. Serious transgressions are treated formally and handled immediately to demonstrate the fact that such behaviour is not tolerated and in fact, results in censuring. Disciplinary hearings often result in first and final written warnings that are kept on record for a period of 6 and 12 months respectively. Any further transgressions of a similar nature are taken as grounds for further disciplinary action or even dismissal as a last resort. Disciplinary hearings are rare at the Centre since employees understand what is expected of them and the consequences of deviant behaviour. A case in point concerns Emmanuel, Father Stan's personal assistant, who had a sexual relationship with a volunteer student from Japan. The two fell in love but Mi Ling knew that her parents would never accept the relationship. A month before she was due to return to Japan, she discovered that she was pregnant. Mi Ling told her parents about the baby and they insisted on disciplinary action against Emmanuel. Mi Ling's parents believed that he had taken advantage of their young and impressionable daughter but Emmanuel insisted that they were involved in a serious relationship. To follow the Centre's protocol, a hearing was held and all procedures were followed as laid out in the Labour Relations Act. Emmanuel was found guilty of breaching the Centre's rules that stated that employees may not be intimately involved with patients, volunteers or visiting students. A written warning was placed on his record and he was informed that any further transgressions would result in severe disciplinary action or dismissal. Mi Ling returned to Japan and gave birth to a baby boy.

Lydia, the Human Resources Officer, decides on the type of action needed where disciplinary measures are necessary and investigates the alleged transgression. The accused is served with a notice informing him/her of the upcoming hearing. Hearings are held in private and Lydia is the chairperson. She explains the procedure and presides over the proceedings, with Eve, the Secretary, taking minutes. Heather, a Board member, represents the Centre by leading the evidence. Following this, the accused is permitted to ask Heather questions to dispute the evidence, after which evidence such as affidavits is introduced in support of the Centre. Witnesses may be called and policies drawn on to support the Centre's evidence.

The accused then gives evidence and provides any documentation or depends upon witnesses called in his/her defence. The witnesses are cross-examined and each representative summarises his/her position, states any factors in mitigation and any aggravating elements that should be considered in the accused's favour. After concluding remarks, Lydia announces when her verdict will be delivered. She does so with an explanation of its implications for all parties. The accused signs the verdict document which is then filed by the Human Resources Officer.

3.8 Financial matters

The finances of an organisation reflect its policy about spending, which in turn, is based on its values, goals and even ethics. Anthony (1994:28, see 1.3.2 above) refers to the economic system of an organisation, encompassing all its financial matters, as an important aspect of the study of an organisation's culture. The Centre that is the focus of this study is a non-governmental organisation (NGO), a non-profit organisation which is always full, and has a perpetual waiting list. Because the organisation is an NGO, thrift is highly valued to ensure that business and spending decisions are always prudent so that the maximum funds are available for the care of the patients. The Centre is mainly funded by private donors. The manner in which money is spent at the Centre is in line with its inclusive and non-judgemental culture, and

funding is used to assist not only the resident patients, but also the outpatients, HIV AND AIDS sufferers in the community and their families. Father Stan makes bi-annual trips to Ireland where his family has stature and influence. They assist him to obtain donations in Pounds Sterling and Euros. He carries a portfolio of his achievements with him when he travels overseas and locally in order to motivate the private sectors in Ireland and South Africa to donate to his causes.

Father Nicholas obtained funding from his sources in Japan and from Japanese businesses in South Africa and across the world. The favourable aspect of obtaining funding from overseas sources is that the exchange rate substantially increases the actual amount of money received by the Centre. Forty-five percent of the funding for the Centre originates from the South African private sector. The Centre itself attempts to supplement the donations by amongst other strategies such as taking its donkey and cart to local flea markets and fairs where donkey cart rides are offered to children for a small fee. The shop that Heather runs also contributes to the income of the Centre in a modest way by selling second-hand goods to the staff and public.

In 2004 the Department of Health gave the Centre a R200 000 grant despite its application for R 2 000 000. Three years later in 2007, government subsidies amounted to R 1 339 092.00 from the Department of Social Welfare and R 511 000.00 from the Department of Health, both of which constituted only a fraction of the total amount required to fund the Centre for the year since in this year monthly expenses exceeded R750 000 out of an estimated annual budget of R9 million. Expenses included the cost of caring for all the patients, payment of services such as water and electricity, and salaries which are provided for by funds provided by private and corporate donors. As a result of the Lottery Board having a backlog in application processing, funding from proceeds of the national lottery for 2007 had not been received by mid-2008.

In 2007/8 the Department of Health notified the Centre that due to internal financial pressures, subsidies would be reduced, resulting in a grant of R 511 000 (when R 1 500 000 had been applied for). This meant that only five out of the Centre's forty-eight beds were subsidised or funded by the government, with the remainder being subsidised by private donations and funders. This reduction is equivalent to a loss in subsidy of R 35 000 per month or 43%. The Department explained that their limited budget had to meet the demands of a growing number of AIDS patients spread across various institutions, and hence the reduction in the Centre's grant. According to Tilly, the Director, four NGOs provide hospice care for HIV AND AIDS sufferers in the Greater Ekurhuleni area with its population of over 2 million people, and all compete for funding from the same limited resources. When funding gets low, the Centre appeals to the public via the local newspaper, the *Boksburg Advertiser*, and to date the Centre has never been disappointed. The Centre received a R1 500 000 donation from the Japanese Film Society in 2006, giving it the financial boost it needed to carry it until the next donation was received. Father Stan believes that "the Centre will never run out of money and that God will provide for us", and so far his faith has been well placed.

The Centre monitors and records all demographics of patients for the Government data base and for funders' records. In order to secure funding for the Centre and to ascertain whether funding could be provided on an on-going basis, the Finance Manager holds regular meetings with private sector funders. Companies such as Afrox, Unilever and 3M provide donations as part of their corporate social responsibility. They select a charity that is suggested by their stakeholders, and one that is identified as playing a significant role in aiding the country and the most needy of people.

The total budget for the Centre's functioning during 2007 was R 9 million. The table below reveals some of the items that constitute the cost of running the Centre. It shows a breakdown of the cost per child and adult patient on a daily, monthly and annual basis:

| Budgetary Items | Cost per day | Cost per month | Cost per annum |
|--|---------------------|-----------------------|-----------------------|
| Cost of maintaining each minor patient | R 139.63 | R 4189 | R 50 268 |
| Cost of maintaining each adult patient | R 282.77 | R 8483 | R 101 796 |

Figure 2 Operating costs for the Centre per patient

The cost of caring for one child amounts to R 50 268 per year and costs for adults amount to R 101 796 each per year. These costs are based on the cost of providing superior care from properly trained nursing staff, provision of nutritious, well-balanced meals, and expenses such as adult nappies, medication and exercise equipment. The costs for children are similar, but involve additional items such as teaching materials, physical developmental equipment and speech and occupational therapists who are occasionally needed to work with the children. The total monthly cost for necessities for the children's ward such as nappies, formula and yoghurt, amounts to R 18 680 per month and R 224 160 per annum, which has to be funded by private donors due to the reduced subsidies received from the Government.

The nurses' salaries are higher than those paid to nurses at government hospitals. The Finance Manager regularly contacts a friend who works at the O.R. Tambo Memorial Hospital to determine salaries paid in the public sector. Hence the Centre is able to keep abreast of the salaries paid to nurses and sisters generally. They are however, not substantially higher, with junior nurses earning R7000 per month while the more senior experienced nurses gross between R10 000 and R12 000 per month.

Obtaining funding for new equipment or for a new initiative is a slow process because approval must be obtained from a line manager, the Training Manager, Finance Manager or Matron, after soliciting three quotations. The Board must approve the initiative before Marinda, the Finance Manager, is allowed to authorise payment of large sums of money. For example, the quotation for upgrading the kitchen with stainless steel appliances and the quotation for new computers for the training Centre took three months each before they were eventually approved since these are large capital expenditures and have to be carefully considered in light of the funding shortage. Small purchases, however, are faster, requiring approval by a line manager only.

3.9 Training and AIDS prevention education workshops

The types, frequency and relevance of training provided by an organisation can be used as a basis for examining the company's attitude towards its staff, i.e. whether the company is people-orientated, valuing its staff by providing training to develop members or whether the company is process-orientated and only provides training when the company deems it necessary. As referred to earlier (see 1.3.2 above, Jordan 2003:45) research into training as a vital aspect for exploration within the organisational context, provided a foundation for exploring this aspect in the Centre. Training forms part of the formal framework of this organisation's culture, with the type and frequency of training provided giving insight into the Centre's culture. This implies that at the Centre training aims to properly equip staff to be able to do their jobs efficiently. Training

is also provided when staff request training in specific areas of their duties as part of their professional development. When Denise was appointed as the Housekeeper she felt that her skills could be enhanced with a management course and this was facilitated through a local training company. Denise said “I was surprised that I was encouraged to do this course because everywhere I’ve worked they’ve expected me to get on with the job without knowing how to manage and motivate people”.

Part of the induction and orientation of employees includes training about the Centre’s formal and informal cultural elements such as policies, structure, goals, values and beliefs. This training facilitates transmission of the Centre’s culture to new members. The Training Manager, who holds a degree in human resources, is entrusted with the role of interviewing and acquiring new staff as well as their induction and training. For this reason, during the research being reported here, she became a crucial contact for understanding staff, their roles, dispositions, issues and concerns.

The Training Manager commented that “In my experience, women pay more attention to the details and are better at expressing themselves and showing empathy for the patients than men”. She performed limited experiments with aspiring nurse aides and volunteers, by placing male and female interviewees in situations with patients where they would need to interact with and help them. Female interviewees out-performed their male counterparts. For this reason many more women have been employed at the Centre, including in administration positions where they showed greater skill in typing and computer usage, and completed tasks faster than their male counterparts. Training results are evaluated by the Board.

All training initiatives sourced and identified by the Training Coordinator must be approved for viability and applicability by the Training Manager and ultimately by the Board. At the training centre, run by the Training Manager and Training Coordinator, nurses receive training in public relations and administration as well as in advanced care of AIDS patients and grief counselling. Training is provided by a private company run by ex-university lecturers and retired teachers. Volunteers are also briefed here on how to deal with the patients in a manner consistent with the Centre's ethics and principles. All staff are given specialised training in first aid, fire evacuation procedures and extinguisher use, as well as general safety procedures to ensure that they are prepared for all potential situations that may occur.

3.10 Communication

As indicated by Anthony (1994:28-32, also see 1.3.2 above), a typical aspect of the culture of an organisation is the peculiar language adopted by the staff. In the case of the Centre there is specific jargon to describe medical conditions and equipment used in the institution, such as a slab (table on which bodies are prepared after death) and 'meds' (to describe medication given to patients). When I first arrived at the Centre one nurse referred to the 'slab', and coming from a construction background, I pictured a concrete slab used as a floor. In fact she was referring to the table in the mortuary where the bodies are prepared for funeral services. Use of this specific 'language' is an element of the culture that identifies them as members of the organisation.

Some examples of the specialised terminology which is peculiar to hospices for patients with terminal disease include: the 'euphoria stage' which is the term used by nursing staff to describe the initial phase after admission, when patients arrive and are still able to perform some grooming and basic functions for themselves. When incapacitated in the final stage of AIDS, the staff refer to these patients as 'bed bunnies' (bed-ridden). In order not to upset the children

lesions are called 'boo boos' or 'ouches'. Many of the children call the oxygen tanks the 'balloon bottle' because they recognise it as similar to the cylinders that are used to inflate balloons at their parties. The injections used to administer Vitamin B serum to the children are nicknamed the 'crab' because it "pinches and stings".

The Centre's newsletter, *The Village Crier*, is a significant means of communication, both for staff and benefactors. This newsletter helps to facilitate relationships with donors and introduces a sense of community with the Centre because they are kept informed about how their money is utilised. The newsletter is written and edited by Heather, a member of the Board, and Eve, the Secretary. It contains sections on fundraising, updates on events at the Centre, curriculum vitae of staff members so that staff members can get to know each other, staff announcements (births, marriages etc.), as well as the Centre's banking details. A prayer ends the newsletter.

Most employees, especially non-managerial staff, use first names, suggesting a more informal style of communication among them. Many of the nurses refer to each other as 'angel, treasure and darling heart', a clear indication of their emotional connections and the bonds that they share. The communication style among management staff is more formal, signifying that staff at this level view each other more as colleagues than as friends. Informal conversations between Father Stan and Tilly, and various staff members are essential to keep management informed about ideas and possible projects and so that support for them is rallied before formal or official communications occur. The Board is informed of all important decisions immediately and information such as numbers of admissions and deaths are sent to the Board once a month. For example, an apparent xenophobic attack occurred at the Centre, where a Zimbabwean patient was attacked by two South African patients. The patients attempted to strike him with their hands and verbally abused him. The South African patients said that he did not belong in South Africa and that he was taking a place that could be filled by a South African patient rather than a

foreigner. The group had watched a documentary film on xenophobia earlier that day and tensions were high in the ward. For his protection, the foreign patient was moved to a ward where the other patients were bed-ridden. The patients were immediately gathered and the Matron made it clear that any patient displaying xenophobic behaviour would be removed and sent to a State facility, this included both physical and verbal abuse. The incident highlighted the need for tolerance and constant monitoring of the patients. This incident was brought to the Board's immediate attention as well as actions taken to prevent escalation of this situation. All operational matters are brought to Sister Claretta's and Father Stan's attention and they decide what should be communicated to the Board.

Often non-compliance and treatment interruption are caused by cultural differences between the provider of the information and the receiver of the information as complex medical information is usually not in the language of the receiver which makes the comprehension thereof more difficult (Weisfeld 1991:88-89). When Eddie, one of the patients at the Centre, shared how he had visited a State hospital to collect his anti-retroviral drugs, his experience corroborated the need for explanations of the prescription and its use. Eddie had worked as a bricklayer in the construction industry prior to being admitted to the Centre. He had acquired HIV from a blood transfusion that he had received after an accident on a building site. Eddie did not receive schooling beyond Grade 6 and found it difficult to understand the complex medical terminology and the benefits of taking the medication, and as a result, he needed the one-on-one explanation supplied by the Centre and anti-retroviral clinic. The nurse at the state hospital had handed him a prescription for the anti-retroviral drugs to be filled at the internal pharmacy. "She gave me a paper; she said I must drink the pills and I will feel better". I asked him if he understood where to get the pills and what the pills would do for him and he replied "I drink the pills and they take away the sickness. I don't know how long I must drink the pills and how I will know if I'm better". Patients like Eddie require a thorough explanation to understand their

condition and the importance of the medication in order to ensure that they adhere to the treatment.

The ARV clinic tries to eradicate this problem by employing staff who collectively can speak all 11 official South African languages. They explain the information in a person's home language and discuss his/her specific health beliefs, i.e. how they believe they contracted the disease, treatment they have received, as well as people from whom they have sought advice and help, e.g. traditional healers and herbalists. In this way they attempt to gain an in-depth understanding of the patient's health beliefs and behaviour and how best to explain biological information about ARV drugs and altered lifestyles, such as safer sexual practices, in a meaningful and credible way.

In the past, the clinic would explain the medical information to patients without proper consideration for the patient's health beliefs. Phumlani, a child patient at the Centre, found it difficult to adjust to mainstream health beliefs and medication because he had been brought up with traditional herbalist medication and treatments. His mother died from HIV AND AIDS but he had believed that she had been afflicted with a curse and that the witch's curse had ultimately been too powerful for her to fight and she had died. He told me that "I thought I had a curse from a witch. I thought it would get better but here they showed me that I am sick and I need pills to stop feeling sick all the time". It was a protracted process to help Phumlani to understand that his condition was not the work of a witch and that it could be treated with medication. He still has not relinquished his traditional beliefs entirely but has adjusted them to suit the situation: "The witch sent the disease to my body to make me sick". Since the clinic began making allowances for the patient's health beliefs, general confusion surrounding the disease and treatment and treatment interruption have declined. When asked about this, Lizzie, one of the Centre's patients, confirmed that because her health beliefs were not being ignored, judged or

disregarded, she was more willing to consider the information presented to her and to comply more readily with the treatment. Lizzie said that she had friends who had visited state-run institutions and that they had been ridiculed for revealing their traditional health beliefs. This had subsequently stopped her and her friends from finding help and treatment for the disease. Many patients have little biological knowledge of HIV/ AIDS, its symptoms and treatments and hence medical information must to be explained in very basic terms to assist those trying to understand and deal with the condition.

3.11 Power relations within the organisation

According to Hamada (1999:1-3, also see 1.3.2 above), power is part of the political system that underpins each organisation and understanding power relations assists in the understanding of meaning created at work and relationships between members of an organisation. This suggests that in a study such as this, one must investigate who the holders of power are within an organisation, how they wield this power and what its implications might be. Power is a sociocultural dynamic that is always present and impacts the running of the Centre. Power is linked to the structure within the organisation and is wielded by those in authority. It is also linked to staff members' influence on and alliance with those in the highest positions.

The Board member with the most power within the Centre is Heather. She also runs the second-hand shop. She has been employed at the Centre for several years and previously held a senior position in the field of operations. As a result, Heather is highly regarded and respected by fellow staff members and by the Board, and she is regularly consulted in connection with managerial and operational issues. I was given access to operational documentation and hence reviewed proposals by external service providers such as vegetable suppliers and building contractors that she, as a member of the Board, would have assessed in order to select the appropriate supplier. I discovered that of all the proposals and quotations on record,

approximately 75% of those that had been successful, had Heather's pre-approval. This suggests that with business savvy and experience, Heather is the most influential and powerful Board member.

As a result of her position and authority, Heather encounters professional jealousy from other staff members. This tension impacts negatively on the organisation, with a number of management staff members, such as the Matron and Finance Manager, confiding that they felt drawn into these feuds and that they needed to choose sides. This in turn, creates difficulty when attempts are made to reach consensus on issues involving all managerial staff. This power struggle is being addressed by top management before it affects all areas of the organisation.

3.12. Discrimination or prejudice

Discrimination or prejudice is the practice of unfair bias or intolerance against another person or group (Hawkins 1988:139; 394). Ten Brummelhuis and Herdt (1995:29-53,79-97) provide insights into the social context of HIV AND AIDS that contribute to discrimination and prejudice. Their ideas laid the foundation for my understanding of the role that these issues play in the context of HIV AND AIDS, and also for the way in which they feature in the functioning of the Centre. Perrow and Guillen (1990:62) examine discrimination and stigma, highlighting the importance of stigmatisation associated with AIDS. Knowing the effect that stigmatisation has on HIV-positive people proved invaluable since I was able to be sensitive when interviewing the patients. I knew that stigmatisation would be a relevant focus area for this study since it keeps many HIV-positive people from seeking help.

The Centre disproves of discrimination in any form, and any acts of this kind carry serious consequences since they may result in unacceptable friction and disagreements. However, intra-organisational alliances and frictions naturally occur between the staff and between the patients. There are also biases or prejudices that occur between staff and patients. For example, two of the nurses told me that they are sympathetic to patients who contracted HIV through non-sexual means and hence bring those patients treats such as food, books and DVDs. Another nurse told me that she does treat patients differently, showing slightly less concern for patients who are ignorant of the causes of HIV AND AIDS, or for those who believe that parsley and beetroot will cure HIV AND AIDS. Yet she does enough to care for all patients so that she cannot be removed from her position. She is less tolerant when she cares for these patients, not really listening to their beliefs and concerns. The favouring of certain patients causes friction between patients and between patients and the staff members concerned, as well as competition for the attention of sympathetic staff members. These issues have been raised with the Management, and the staff members involved have been censured with informal hearings and have been warned that their behaviour is being monitored. Other staff have been warned to avoid such behaviour or they will face disciplinary action.

3.13 Emotional challenges: trust and frustration

Trust is regarded as a feature of an organisation whose members view each other as individuals of integrity, character and ability (Robbins 1998:193). Trust is a key issue in the Centre since only in an environment of trust will patients be able to reveal their status to others. Many do not do so in their home environments because of the fear of discrimination and isolation. Most of the adult patients admitted to feeling a strong sense of relief when they arrived at the Centre because here they no longer needed to hide their HIV-positive status. Many of them have developed a sense of mistrust of people regarding their HIV status, and the ability to reveal their status allows them to work on self-acceptance and to develop faith in the staff at the Centre.

Trust between staff members, especially the nurses, is strong as they rely on each other for support and help. For instance, two of the nurses told me that especially in winter, the patients contract secondary infections of colds and influenza, and many become bed-ridden, requiring extra care and attention, thus creating more work for the nurses. During these times the nurses rely on each other to care for the patient body as a whole, and no longer identify the wards or areas to which each one will attend. They trust each other implicitly to provide the same level of care to all the patients.

Frustration is a fairly common occurrence in the Centre. This is evident from the high levels of frustration experienced by the fundraisers since their role is to raise funds for the Centre's operations. Yet frequently they are refused meetings with companies and state-related agencies that could provide funding. The outreach staff experience frustration as a result of their participation in initiatives to educate the community about the causes of HIV AND AIDS. They feel that the number of people still being infected by unprotected sexual intercourse is high and that their initiatives have limited effect. The volunteers also experience high levels of frustration as a result of the growing number of families affected by HIV AND AIDS and the number of families who are affected by the stigmatisation and discrimination associated with HIV AND AIDS. The patients are also frustrated by their own bodies failing them when many are in the prime of their lives.

3.14 Elements of the organisational culture of the Centre

According to Wright (1994:17), organisational culture is the set of values, beliefs and acceptable practices that link the individual to the wider group or organisation. In order to understand people's behaviour within the organisational context and the meanings attached to it, we need to observe, question and understand elements of the organisation's culture. Anthony (1994:18)

states that while culture does change and adapt, it offers a relatively stable way in which to interpret behaviour and events at work.

The Centre was founded on religious values and this influenced its culture. Staff are always conscious of the influence of religion because of the chapel and the presence of the priests. As a consequence of this, the founder, Father Stan, perceives the Centre's culture as a resource, a system of shared meaning among its members, providing stability while influencing the attitudes and behaviour of staff. Staff are conditioned to care for the patients according to ethical and compassionate Catholic beliefs and practices. I observed the staff adhering to the required practices of the organisation, which suggests that its values are widely accepted by employees. There is also a common understanding between members about appropriate behaviour. According to the Human Resources Officer, many of the Centre's employees sought out the Centre because its values, ethics and practices correlate with their own. Four of the nursing staff whom I interviewed, and who had worked at state institutions prior to being employed at the Centre, said that they immediately identified with the way the patients were treated, the mission of the Centre and the overtly family-orientated nature. In general, the staff at the Centre are Christians. At least half of the nurses stated that as a result of working in an industry where human life ends daily, they have adopted stricter adherence to religious practices because their own mortalities seem more real. Staff members choose to attend daily services in the chapel with Father Stan as voluntary adherence to organisational practices. Staff members who join the Centre are informed of the Christian influences in the organisation to ensure that they are aware of the religious elements and that they are in favour of working in such an environment. Patients are given the option of attending services but it is left entirely to their discretion.

Policies and practices at the Centre ensure that each staff member is accountable for their actions and staff understood that their actions have consequences and that all possible outcomes of their actions should be carefully considered before taking action. The set of policies and procedures in place are intended to ensure consistent behaviour among the staff and to provide clearly defined standards that produce effective and efficient patient care (see 1.3.2 above). The Centre has an entrenched set of health policies and practices which are biomedical in nature. Policies also prescribe the working hours of staff, admissions, transfers, adoption, and purchasing standard equipment. As mentioned previously (see 3.12 above), discrimination is strictly forbidden among patients, and policies are in place to regulate staff behaviour relating to discrimination following an incident with a patient in the past. As mentioned in 3.10 above, discrimination against foreigners by South African patients was the catalyst for a xenophobic attack on a Zimbabwean patient by two South African patients in 2007 and the Centre's policies and implementation of these policies and procedures are strictly adhered to for these reasons.

Among the patients, nurses, sisters and volunteers at the Centre, a high degree of sociability and high levels of solidarity were observed. When this observation was put to the staff and patients, they attributed it to the high value placed on their friendships with one other. The nurses in particular, said that they felt that because their environment, one where terminally ill patients are cared for, is more stressful and emotionally draining than most other jobs, they form closer bonds and a higher degree of solidarity. Thuli, one of the nurses, said that in an institutional environment it is a necessity for co-workers to function as a team, especially in emergency situations that arise regularly at the Centre, to offer the patients the best care possible. Being professionals, the majority of staff that I interviewed felt that in an institutional environment, their job performance had to be impeccable. Sr. Claretta shared that she believed that the high quality care exhibited by the nursing staff has contributed to the success of the Centre and the overall well-being of the patients. According to Goffee & Jones (1996:133-148),

relationships among the management staff are 'fragmented', with staff showing low levels of sociability and solidarity. Managerial staff are more task-orientated than team-orientated, concentrating on their specific tasks within the organisation.

New patients and staff have norms and values transmitted to them through formal 'induction' procedures and by following the example set by fellow patients and staff. This 'induction' process involves patients being informed by the Matron about the rules of the Centre and consequences for non-compliance, staff members from different business units are introduced to them and their roles explained (e.g. fundraisers, training staff, outreach staff and even finance staff) and they are introduced to other patients to facilitate integration. In addition, new patients and staff are taken on a tour of the property to familiarise them with their surroundings. The majority of patients adopt behaviour deemed to be acceptable.

Management at the Centre reveals a high degree of formality, which is indicative of lower people-orientation in this division, with many addressing each other by their surnames. The nursing staff are more informal, addressing each other by their first names and thus revealing greater people-orientation (see 3.10 above). The managerial staff wear business suits, whereas the nursing staff are slightly more casually dressed. Even though they wear nurses' uniforms, the uniform and flat shoes appear more casual since the uniform is made from flexible fabric to accommodate the care of sick patients. Another important difference between management and other staff members is that the turnover among staff at managerial level is higher than among the nursing staff, and Father Stan believes that this is because the nursing staff identify with the values and ethics instilled by him, while the managerial staff are more closely aligned with the individualistic and task-orientation of the new Board. Furthermore, interviews with the managerial staff revealed another reason for the higher managerial staff turnover, namely that their roles are more individualistic and extremely pressurised as a result of having to raise

funds, comply with accepted Medical Council standards and be accountable for patient safety and care. Since management constitutes such a small percentage of the staff complement as a whole, even though their turnover levels are higher, it does not have a significant impact on the organisation nor the stability of the staff as a whole.

The emphasis on patient care for the nursing staff means that time management is always a priority because terminal patients require more intensive and time-consuming care. This means that the nurses are constantly busy and have strict schedules to adhere to when administering medication and checking patients' vital signs. In contrast, the managerial staff have more flexible schedules in that they are able to spend time ensuring that they complete their tasks correctly and meticulously. The management staff spend a greater amount of time planning for the future through meetings, discussing forthcoming expansion plans for the Centre, possible donors to approach and innovative ways to reach the community, while nursing staff have to concentrate on caring for patients in the present and often have to handle crises. The managerial staff keep more flexible hours, arriving between 8h00 and 9h00 and leaving between 15h00 and 16h00. In contrast, the nursing staff have fixed hours that are strictly adhered to.

According to Anthony (1994:37, also see 1.3.2 above), the founder of an organisation can play an important role in shaping its values and goals, amongst others. The values and beliefs of the Founder, Father Stan, encouraged a certain way of doing things when the Centre was established and became a driving force behind the Centre's traditions and customs. As the founder of the Centre, he has always been viewed as the hero of the organisation, playing a meaningful role in the creation and maintenance of the organisational culture by being a role model to the staff and by always modelling behaviour that results from his values and ethics. For example, when Father Stan was attacked in his friary by thugs demanding money, he went to court and publicly forgave them, even offering financial aid to their families to help alleviate their

financial burden which he believed was the reason for the crime. He hires staff whose aims and beliefs are in line with his vision, consequently employees become 'enculturated' into the Centre's way of doing things. New staff identify with and internalise the accepted beliefs and values, thereby perpetuating the organisational values and customs. Father Stan visited local communities, such as Daveyton, Ramaphosa and Vosloorus, and identified people who would meet his criteria for nurses and careworkers and whom he felt would identify with and portray his values and ethics. These people he invited to join his organisation. Other staff members he recruited through his church and still others came as a result of recommendations by his well-respected acquaintances.

Anthony (1994:37) has noted that the ways in which the organisation's leaders manage the organisation influences the overall values and beliefs of the company. Father Stan's management style is also crucial to the success of the organisation. He allows people the benefit of the doubt when someone is accused of wrongdoing, while disallowing poor excuses for bad performance. He is compassionate and understanding while still expecting the best from his employees. He sets high standards and staff are rewarded for complying with these standards with promotions and incentive bonuses, amongst others. Father Stan has always set the example for his staff to follow. However since the Board assumed authority over most decisions and daily functioning of the Centre, the new management style may vastly alter its operations, and have important consequences for the atmosphere in the Centre. The majority of staff members to whom I spoke knew the history of the Centre and said they felt a connection with the founder and his vision for helping the afflicted.

The furniture and spatial layout of the Centre is symbolic of relations within the organisation (see 1.3.2 above). As in any open-plan area used by people in management positions, desks are spaced with partitioning between them for maximum privacy, suggesting a place of importance within the organisation. Their offices are painted in darker colours and contain fewer sentimental items such as family photographs. The non-management areas in turn, are painted in light colours and many more photographs and pictures drawn by children adorn the walls and desks.

There is openness regarding money-related issues. The salary structure is based on rank within the Centre, experience and display of tangible commitment to the Centre. All salary-related concerns are addressed by Marinda who maintains transparency in this regard. Everyone within the Centre is made aware of the various salary levels and the salaries that are applicable within each level or band. There is total transparency as regards the turnover and operating costs of the Centre, and all donations of magnitude are announced to all the staff so that everyone is made to feel part of the institution. Management encourages a culture of thrift hence saving money on operating expenses has become important among all employees for the greater good of the Centre. Every month on the 25th day salaries of employees are paid into their bank accounts. The regularity with which this occurs is important to employees and they feel that they do not have to be concerned about not being paid.

As with all organisations, the Centre is influenced by external forces. It functions as a social community in its own right, but also has relationships with and interacts with the broader community, which in turn influence the organisation (see 1.3.2 above). The Centre is visited daily by volunteers and regularly by donors who come to assess it before making a donation, or after making the donation, to witness the difference their contribution has made in the lives of the patients. Volunteers in particular, have a significant influence since they interact with both patients and staff and bring their 'outside' experiences with them into these relationships. School

children spend limited amounts of time at the Centre to understand the effects of HIV AND AIDS, bringing with them stories and incidents from the 'outside' world. These children often engage with the child patients, relating their lifestyle to them and answering any questions the little ones have. All the staff represent relationships with the 'real' world for the patients which is important in view of the fact that most patients do not leave the Centre. The Centre also, on occasion, is visited by Japanese television crews who make documentaries about the AIDS epidemic in South Africa which are then used to secure further funding from the Japanese government for expansions to the Centre and new projects (see 3.8 above). A negligible number of family and friends visit patients, which indicates that patients' exposure to the 'outside' via relatives is limited.

3.15 Shift in management style

With the advent of the change in Board leadership in late 2005, a shift in management style emerged. Staff were seen to become more individualistic in order to adapt to the new more dominant, cash-focused Board members. The shift involved all departments, with the finance department stressing the need to cut down on supposed luxuries such as changing from 2-ply to 1-ply toilet paper, refusing to stock the kitchen with more than a few tea bags and the announcement that only discretionary bonuses, based on performance and merit would be paid. The supposed luxuries were regarded as unnecessary 'frills' offered by the previous Board. The training department was mandated to provide fewer training workshops in the community with the express objective of cutting costs and a moratorium was placed on all building and improvement projects. This shift seemed to have a negative impact on the dispositions of some of the staff, with staff members feeling less able to provide quality services to the community and patients.

The new management style embodies a more mercenary managerial style and greater concern for maximum performance in spite of the difficult circumstances in which the Centre's staff operate. Currently, the success of the Centre is still seen as a product of the values and traditions that are in place, as well as of Father Stan's vision. Many staff members, especially the nursing staff, said they were struggling to relate to the new style of management.

3.16 Monetary incentives, recognition and performance evaluation

Within the Centre innovation is encouraged, with staff being motivated by the Matron and Father Stan to create new activities for the children and even to make existing processes, systems and procedures more efficient and effective. Nurses dedicate individual time to each child and prizes are awarded for the most creative ideas in that arena as well as for customising Centre processes and systems. Despite the frugality being implemented, the staff are offered monetary or cash bonuses and incentives such as extra leave in exchange for their loyal service, thereby also ensuring that the staff become a 'family' to the patients. This results in lower staff turnover, especially amongst the nursing staff, which provides stability for the patients. Risk-taking is discouraged by company policy since the patients need consistency and one cannot afford to take chances with their welfare.

At the Centre staff performance is assessed and evaluated on the basis of key performance area reviews which are done bi-annually. These evaluations are made more relevant by the fact that peer evaluations are also done, i.e. colleagues evaluate each other's performance and these reviews form part of the person's overall evaluation. Performance is also monitored by the Matron and resident Doctor to ensure that performance is consistent and conforms to standards that have been set for each position. There is a set of standards on which performance is judged. Conformity produces rewards while deviance leads to penalties such as performance

review meetings with the Human Resources Officer. Staff members whose performance do not meet the standards receive lower salary increases than those meeting compliance standards.

3.17 Social structure: interpersonal relationships and group formation

Interpersonal relationships and group formation are associations that are entered into voluntarily by staff members (Jordan 2003:5–7, also see 1.3.2 above). These associations are indicative of the dynamics and culture of the organisation. Identifying and understanding these dynamics from the 'inside' are a crucial element of an ethnographic study (Bate 1997: 8). Such relationships may represent alliances within the organisation and can provide information that reveals how divisions between the groups operate, i.e. sometimes groupings are based on staff with similar demographics e.g. gender, race or even religion, other groups may be occupation-specific or perhaps even hierarchically based. Interpersonal relationships are the dynamics that exist between staff members and drive interactions between them. Group formation describes the way in which staff members form alliances and how staff cluster together, i.e. with whom staff members choose to spend their free time and what similarities trigger establishment of the groupings. It is important to understand interpersonal relationships in the context of the organisation since these relationships impact on the functioning of the Centre. The nurses have little contact with the managerial staff; hence they said that relationships between themselves and management were without conflicts.

On one occasion, a patient had managed to leave the Centre without permission. Heather was livid and in a public forum proceeded to lay the blame firmly at Denise and the shift nurse's door. Denise had been serving lunch and was the last staff member to see the patient but she made it clear that it was not part of her directive to be responsible for ensuring that patients are accounted for. The shift nurse stated that the security at the entrance had taken a bathroom break and hence the patient had escaped. The remainder of the nursing staff backed up the

nurse in question and offered to assist in the search for the patient; the camaraderie between the nurses was evident in their support of each other and their focus on solving the problem rather than assigning blame. The patient was found two hours later when it was established that she had been taken by another member of the management team to keep an off-site appointment with a physiotherapist for an injury sustained to her knee when she slipped in the bathroom. The lack of communication between the management staff and the individualistic-orientation was highlighted by this incident as was the practical mind-set and teamwork of the nurses compared to the less pragmatic and more defensive behaviour of the management team in seeking to lay blame rather than resolving the problem.

At another level interpersonal relationships at the Centre are complicated, with friction being evident between various staff members (see 3.11 above). This division is directly linked to the management styles adopted by the persons concerned, i.e. those who represent the new management style and those who identify with Father Stan and the conventional values of the organisation. When questioning the staff about this perceived divide, one of the research participants told me that as a Board member she is superior in authority and rank to those staff members who are in conflict with her, and that this superiority gives her the right to usurp any decisions made by them. In contrast, other participants commented on the fact that they were told that they were being discriminated against because they speak Afrikaans as a home language which they should not speak at work, even if the conversation is between the two of them. Heather confirmed to me that English is the official language used in the Centre and that she had insisted that staff members speak English only unless it involved staff who were unable to speak fluent English.

3.18 Symbols

According to Jordan (2003:40-48) and Anthony (1994:28-29), symbols are a component of the organisation's culture that help to interpret the meaning attached to behaviour and objects within it (see 1.3.2 above). The red ribbon on the Centre's logo is symbolic of the culture of care and tolerance for AIDS sufferers and it reminds staff of the purpose of their job. The medical uniforms are symbolic of the health profession, while the jargon used by staff at the Centre symbolises their identity and membership of the organisation (see 3.10 above).

3.19 Regular meetings ('ritual' behaviour)

Rituals are patterns of behaviour that occur within the organisation and, as pointed out by Jordan (2003:45-52), focusing on them helps one to understand the meaning attached to the behaviour involved. Rituals within the organisation occur regularly and are adhered to by organisational members; they follow specific rules and involve certain members. Examples of rituals within the Centre include meetings, parties and regular events such as celebrating World AIDS Day.

Meetings fit this description as they occur regularly and have a particular structure and process with specified role players/ participants. They also have specified goals as outcomes. A management meeting takes place once a month and involves all management staff, namely, the Matron, head of maintenance, training manager, Father Stan, the Founder, the Director, Housekeeper and the Physician. The meeting functions to give feedback on each aspect of the organisation and to secure input on all forthcoming decisions that will have an impact on it.

The Annual General Meeting occurs once a year and is attended by Board members elected from amongst the staff, nominated staff members, clergy, volunteers and community members. This meeting occurs in the Nemoto Boardroom with the objective of assessing the Centre's performance during the previous year, to improve already successful areas, and to identify, address and resolve problem areas.

Having attended the AGM, I observed that the seating placements chosen reflect the groupings or factions within the organisation. Father Stan chooses to be seated with some of the Head of Departments, while Heather associates with other Board members. These tensions are evident in their body language, with Heather folding her arms and narrowing her eyes when speaking to an HOD, and one of these HODs answering Heather's questions with short, abrupt sentences spoken in a curt tone. These HODs are very accommodating of requests made by clergy, staff and volunteers with the exception of requests made by Heather. One HOD in particular, without being openly rude manages to circumvent suggestions made by Heather, recommending other staff members who can assist with the request. This HOD told me that "I try never to work closely with Heather because we can't see eye to eye", and in order to avoid conflict, she avoids contact with Heather wherever possible.

There is some whispering in the meeting. Whispers are between colleagues eagerly discussing points highlighted in the presentation, while other whispers are between 'alliance' members mocking the other faction. The meetings begin with a presentation by Tilly of the Centre's recent achievements. The Matron reports on figures of patient intakes, deaths, etc. The meeting is very dynamic and almost takes the form of a workshop, with members asking questions and providing suggestions and possible solutions to challenges being faced. Following this is the financial report and the medical report about new drugs and therapies which in turn, is followed by a discussion of current and future training initiatives. A couple of the Board members are

distracted and read their email on their Blackberry mobile phones but are called to order by Tilly. Each Board member is thanked for their participation in the running of the Centre and finally closure of the meeting takes place. The meeting is followed by a less formal tea and cake gathering where members discuss their thoughts and feelings about the Centre's difficulties and its triumphs.

Other rituals include the year-end staff party, which takes place in a standardised way. It is held in a specific venue, the function diningroom; has regular participants, namely all staff members, and events that occur in a specific order. About 11am on the last Friday before annual leave commences, usually around 15 December, all the staff complete what they are doing and walk, chattering on the way to the dining room. Christmas carols play in the background and a large Christmas tree, heavy with decorations stands in the centre of the room. Each glittering ball hanging on the tree has the picture of a patient who passed away during the time that the Centre has been in existence. The smell of roast turkey and fresh cranberry sauce wafts across the room and the party commences with everyone joining in singing a Christmas carol while Eve plays the piano. The enthusiasm of the group is tangible as is the outpouring of love and compassion as the staff share memories of meaningful moments with patients during the year. The Matron talks about Nathan and how he "loved to sing the Barney, I love you, you love me, theme tune" and Denise spoke about Hennie and how he had been the Centre's 'handyman' until he became bed-ridden.

Father Stan gives a speech about the success of the Centre and the dedication and wonderful work done by the staff. This is followed by a few short speeches and an award for the "staff member of the year", who is voted for by staff and patients. The purpose of the award is to recognise someone who has gone beyond the call of duty. The award is given to a staff member who is seen to offer support to other staff members; one who has worked exceptionally hard

with the patients or who has introduced some innovation to the Centre. During 2007, the award is given to Sewela, one of the nurses, for her dedication in visiting those who are HIV-positive in her community and her exceptional compassion shown to patients even after her shifts are over. Sewela gives a short speech saying “I saw my sister suffer with AIDS and I understand how the families and patients feel and I feel blessed that I have the chance to work with people who need my help as much as these people do”. A meal consisting of a large carvery and desert follow the speeches. All the tables are decorated with crackers and streamers. The atmosphere is festive and most see it as a stress-reliever at the end of the year.

Functions such as the World AIDS Day event are organised by Father Stan and an assistant, with the specific purpose of raising funds to help support the Centre. Prospective donors are invited and treated to a day of ‘celebration’. The day involves the choir singing hymns, a full mass and a personal testimony from a person living with HIV AND AIDS. Candles are lit to commemorate all the lives that have been lost to AIDS and a special prayer is said for the victims and their families. The day is rounded off with a meal, usually a lamb on-the-spit. The World AIDS Day event is held on 1 December every year and coincides with Father Stan’s birthday, leading to a double celebration. Birthday parties for the children also have a specific organiser, standard food is served, the party has a set venue and regular participants, namely staff and patients. Birthday parties are held once a month to celebrate all the birthdays that occur in a particular month at the same time. Cake, balloons, singing and dancing all form part of the celebrations.

3.20 Death at the Centre

I informally spoke to three of the families of the deceased patients to understand their beliefs of how bodies ravaged by AIDS are treated and the rituals involved in the burial process. I further observed the funerals of two other patients in order to corroborate the information obtained from the families to whom I spoke.

Since AIDS is incurable those infected are considered to be the 'living dead' and often deemed capable of polluting others with AIDS through any form of contact before they die (Das & Poole 2004:155). Among some of the black patients resident at the Centre there is a belief that whereas death is normally a process whereby the person becomes an ancestor, in cases where AIDS is the cause of death, death is seen as unsettling and uncontrolled and the person cannot become an ancestor due to the slow wasting nature of his or her death. They believe that the ancestors would help them 'across to the other side' but that they could not become ancestors because blood and the contamination of the body by the disease were involved and because their disease was not considered 'natural'. Zelda told me, and this was substantiated by several patients at the Centre, that dead bodies are customarily treated with care and respect because this is a tribute to a person's memory, however, this is not the case when HIV AND AIDS is involved. Among many black communities in South Africa, death resulting from contagious terminal diseases such as HIV AND AIDS means that the actual body is seen as dangerous and polluting. In black communities after all funerals one must undergo a ritual cleansing ceremony to eliminate the 'pollution of death' (Das & Poole 2004:155). After Fundi's funeral all the mourners lined up to wash their hands in a steel bath tub that was positioned on the lawn outside the church. There appeared to be flower petals in the water. Many of the mourners said a prayer while the ritual washing was being done for Fundi's soul. Despite the differentiated treatment of bodies of those who have died from AIDS, Fundi's coffin was still covered with a

thick, soft blanket “to keep her warm on the ‘other side’”, which shows there is still respect and care used in the handling of the body.

As noted by McCombie (1989:59), patients often die in isolation because their family and friends fear being contaminated by them and hence do not visit them or attend their funerals. This isolation experienced by many patients is due to their families and friends believing that casual contact could spread HIV AND AIDS, resulting in the fear of contamination (Leukefeld & Fimbres 1987:41-43). This was borne out by several patients at the Centre whose families and friends did not visit them at the hospice for fear of stigmatisation in their communities. Ntombi experienced this when her family disowned her because she was seen to be shameful and scandalised the family’s well-respected name. Ntombi’s family never spoke to her again and she told me “I felt so alone and unlovable, I thought I would have to crawl into a dark hole and die alone and if it wasn’t for a few good friends that stood by me I would’ve died alone”. Lennox’s friends made excuses to avoid him after his HIV-positive diagnosis was made because they feared his disease was contagious and they were concerned about their own lives. Lennox said “Before they had too much time for me, when I get sick they tell me they got no time to visit with me anymore”. Lennox said that he was hurt and disappointed and this abandonment left him feeling worthless and with lower self-esteem than ever before. He was grateful for the support of his ex-wife and daughter because without their support he too would have been completely isolated.

When an adult patient passes away it is not always noticed immediately, and unless the patient in the adjacent bed notices, he/she may be dead for an hour before nurses are alerted to the death when doing their rounds. The patient’s bed is wheeled out as quickly and inconspicuously as possible, with the body covered in a sheet and taken to the mortuary for preparation and storage until the funeral. The social worker is called to counsel the patients, especially children

who are traumatised by the death of another child. A minute's silence is held by staff to pay tribute to the patient's life. Any next of kin are informed of the patient's death by the social worker. If the family cannot afford to bury the patient, the Centre sponsors the funeral from a fund that was created to aid families with this financial burden. The family is invited to the Centre for counselling as well as for a private blessing and memorial for the deceased, after which the burial arrangements are made. The day after the death, volunteers come to help the patients to get their minds off the death. Children who are identified as in need of counselling are separated and given trauma counselling in a quiet and safe environment.

Funerals are simple with candles, flowers on the aisles and a photograph of the deceased at the centre of the chapel. The body is prepared by the mortician and dressed in clothes chosen by the family or by the Centre if family members cannot be contacted. A choir sings songs to commemorate the patient's life and the congregation sings hymns and listens to Father Stan's stories about the deceased. The counsellor and priests comfort the grieving family in a meaningful way. Most families choose to keep the coffin closed due to the deceased's body being ravaged by AIDS. After the service the hearse awaits to take the body to the cemetery. The patient is given a private burial at the town's cemetery. Many of the black families of deceased patients to whom I spoke at the Centre said that they did not believe in desecrating the body and therefore cremation was not an option. Family members of the deceased may be accommodated in the friary guest cottage on the premises.

3.20.1 Impact of death on adults at the Centre

In 3.20 above the incidence of death at the Centre was discussed. In what follows its impact on adults is examined.

Adult patients are highly traumatised by a fellow patient's death since the reality of their mortality and imminent death disturbs them. Many patients wail and cry when they see the body being removed, while others realise what has happened when the hearse approaches the mortuary.

As with children, counselling is offered to fellow patients. The atmosphere after a death is one of despondence, with patients' morale being low. The nurses attempt to cheer the patients up with special movies or treats because Dr Ngumbe says that a pessimistic emotional state can negatively influence their physical states. Counselling at the Centre is highly effective and draws on the input from and the reactions of the patients.

3.20.2 Impact of death on the family

Many families who have lost a family member to HIV AND AIDS, feel that death should be a private affair so that they can grieve in peace (Macklin 1989:91), but one family who had come to the Centre to bury their daughter said that they would have preferred a more public service and mourning with the community support. However, because their daughter died of HIV AND AIDS, they had to settle for a private service due to the fear and stigma attached to HIV AND AIDS. Father Stan concurred that most families burying their dead at the Centre wanted to mourn without anyone in the community being informed of the cause of death. Families need some closure to deal with loss and bereavement properly (Macklin 1989:82).

Approximately 25% of female patients at the Centre and 50% of women visiting the ARV clinic said that they had not made any arrangements for their children once they have passed away from AIDS, although they were worried about what would happen to their children and families when they were no longer around. It is, however, considered improper to discuss issues of who will raise the children after a parent's death. Fundi had a three year old son and was not sure how to secure his future without her. "I knew I should get someone to raise my son but I didn't want to burden someone with my child but I asked my sister to raise him because her child was two years older than my boy and he would fit into that family easily. I was scared he wouldn't remember me one day. I asked her to take my child when I died but she said it wasn't right to talk about me dying before I died. When she said she would take the boy I felt like I could die in peace". It is said to be unacceptable to talk about death before it has happened because the person raising the issue may be accused of causing the illness or death of the sick person by showing too much interest in it. Lizzie was concerned about Dumisani outliving her specifically because he had already indicated that he was afraid to die without his mother by his side. Dumisani told me that he had never experienced a day without his mother and he feared what would happen to him after her death. Lizzie however, was comforted by the knowledge that Dumisani would be cared for by the Centre. The psychologist felt that women at the Centre were more inclined to make arrangements for the care of their children because they, as a result of being admitted to the Centre, realised their mortality and that death was imminent, whereas those attending the ARV clinic as outpatients felt that they had time to make contingency plans. The ARV clinic and the Centre promote discussion of these issues in workshops facilitated by Zelda to make patients aware of all available options and to ensure the patients' peace of mind and the best interest of the children.

What follows is an account of the situation of AIDS orphans at the Centre. The challenges faced by these children, and the care that they require and receive are examined. The position and behaviour of the children at the Centre are examined as part of the holistic investigation of the Centre as an organisation.

4. AIDS ORPHANS AT THE CENTRE

4.1 Introductory remarks

Now that the ground work has been laid for understanding the Centre as an organisation caring for terminally ill patients with HIV AND AIDS, attention can be focused on the children's experiences of the organisation and how they came to be there. The general care provided to them, together with assessment procedures and special events, receive attention.

4.2 Admission, assessment and care

Children are referred by doctors, hospitals, social workers, employers as well as clergy, family and friends. The Centre functions on the basis of various policies and procedures regarding the children in order to ensure that they are dealt with in a compassionate way. At the Centre each child is assessed as an individual and treatment and care are given to each one based on his/her specific needs, background and situation. Children are seen as unique, having their own needs, thoughts and talents. The Centre offers holistic care to the children in order to live up to its mission of developing their full potential: physically, emotionally and spiritually. According to Zelda, many children who cannot be placed at the Centre are sent to state facilities where they are rarely offered specialised and individualised care since state facilities lack the manpower to offer such services. The following care is dispensed to the children:

As an NGO, the Centre spotlights the needs of the children as victims of HIV AND AIDS, and one of its basic values is a sense of duty to care for the children and the communities from which they come (cf. Joint United Nations Programme on HIV AND AIDS 2008:177).

Procedures, especially involving children, are clearly defined to all the staff. The staff were observed to implement proper procedures (see 3.7.1 above), namely ensuring that children are assessed by the physician and the psychologist upon arrival. They are introduced to the other

children and generally made to feel comfortable. On arrival, the children with their fragile emotional states, have consultations with the social worker and the psychologist who assess their emotional state to ascertain the type and degree of psychological counselling they need. The children are encouraged to talk about their feelings and their beliefs and, based on this, they are counselled to deal with any concerns and issues they have experienced. The physician starts their antiretroviral drug treatment as soon as possible.

According to the Centre's psychologist, sick roles are more difficult for children to understand since their full comprehension of sickness is limited by what they are able to understand at their particular ages. From my interviews and consultation with the psychologist, I established that even though the children are too young to fully understand the biological implications of their disease or how they contracted it, they do understand that they are sick and that they live in a hospital. Most of the children would not have had to adjust to a sick role since they will not remember a time before they were infected.

The psychologist mentioned that she found that the majority of the children had never been part of a conventional family and could not conceive of the idea of having a mother and father or even of a home that they did not have to share with many other children. Children at the Centre are largely isolated from social networks outside of it (cf. Joint United Nations Programme on HIV AND AIDS 2008:76, also see 2.5 above).

While antiretroviral drugs are the lifeline for many of the patients, they have different effects on people and two of the children at the Centre had side-effects that included nausea, vomiting and even some dizziness. After these effects were noted, the doctor altered the specific drugs he had prescribed for each child.

4.3 Schooling and emotional, spiritual and physical development

A consulting child speech therapist specialising in neuro-development assesses each child in terms of IQ and ability before he/she is placed in a specific class. Each child is allocated to one of two classes according to his/her developmental stages as determined by the speech therapist and by the psychologist. The 2 – 4 year olds are grouped for foundational learning such as learning about colours and shapes, while the 5 – 7 year olds are grouped in a separate class where activities carry higher comprehension requirements, e.g. they learn to read and write. Children above 7 years of age are quite rare but any that there might be are usually assimilated into the 5 – 7 year old group. This differentiation in terms of classes ensures that children learn at the correct level and pace and are not pressurised to perform beyond their capabilities. The pace is determined by the speech therapist as appropriate for children such as those at the Centre.

The older children are taught by the experienced, qualified teacher, Louise, who teaches them the same subjects that are taught to children of their ages and abilities at other learning institutions. They are taught languages, counting, arithmetic and handicrafts amongst others. The younger class of children is taught by one of the volunteers who is also a qualified teacher. The syllabus is approved by the Department of Basic Education and ensures a balance of academic and practical exercises, i.e. exercises done by hand such as basic sewing and collage-making, versus more intellectual learning such as mathematics, spelling and writing paragraphs. This approach aids in maintaining the concentration and interest of the children. There is a 15-minute break between each subject. Subjects vary from day to day.

The volunteers teach the children skills such as tying their shoe laces, and dressing themselves. They also develop their hand-eye coordination, usually with ball games. This complements their education in a practical way.

In line with the Centre's goal of developing the children holistically, the children are stimulated emotionally by making them participate in team work which helps them to realise that their input is valuable. This practice also facilitates development of leadership qualities among the children. The group schoolwork projects further help to promote interaction and sharing with others. There is no segregation of activities, i.e. the girls are allowed to do basic woodwork and boys are allowed to participate in the knitting and baking activities. All of the children have developed skills in areas such as art and crafts.

As regards emotional development, the children are provided with counselling by the psychologist. This includes exercises and drawing to ascertain how they feel in order to overcome their fears of death and issues surrounding their disease, as well as the deaths of their parents and friends from HIV AND AIDS. The psychologist reassures and comforts them in a secure and comfortable environment (see 3.3 above). For example, Lizzie and her son, Dumisani were both patients at the Centre, and Dumisani was disturbed when his mother's condition took a turn for the worse. The psychologist used these sessions to address these concerns and comfort him, and created a reassuring environment for him in which he could talk about his fears and use 'show cards' to articulate his feelings. Show cards are laminated cards that depict pictures of situations so that the children can express their feelings and concerns in a simpler way, namely by pointing to the appropriate show cards to highlight their problems and feelings. Siphon, a child patient at the Centre, was an extremely skittish child who frequently awoke in the early hours of the morning after nightmares. He was reluctant to talk about the content of his dreams and in fact, asking him to talk about the dreams caused him great distress. To explore the content of the dreams and to resolve the issues experienced by Siphon, the psychologist asked him, in an informal setting, to draw pictures. He drew a series of drawings over the next few weeks and these were analysed. The drawings were interpreted as

showing fear and anxiety and when the child had developed a trusting rapport with the psychologist, Siphon revealed, "They're coming to get me, when I stay under the bed they can't find me", referring to the Nigerians that his mother had worked for as a prostitute. Siphon had been exposed to prolonged violence and abuse prior to his arrival at the Centre, and the emotional scars were still present in Siphon. The psychologist worked with him on a weekly basis to re-establish his sense of trust and security and to help him to have closure from his past. The results are noticeable: Siphon sleeps through the night with few nightmares and he no longer hides under his bed.

Spiritual growth is integrated by means of a prayer each morning, and most of the children are able to recite the Lord's Prayer by heart. The children are told Bible stories and are taught the ethics of Christian teachings by the Sisters of Mercy nuns who attend the services on Sundays, to help the children to be at peace with their illness and their ultimate fate.

The Centre consults a physiotherapist who develops exercise programmes that allow the children to run and play for a few hours a day, thus ensuring that their physical development is not neglected. As with all HIV-positive people, nutrition is a key concern, especially to stave off secondary infections and maintain relative health (Joint United Nations Programme on HIV AND AIDS 2008:174). In line with this, a dietician formulates well-balanced meals for the children, especially in winter when their immune systems may be compromised.

4.4 Adoption and fostering of children

In the interest of offering the children the best life possible, the Centre provides interested people with the option of foster care for or adoption of a child. As noted in the Joint United Nations Programme on HIV AND AIDS (2008:166), provision of social protection is essential for vulnerable children and the Centre offers social protection by caring for them in a safe

environment. However, for the lucky few, it tries to facilitate adoption or fostering to ensure social protection. "Adoption is the best solution for these children especially when they are very young since this gives them the opportunity to be part of a family environment and to develop into well-balanced individuals with all the necessary influences and security of a family" is the professional opinion of the social worker. Nonetheless, according to the social worker, very few children are ever placed in foster care or adopted because most families or couples would rather adopt a healthy child rather than one with a terminal disease. Children with longer life expectancies who do not require as much costly medication or anti-retroviral drugs, consultation with doctors and hospitalisation are preferred. In the past two years, eleven AIDS orphans have been placed in foster care by the Centre and four have been adopted. According to Zelda, "children younger than 5 years of age have a better chance of being adopted because prospective parents prefer younger children to adopt". If, however, children have been at the Centre since they were babies and they are now, for instance, eight years old, the psychologist and social worker agree that it would not be beneficial to the child to be removed from the only 'family' and environment that they have known, since children need stability and they have also formed critical attachments to staff and patients.

Families considering adopting HIV-positive children are made aware of the financial burden that such a child would place on them by the counsellors and the social worker whose responsibility it is to give foster or adoptive parents all the information pertaining to the child concerned. After listening to a seminar on the challenges of caring for HIV-positive children given to all prospective adoptive or foster parents, two families who had considered fostering children from the Centre told the social worker that they had not fully realised the dangers associated with HIV AND AIDS and feared for the safety of their other children since accidents may happen and they feared that their children might come into contact with HIV-infected blood or bodily fluids. For this reason they decided not to adopt or foster a child.

The office administrator, Eve, had a special interest in a little girl who had been at the Centre her whole life. She adored the little girl and took her on her errands during the day for company. Eventually the girl died, leaving Eve devastated. After a while, Eve decided to take two boys, Sibü and Bheki, with her on her daily errands instead. After her own children visited her at work one day and met the boys, Eve decided to take them home with her over the weekends. She asked Father Stan for approval and he spoke to the boys (who were in favour of the visits), after which he consulted the psychologist who said that such visits would benefit the boys. Eve explained that the boys had never known a real family life and had said how they dreamt that they would belong to a family one day. She felt that she was helping to fulfil that wish by exposing them to her own family. Eve has two children, a boy and girl, both of whom said that they loved having the boys around because they were “very kind and sweet and grateful for everything”. Sibü and Bheki said that they could not wait for weekends because they knew that they would be at home with the people that cared for and loved them.

The psychologist agreed that “for these two boys to be involved with a loving and caring family will be beneficial and will provide the boys with a change of setting and a broader set of experiences beyond the Centre”. Consequently, the Centre started a programme where volunteers, Centre staff, who had been screened by the Board, the psychologist and social worker were permitted to take children home for certain weekends. The children alternate between volunteers so that each child has the opportunity to be ‘fostered’ for weekends. Feedback from this programme has been very encouraging, with the children excitedly relating the things they were able to participate in over the weekends. The Centre’s staff and volunteers reacted favourably to this arrangement. The children understand that this situation only happens over the weekends and that they will return to the Centre on Mondays. The psychologist felt that this could strengthen them emotionally.

Caution needs to be taken, however, to avoid careworkers becoming too attached to the children. An example of excessive involvement in a child's well-being follows. As mentioned in 3.7.1 above, Boitumelo is a nurse at the Centre who specifically cares for the children. Her daughter died when she was a toddler and coincidentally one of the patients at the Centre bore a strong resemblance to her deceased daughter. Karabo was 'chosen' by Boitumelo to be given special attention and love, with Boitumelo behaving as if she were Karabo's mother. In this case, the pitfall lay in the fact that only Karabo was given this attention, leaving two of the other children feeling rejected. The psychologist spoke to the children and asked them to draw pictures about their feelings towards Boitumelo and she established that these children felt that they had done something wrong because they were not treated in the same way by Boitumelo. The danger for Karabo was that she was emotionally attached to Boitumelo and even though it was unlikely, if she were to be retrenched or fired, it would be emotionally devastating for Karabo since she would not understand and would feel abandoned and rejected by Boitumelo.

4.5 The children's daily routine

The organisation provides an environment of stability by prescribing fixed procedures and ways of behaving. A routine for the children provides a framework within which they function so that they know what to expect and can feel safe with this consistency. The child psychologist pointed out that stability is vital for children who have come from circumstances of insecurity and impermanence.

At 06:00 the night duty nurses change the nappies of the babies and then bath the children. They dress the children in clean clothes, teach them how to choose clothes and help them, along with the volunteers, to tie their shoe laces. Around 07:00 they have breakfast which consists of hot porridge, followed by scrambled or boiled eggs on toast.

At approximately 08:00 the nurses brush the children's teeth, showing them how it is done. Children younger than two years of age are kept in the playroom or supervised while playing outside on the jungle gyms. Volunteers assist these children to create finger-painted artworks, collages and even just by pushing them on the swings or reading stories to them. The days of the older children are more structured, with regular activities occurring at scheduled times. From 08:30, children from the age of two years upwards, attend school for 2 hours. At 10:30 in the morning their tea break starts and sandwiches and juice are served. The break lasts for 15 minutes whereafter the children go to the petting zoo where they are taught to identify the animals and are given rides on the donkey. At about 11:15 the children are taught computer skills and play computer games for half an hour, after which they wash for lunch which starts at 12:00. Lunch consists of meat and vegetables. On Mondays, Wednesdays and Fridays the volunteers take the children for finger painting, dancing, singing, playing on the jungle gyms and riding on plastic motor bikes. On the in-between days the children are allowed free time to play with their friends or just to relax as they see fit. On a few occasions every month, two thirty in the afternoon involves children from various schools coming to interact with the orphans and tell them about 'big school'. For an hour they have outdoor activities such as cricket, skipping or ten pin bowling which aims to build a team and competitive spirit. At 16:00 there is a 'tea' break consisting of pudding and fruit, after which the children watch educational programmes on television and some cartoons. At 18:00 the children have supper consisting of pasta or vienna sausages and chips, and 19:00 is bedtime. The nurses tell them bedtime stories and sing lullabies to them. The night nurses are constantly present to assist children during the night to change wet nappies, deal with sickness and to provide comfort following bad dreams.

4.6 Relationships among the children

In all social settings, new-comers are evaluated by existing members to determine their suitability as potential members. Conformity with group norms is sought by socialising and inducting the new members into the group (Anthony 1994:30). New patients are viewed as new members of the 'team' and ultimately seem to attract a great deal of attention from existing patients and everyone is interested in knowing more about them. When Doctor arrived at the Centre he was relatively short for his age which made him stand out from the other children, and attract more attention and ridicule from them. The other patients give the new patient a 'label' that epitomises the way they perceived him/her. This label often lasts a long time and may later even become a nickname. "The other kids used to call me 'short stack' and 'baby' but then the cool kids said I could hang out with them and then they stopped calling me funny names". Doctor's friendships with Sibü and Bheki ensured that he was known by his proper name, Doctor. Doctor gained acceptance and overcame his nicknames because of his friendships with Sibü and Bheki who are respected by the other children. As the 'newness' of the patient wears off, the dynamics of the group change, with the patient becoming a member of the group.

Children at the Centre, especially Bheki and Sibü, show immense empathy and compassion for the other children when they contract secondary infections, helping to wipe their runny noses, replacing their cold compacts, and spending time talking or singing to them. A special bond is evident between these children since they understand the challenges and negative experiences associated with being HIV-positive.

"Ryan and Sarah live in a big house with their own rooms and lots of toys. When we go there we eat and play and we go to cool places like the zoo". "We like going there on weekends coz they're very nice and it's fun to go away from here". Sibü and Bheki have realised that there is a difference between the way they are being raised in the Centre and the way in which Eve's

children are growing up, but “we like being here with our friends” and they are content because they are loved and cared for at the Centre. Most of the children have no reference for comparison since they have never known life outside the Centre.

4.7 Special events involving the children

Ceremonies are symbolic representations within the organisation and are important events that depict elements of the organisational culture (Jordan 2003:46). Special ceremonies or events at the Centre involving the children are practiced at specific times, with pre-determined participants. Birthday parties are the epitome of special events at the Centre, representing an important break from the monotony of daily institutional existence. Birthday parties reverberate with the sounds of children’s music playing, laughing and playing outside and many balloons hanging on the fence. Coloured plastic tables are placed in groups and streamers and glitter are arranged on the tables. During Zandile’s birthday month she was the only child celebrating a birthday and hence she had her own personal birthday party. Zandile is one of the patients at the Centre and for her party there were ‘party packs’ for each child consisting of plastic toys, musk sweets, toffees, and miniature chocolate bars. The cake was a brightly coloured pink Barbie with six striped candles with edible glitter adorning it. Pastel-coloured Tupperware bowls contained crisps, muffins, sweets and pastries. The air smelt like rubber balloons and vanilla essence, and an atmosphere of joy was present, in contrast to the more clinically sombre atmosphere that usually prevails at the Centre. A large fuzzy bear handed out ‘Fizz’ pops to the children, while a pink banner with Zandile’s name on it, wished her a happy sixth birthday. She danced as everyone sang to her, oblivious of her terminal condition and revelling in the spotlight and attention. Junk food such as sweets and crisps are seldom given to the children at the Centre, and on occasions such as Zandile’s birthday, she and the other children take advantage of their availability. Zandile told me “I’m going to hide some cake under my pillow for tomorrow

so it will feel like my birthday again". The birthday party has considerable significance and meaning for these children because they feel valued.

One of the Centre's volunteers dressed up as a clown for the party and behaved in a silly way to entertain the children, such as throwing cream pies in his face and squirting water from his trick nose. Another volunteer was the regular magician performing magic acts to the amazement and awe of the children. Games such as 'pin the tail on the donkey' and 'pass the parcel' were given new life among the children and a donkey ride provided the closing activity for the party.

4.8 Some comments on the origin of the children and their status as HIV-positive persons

4.8.1 Household heads

As is often the case among AIDS orphans in the larger society, as noted by the Joint United Nations Programme on HIV AND AIDS (2008:166), Princess, who was eight and a half when she arrived at the Centre, had not received any schooling because she had to care for her younger twin brothers (cf. Fox 2001:65-66). She unselfishly put her own needs aside and made their welfare her priority. The psychologist said "she feels that she has to put the needs of her brothers' above her own welfare". Princess admitted "I had to look after the twins because I promised my mama when she was very sick, and I couldn't let her down". Princess had been born HIV-positive, but had experienced relatively good health which helped her to cope with being responsible for the twins. According to Zelda, this situation of child-headed households occurs often, and is being addressed by the Department of Social Welfare.

Princess said she felt as though she was treated as a 'second class citizen' by representatives at the local clinic and by welfare centres and that this deprived her of getting help sooner – "the people at the clinics never listened to me because I'm little. They said I must bring my mama with to tell them what is wrong with me and the twins". For this reason her survival strategy was

simply to avoid detection in order to keep her family together without attracting attention to themselves. According to a case worker from the Department of Social Welfare, the child had been reported by a neighbour who had been friends with the children's parents and who knew that the children had been orphaned. Princess's mother had saved money for when she passed away and the neighbour helped Princess to understand what essential foodstuffs she needed to buy with the money. She scrounged for food from neighbours, out of dustbins and learned to cook, clean and take care of her siblings as best she could. The psychologist in fact found that by pretending that nothing had changed in the home, Princess did not get a chance to deal with her loss and grief over her mother, but counselling has resolved many of these issues. Princess eventually discovered she could not support herself and her and her siblings and ended up at the Centre, where her brothers were found to be HIV-negative and have been placed in a foster home.

Children who were forced to become household heads, including Princess, said that they regarded not being able to attend school or obtaining medical assistance for their disease as just further problems with which they must deal and they focused on the basic, immediate necessities such as food and shelter before they concentrated on their health. Many girls are taken out of school to care for sick relatives, leaving them unable to secure employment later on, disallowing them the opportunity to live a 'normal' life, and burdening them with adult responsibilities (Fox 2001:65-66).

4.8.2 Stigmatisation and discrimination relating to children

The notion of stigma was discussed in section 3.12 above. This idea is taken up here again, specifically as regarding the experiences of the children. HIV-related stigma is defined as: "...a 'process of devaluation' of people either living with or associated with HIV and AIDS" (Joint United Nations Programme on HIV AND AIDS 2008:76). HIV-related discrimination follows

stigma, and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status (Joint United Nations Programme on HIV AND AIDS 2008:76). For those patients who did know their status, many chose to keep it a secret since they were afraid of the fear, rejection and stigma attached to being HIV-positive. Phumlani (aged 8 and a half years) was diagnosed with HIV after his mother had been diagnosed and the nurse at the clinic advised his mother to have him tested for the virus. Phumlani's mother told me "the witch put the curse on us and it made us very sick. We didn't tell no-one about the curse". Phumlani's mother explained to him that the disease was a spiritual affliction sent by a witch and he therefore, had to withhold his status from the community as 'cursed' people were not well received in the community. The psychologist explained that when patients first come to the Centre, trust is a challenge for them since they fear rejection.

Lebo, who contracted HIV through unsterilised equipment used by her dentist, was discriminated against and shunned by her parent's neighbours when they discovered she had HIV AND AIDS. The family shared their story with the social worker at the Centre when Lebo, who was almost seven at the time, was admitted. The crèche that Lebo attended before she came to the Centre had lost a child to HIV AND AIDS and consequently, the children, under guidance from their parents, had asked to be tested for HIV in support of those living with HIV. This was also an effort to teach the children compassion for others. Lebo's father said "When the results came that she was positive we didn't know how that could be. My wife and me didn't have the disease, we didn't know how she had the virus. We were scared because we knew she was going to die and I didn't want to tell our family, I needed to protect the child because people are scared of people who are infected." Following weeks of wondering how she had contracted the virus, they traced the dentist who had performed Lebo's dental work and discovered that allegations of misconduct and HIV transmission levelled against the dentist had been placed with the Health Professions Council of South Africa. They then realised what had happened.

The dentist had had previous allegations lodged against him for using unsterilised equipment and was facing a hearing with the Medical and Dental Council. Lebo only started showing symptoms approximately eight months after the infection. Years after Lebo's infection, the dentist had his licence revoked but this provided little comfort to the family.

As is the case with many HIV-positive people, discrimination occurs in families and social networks involving infected people (Joint United Nations Programme on HIV AND AIDS 2008:76). "People called us and left letters at the door of the house and they said they would kill us if we didn't go away with Lebo" said her father. Because she was growing weaker, they felt it wise to let her be cared for by experts and because they felt this would alleviate the threats they received from the community. Lebo has undergone therapy to help her deal with her experiences and feelings of fear and sadness about being shunned by her community because of her status. Her parents, however, have always supported her and showed her only love during this difficult period.

Nathan, one of the children at the Centre, died after a short secondary infection. His family confided in Father Stan that they were grateful that his death certificate listed a secondary infection as his cause of death since his mother said that the community in which they lived was known to stigmatise and isolate families of those who had died from AIDS, mainly because of a lack of clarity on how the disease is contracted.

When Promise, one of the Centre's adult patients, realised that she could no longer care for her daughter, she sent her to live with relatives in KwaZulu-Natal. "My sisters and aunt promised me that my child would be safe and raised well. I didn't want her to live her life with the other children making fun of her and being without friends, an outcast". Her daughter had been discriminated against and shunned by the other children at her school when they discovered

that her mother had HIV AND AIDS. In an attempt to protect her daughter and give her a 'fresh start' she sent her away. Her sister agreed to care for the child, hence she would have a 'parent' that was from the same generation as her own mother which, according to the Centre's psychologist, would help her to identify with her caregiver.

From the interviews conducted with patients, I was able to confirm that stigmatisation and discrimination are indeed factors creating stress and sorrow in the lives of those suffering from HIV AND AIDS. Khanyi, one of the children of a patient at the care Centre, lived in the shadow of the stigma of AIDS because one child at her school had somehow discovered that her mother had AIDS and had shared this information with many of the other children. Khanyi confided in me that "The kids from down the road play with the ball outside but they never want me to come and play with them. They told me that I've got cooties and I'm gonna make them all sick like me. They make me feel sad coz I want to play with them". These children were under the misapprehension that if they were near her or touched the same objects as she did, they would contract AIDS even though she is HIV-negative. Khanyi's mother, Promise, told me "One day the ball landed in front of Khanyi and when she tried to throw it back, one of the children screamed and told her that she was sick and she shouldn't touch their toys again because I had AIDS and this made both of us 'unclean and dangerous'". Promise said she felt powerless to help her child and realised that she would never be able to exist without being discriminated against because of her illness. Khanyi was devastated by this incident and cried for hours. She did not fully understand why she had been excommunicated from the group, but she came to Promise and told her that she would always love her and that she was a "good mommy even if you are sick". Promise said she felt crushed every time she saw her child being teased and tormented or humiliated because of her own HIV-positive status. Promise was subsequently treated for depression. "I was diagnosed with clinical depression when I understood that my disease was going to kill me and I had to tell my daughter that I was not going to be around to

see her grow up; very hard to do". When she had to send her daughter to live with family members she slipped into a deeper depression at which point she was prescribed medication. Once her depression was under control, Promise accepted her disease and was able to maintain a stable relationship with her daughter.

4.8.3 Concerns about institutionalised children

An organisation such as the Centre provides stability and stable relationships for its members which in turn, act as a foundation for other aspects of their well-being (cf. Anthony 1994:29). Against this background it is easy to understand the concern among the staff members about the fact that approximately 75% of the children were under the age of three years when they arrived at the Centre from state institutions. These children have been raised in the Centre since they were babies and do not know what it is like to have a biological family and a 'history'. In some cases their origins are obscure and in others it is obvious that they are the products of dysfunctional members of society. Doctor, for instance, was dumped by his mother on a rubbish dump close to Alexandra where he was found by municipal workers and taken to a state hospital where they discovered that he was HIV-positive. He was placed at the Centre by the state. Siphon was sent to the Centre from a state hospital that did not have the facilities to care for him; while Sibon and Bheki were left outside the Centre and with the state's approval, both became resident. Karabo was placed at the Centre by state welfare as she was under a year of age and it was hoped that she would be adopted.

Because the media depict images of children raised in families as the norm, as opposed to children being raised in institutions, a few of the children have questioned why they are different from the children who have mothers, fathers and siblings that they see in advertisements. This creates a lack of self-worth which often requires counselling. Counselling serves to dispel the idea that something is 'missing' in their lives by providing them with comfort about their

situations and their place in the Centre's 'family'. Karabo asked me "Why isn't mommy here with me, doesn't she love me?" She felt abandoned by her mother and was counselled by the psychologist to help her realise that she had in fact not been abandoned and had not done anything wrong that resulted in her being placed in the Centre.

According to records shared with me by Zelda, three of the nine children interviewed had not known their father, while a further two had lost their fathers to HIV AND AIDS. These children were raised in a one-parent family situation before being admitted to the Centre (cf. Joint United Nations Programme on HIV AND AIDS 2008:163). A further area of concern in my study is the lack of male role models for the children at the Centre. They have the nurses, the Matron and Eve, the Secretary, as well as the volunteers as positive female role models, but the only man present is Father Stan who is seen more as a grandfatherly figure than a father-type role model for the boys. Father Stan reads to them, plays with them and brings them toys and treats. I asked the boys if they would be comfortable with anyone teaching them sports, and if they have any personal problems, who would they like to speak to and get advice from. The boys said that they would like a "boy" to teach them to play sports and to talk about "stuff that girls can't hear". They also mentioned that the girls had "other girls", namely the nursing staff, volunteers and staff members such as Eve to talk to so why did they not have any males to talk to. The psychologist is addressing the issue of the lack of male role models by bringing male guests, such as soccer stars and male paediatricians to speak to the boys about their concerns, interests and talents.

In spite of concerns such as those mentioned above, the children learn to adapt to their situation. Phumlani, for instance, said that having a 'family' at the Centre has made him happy. Phumlani expressed that "I'm scared to die, when I sleep I don't know if the witch is going to take me away, I don't want to die". He had expressed his fear of death to the psychologist

during early counselling sessions through drawings and exercises that enable the children to articulate their fears in a non-threatening way. Subsequently, the psychologist determined that having friends would help him to deal with his fear of death as would regular counselling sessions.

4.9 Behaviour among the children and disciplinary measures

As Anthony notes (1994:29) provision of stability can constitute a facet of an organisation's culture (see 1.3.2 above). This is true of the Centre where stability is provided in the children's lives, through rules to live by, accompanied by rewards if the rules are followed and punishment when the rules are broken. Children who hit other children or run in areas where they are not allowed to, for example, are given 'time out' where they are confined to a room on their own for a short period to reflect on their actions before being allowed to join the group again. Sibü, for instance, was chasing Bheki one day when a nurse came through the playroom with a tray full of medication. Sibü could not stop in time and knocked the nurse, sending the tray flying into the air, resulting in a shower of medication. The nurse explained to Sibü that she was upset because of the danger he caused to everyone else by disobeying the rules. Running in the playroom is dangerous and thus prohibited. Children can slip on toys left on the floor or could knock over the nurses and volunteers. After apologising to the nurse, Sibü was told to stand in the corner for an hour and think about what he had done wrong. Generally, however, the children understand the rules and processes, and behave in predictable and consistent ways.

From what I experienced, the behaviour of institutionalised children is more structured than that of non-institutionalised children; they have a strict routine to which they must adhere. These children are limited in their socialising since they do not often socialise with HIV-negative children. This only occurs occasionally when school children come to the Centre to understand

the reality of HIV AND AIDS and this engagement gives the institutionalised children an idea of what life is like outside of the institution.

Happiness was abandoned at a state hospital after her mother discovered that she was HIV-positive. After integrative counselling and adjustment therapy as part of the standard care and services, Happiness was asked by the psychologist to draw a picture to represent her family. I asked Happiness what she drew and she responded with "I draw my friends, my teacher, the nurse; we all hold handies and I draw the sun and a cloud". Happiness even included Father Stan in the pictures. The psychologist interpreted this as an indication that she sees her caretakers and fellow patients as her family. The nurses told me "we have the role of surrogate mother, we help the kids to get dressed, we clean them and we teach them how to feed themselves. We also play with them and have fun with them". They spend the most time with the children and consequently develop close bonds with them.

The majority of children at the Centre are self-confident which signals a good sense of security and belonging. This, according to the psychologist, indicates that the children have adjusted well to their environment and circumstances. For instance, when she first arrived at the Centre, Lebo was emaciated and depressed and had difficulty socialising. However, after a few months at the Centre, she was nursed back to a reasonable semblance of health and regained her confidence and lively personality. Sibuy and Bheki are both eager to become performers and both boys relish any opportunity to sing and dance for the other children. This evaluation was provided by the psychologist who regularly assesses the children to ensure that their emotional development is not lacking.

4.10 Impact of death on the children

Earlier the occurrence of death at the Centre was discussed (see 3.20 above). Here attention is given to the influence of death on children and how they are assisted to cope with it.

Some children are not old enough to comprehend death while those who are old enough are told by the counsellor that the child has gone to heaven where he/she is happy and no longer in pain. The children seem to accept this explanation. When a child dies, school is cancelled and the children are asked to draw pictures to assess whether or not they have been deeply affected by the death and thereby to ascertain which children need further counselling.

The children's counselling room is warm and inviting to encourage children to feel relaxed and safe. The session begins with the counsellor asking the child to sit where he/she feels comfortable and he/she is given a teddy bear to hold to add a further dimension of comfort. Most children make use of the miniature plastic chairs at the side of the room. The counsellor proceeds by asking the child to draw a picture of anything that comes to mind. The pictures assist the counsellor to understand how the child feels and to guide her in how best to facilitate the therapy of the child. She permits the child to speak freely because this allows the child to articulate his/her grief and feelings surrounding the death. In this way the counsellor tries to comprehend the child's perspective of death. This frequently leads to a discussion about the child's health and may even lead to the child admitting to a fear of his/her own death. The counsellor guides the child through his/her experiences, dealing with them one by one, and offering aid by verifying the legitimacy of the child's feelings. It is also stressed that what has happened is in no way the child's fault, as many children seem to blame themselves when those they are close to die. The child is taken back to the playroom after the counsellor gives him/her a hug. Each child attends counselling and is given follow-up sessions to ensure that the therapy has been successful.

The following chapter deals with the perceptions, experiences and understanding of HIV AND AIDS by the adult patients at the Centre. This includes an examination of the meaning of illness for the patients, the sick role and the stigma that is attached to an HIV-positive diagnosis. The fear of contamination by family and community members is addressed along with sexual practices and beliefs linked to HIV AND AIDS. Shared practices and beliefs are focused on, as is witchcraft as an alternative explanation for the disease.

5. ROUTINE, PERCEPTIONS, EXPERIENCES AND UNDERSTANDING OF HIV AND AIDS AMONG THE ADULT PATIENTS

5.1 Introductory remarks

What follows is a discussion of the various perceptions, experiences and understandings of HIV AND AIDS among the adult patients at the Centre. The discussion deals with informants' ideas about sexual behaviour as a foundation for how they comprehend their illness, the meaning it has for them and issues such as stigma and fear of contamination that they faced prior to their arrival at the Centre. The concept of witchcraft in relation to HIV AND AIDS is addressed as part of a holistic evaluation of the patients' perceptions of the disease. The ethnographic information gathered from the adult informants has been incorporated into the following discussion to contextualise the experience of the patients and their situation at the Centre. Where patients are unable to provide biographical information, the psychologist and social worker provide these detailed profiles of the patients.

5.2 The position of adult patients at the Centre and their daily routine

As in all organisations, specific routines and patterns of behaviour can be identified in the Centre. The nurses do the first round of checks on the patients at 05:30, changing bed pans and incontinence 'nappies' and running baths for patients. Some patients are able to walk and can bath and care for themselves, while those in the final stages of the disease are bed-ridden and require constant care and attention. Nurses and nurse aids carry the bed-ridden to the bath and give them sponge baths, using antiseptic liquid and soap to ward off germs and infections. The sponges that are used are specially designed to release most of the foam and thus differ from commercial sponges that can retain too much foam, trapping dirt and creating a breeding ground for infections. After the baths, the patients are dressed in fresh hospital gowns and

returned to their beds for breakfast. Breakfast consists of small quantities of foodstuffs containing protein, fibre, carbohydrates and a small amount of fat. Most battle with proper digestion due to the advanced stage of the disease which ravages their bodies. Those that battle to chew or digest solid foods are given health shakes. Sores inside their mouths make solid foods unbearably sore to chew or even to have in their mouths. Following breakfast, the patients are wheeled outside onto the lawn to enjoy some sunshine and the volunteers assist by reading to them from the scriptures. On the lawn, volunteers cover the patients with blankets and play music to them. More than 80% of the patients develop some form of dementia or a sense of hopelessness. Hennie, one of the patients, said that he was waiting to be released from his painful, emaciated, diseased body because he was unable to take care of himself and saw himself as a burden. Hennie told me that he wished he had committed suicide while he was strong enough to do so, but instead has had to suffer helplessly waiting for a relieving death.

Lunch is served at 12:30 in the dining room in an informal setting with the television on in the background. Tables are designed and spaced to accommodate wheel chairs around them, and meals are devised and planned by a dietician in accordance with the specific nutritional requirements of AIDS patients. The patients return to their rooms after lunch to rest and watch television from their beds. Their vital signs are checked in the morning and in the afternoon. Nurses enquire after their physical and emotional states of mind. The 'nappies' of the incontinent are changed several times during the day and those that are not incapacitated take part in activities such as gardening, painting and even yoga exercises. In the evening patients gather around the television in the dining area and watch old videos that have been donated to the Centre. Bedtime is between 20:00 and 21:00. Thereafter, reading is by bedside light only and nurses check the patients every hour. Finally, lights are put out at 22:00.

Assessments and evaluations are commonplace within a health organisation and at the Centre such processes comprise assessment of the psychological and physical health of the patients. Once every three months patients have blood tests to assess the progression of the disease and the effects of the antiretroviral drugs on their health. They are regularly assessed by the psychologist to determine the extent of dementia or psychotic development. In severe cases, patients are isolated from other patients since many of those with dementia become delusional and violent. Neo, one of the Centre's patients, managed to convince a naïve volunteer to give her a lift to see her mother with the purpose of saying goodbye to her. Upon arrival at the destination, Neo became violent and attacked the volunteer, trying to gain control of the vehicle in order to 'escape'. Fortunately the volunteer was able to restrain Neo and return her to the Centre before the incident became unmanageable.

From the interviews it was established that as institutionalised patients, they believe that they are in a better position than those with HIV AND AIDS who are cared for at home. At the Centre the nurses ensure that they take their medication without missing a single dose, their diet is optimally planned in terms of nutrition, and they have medical staff on hand around the clock should an emergency arise.

5.3 The meaning of illness for patients

Illness is a patient's interpretation or the meaning that a patient attaches to a condition of ill health and can therefore take various forms (Singer & Baer 2007:70). Illness involves a mental and emotional transition from a healthy status to a sick one, i.e. the acceptance of illness.

The religion of a victim and his/her family plays a vital role in determining the meaning attached to AIDS and death. In Sudan, surveys indicated that it is common for people to reject condoms because the church taught them that condom usage was 'wrong' and because women wanted to bear children (Allen 2007:373). Father Stan admits that "previously the Catholic church contributed to the blame that those with HIV had assigned to them, the church played a part in condemning these sufferers because they were seen as 'deviants' because they contracted HIV from sex before marriage, some of them are drug users and others have been involved in prostitution. At the Centre we encourage acceptance and the non-judgement of patients, those who are HIV-positive need acceptance irrespective of how they were infected".

As a background question, I asked the patients about their religious beliefs and practices. Six Catholic patients said that they had been afraid to admit that they feared they were HIV-positive since the priests had always taught them about abstinence before marriage and they felt their contravention of this teaching would result in them being ostracised and berated. All the patients agreed that they were fearful of some form of marginalisation since AIDS invokes panic and fear in the communities from which they originated where it is regarded as incurable, and levels of ignorance about the methods by which HIV AND AIDS is contracted are high.

It is important that careworkers understand patients' culture and their health beliefs to ensure mutual understanding and cooperation (Macklin 1989:94). To understand illness and coping mechanisms, the Centre explores individual members' experiences of illness as well as how a patient's family organises itself around illness and loss (cf. Macklin 1989:90). This assists staff to customise care plans in the form of counselling and support for each patient so that the care received will be most appropriate and effective. Patients and their families are encouraged to articulate what they understand about the disease and how they feel about it so that facts can be explained to them and their feelings about the disease can be addressed. Furthermore, they are asked how HIV AND AIDS is viewed in the community in which they live in order to ensure the family can be contacted without creating circumstances in which the family will be discriminated against because of their association with HIV AND AIDS.

Sickness is given meaning by a patient in terms of the diagnosis, prognosis and how the patient experiences its symptoms i.e. the actual illness experienced. According to Dr Ngumbe, "the meaning of illness depends on whether patients accept the sick role and how they react emotionally to the disease". The patient is often affected by the perceived origin of the illness, e.g. one patient, Ntombi, believed that she had contracted her illness as a result of a curse put on her by a jealous neighbour. For her, her illness stemmed from her successful career and flourishing family life for which her neighbour meant to "punish" her. Dr Ngumbe noted that the patients at the Centre are more at ease with their condition when they know that their beliefs and views are understood, and when they themselves understand what to expect from their illness in terms of the course and nature of the illness. For Hennie, his illness had been the result of risky and careless behaviour, but as a Christian, his illness signified a chance for him to 'redeem' himself. "Because of how I got AIDS I have street cred with the teens so I go and teach them how to use condoms, how I got AIDS from unprotected sex and not to take any chances with their life", said Hennie. He believed that his illness had given him a purpose by entrusting

him with the important job of attempting to save as many lives as possible by using his own life as an example.

At the Centre patients' views are considered by medical staff regarding the treatment they receive and the reasons underpinning their beliefs and reactions to the treatment. Health beliefs form part of this pattern of beliefs and the doctor and patients may have differing beliefs in this regard. As a medical practitioner, Dr Ngumbe commented that he was more objective about the medical facts, medical status of patients and about medication to delay the onset of AIDS, having had many years of medical school training. However, both the doctor and the patient have subjective perspectives dependent on their specific health beliefs and practices and the meanings they give to an illness. Dr Ngumbe's health beliefs are based on his scientific background; "I don't believe that curses and witchcraft cause HIV AND AIDS and in the Congo not many HIV-positive patients believe witchcraft is to blame for their diagnosis. In South Africa, witchcraft is a relatively popular explanation as a cause for HIV AND AIDS, meaning that South Africans are less accepting of the medical facts about their disease and embarking on treatment can be delayed because of this". Patients are influenced by their traditional beliefs about illness and treatment, and in the South African context, some patients may consult traditional healers and make use of indigenous medications to treat illness which may be seen by them to be caused by curses and witchcraft (Das & Poole 2004:147). The meaning of illness for these patients is one of malice and malevolence sent by another person which manifests in the illness (Das & Poole 2004:147). This meaning of an illness is significant since the person must contend with both the illness and the fear of the malice of the person sending the illness, and until those 'bad feelings' are resolved, the illness will not retreat. Dr Ngumbe explains the medical facts to patients and tells that even if they do not entirely believe what he is telling them, that they should try taking his medication to see if it has an effect on them. In this way a temporary solution is found to ensure that the patient is treated and his or her concerns about modern

medicine are addressed. Dr Ngumbe does not discount the possible healing effects of traditional medicine and admitted that many such treatments actually do have medicinal properties. He explains to patients that they also need biomedication and that the two types complement each other; the two types of treatment do not have to be mutually exclusive. He said that this ensures that the patient's beliefs are respected, while also ensuring the acceptance of biomedical treatment.

5.4 Patients' reactions to their condition and questions they ask at the Centres

When Hennie first realised he was sick, he decided to ask for advice and tried all types of, what he called, 'boereraad' treatments because he was brought up to believe that 'men are men' and not 'sissies', and they do not consult physicians. When he realised that he was not recovering, Hennie agreed to placate his friends by seeing a doctor. Hennie confided in me that "I wasn't very careful when I was a 'laaitie'; I slept with a few girlfriends without using condoms. I started to feel like I had no energy and not like myself, I thought I might have HIV so I went to the doctor and had a bunch of blood tests". The doctor told him that he had contracted HIV, most likely as a result of the unprotected sexual relations, and that the disease had progressed quite far without treatment. When Hennie first arrived at the Centre, he believed that hospitals were only for those who could be treated and recover and therefore, he felt that being in a hospital would waste everyone's time since he was never going to recover. Hennie later adjusted to the Centre, but he also used to tell fellow patients that he wanted to die at home. He understood that it was necessary for him to be at the Centre where he was provided with appropriate care and he was not a financial and emotional burden on his family.

Hennie felt exceptionally helpless after he had been bed-ridden for over one hundred days, and he admitted to feeling worthless when he asked the nursing staff and me to help him end his life (see 5.2 above). The psychologist assured me that such feelings are normal since they are associated with the mindset of a patient with a terminal disease and that it is their perception of themselves that has changed in a negative way.

Eleven of the black adult patients at the Centre and fifteen of the black patients at the anti-retroviral clinic believe that HIV AND AIDS can be treated with some degree of success by traditional healers. I felt it necessary to consult a traditional healer to corroborate what the patients told me and to understand the role of the traditional healer in the beliefs of patients who had consulted traditional healers. I was referred to Lennox by one of the outpatients at the ARV clinic. Lennox is a traditional healer who operates under a bridge leading to the M2 highway near the Johannesburg central business district. He operates from this area because he says most of his clients have access to or come to the Johannesburg central business district for work or entertainment. We met at his shack which functions as his business premises. He gave me a quick lesson about the herbs he uses and their medicinal properties. He does not use any animal parts and condemns the use of human parts for any medicine. Lennox has been practicing for almost 15 years since he was first 'called' to the profession. He helped me to obtain a sense of the treatment dispensed, the type of people utilising his services and the treatment people expect. Lennox's patients are predominantly from a less educated and lower income category, and based on their symptoms and lifestyle, he estimates that 60 – 70% are HIV-positive. He said "I know a lot about AIDS because I did two years at med school, then one day I just knew that I had been called to be a traditional healer. The first thing I tell my patients is that I can't cure AIDS. I know a lot of healers that tell their patients they can cure AIDS". There is one traditional healer in the same area as Lennox who is notorious for advising men to have sexual intercourse with a baby girl in order to rid their bodies of the disease. Upon attempting to

approach him, he became defensive and said he would not speak to me because I would not understand how his cures worked and that he would not speak to a woman about “things that only men know about”.

I questioned Dr Ngumbe about the most frequently asked questions in doctor-patient conversations and he identified the following:

- Will I die?
- Will the medicine cure me?
- Can beetroot and garlic cure me?
- How long will I live?
- Can I still have sex?
- Is my girlfriend sick as well?
- How did I get sick?
- Can I still work?
- Who will take care of my children?
- Do I have to tell anyone that I am sick?
- Can my children have the disease?

5.5 The sick role and status change

Patients undergo a status change from healthy to sick before they are admitted to the Centre, but counselling is done with patients to ensure that they embrace their status and address implications for their families. For the patient, the sick role is assumed immediately after they accept that they are sick. This sick role involves a new status with a change from being healthy to being sick, implying that they are in need of care and attention. This new status means changes in lifestyle, such as taking medication, acquiring less stressful jobs, making provision for their children’s care, and sometimes even different roles in the family. The sick role may

involve pity and compassion or alternatively, discrimination and isolation for some patients. They are seen as 'weak' and fallible and as a result, many patients command less respect. For patients at the Centre, this new status requires much adjustment on their part as well as acceptance that the disease is terminal, and acknowledgement that their role will change as they get weaker and as they go from being independent to dependent (cf. Macklin 1989:105-108 & 116).

5.6 Biopsychosocial stages attached to AIDS

According to Macklin (1989:105-123), and corroborated by the Centre's psychologist, there are certain biopsychosocial stages associated with HIV AND AIDS, through which patients pass. Some of these stages, which are apparent in patients' emotional and physical states, are evident among patients at the Centre.

First is the stage of 'worried well' during which the fear of diagnosis, especially based on past experiences that may have exposed someone to the virus, e.g. Hennie's fear of being diagnosed with HIV due to his unprotected sexual experiences. This stage is accompanied by anxiety, depression and even rage. Patients may also fear being tested because of the stigma attached to AIDS (Macklin 1989:105-106). Many of the patients that I spoke to at the anti-retroviral clinic fell into this category before being diagnosed with HIV. Two patients in particular, Charity and Julius, admitted to me that they had feared being diagnosed with HIV since they had indulged in risky behaviour which had possibly put them in danger. Julius engaged in unprotected sexual intercourse and, as a teenager, Charity had been a drug addict who used needles to inject herself intravenously.

Following this, is the stage of seropositivity when a patient's identity shifts from healthy to sick, and from unstigmatised to differentiated from the community by their HIV status. Lennox, a patient at the Centre, was in denial when he was diagnosed with HIV. He told me that "if I am sick I can't work and I can't buy bread for my child. I don't tell nobody that I'm sick, I go to the 'sangoma' to make me to be better." Lennox was not very knowledgeable about HIV AND AIDS and consequently he consulted various sources, both mainstream and herbalist, to understand his disease and to help him to accept his sick status. Lennox confided that he was terrified that the community would ostracise him if they knew that he was HIV-positive and he further feared that he would be dismissed from his job if the company owner knew that he was sick and that the HIV would progress to AIDS because he had not embarked on treatment soon enough.

Although patients are asymptomatic, they need to develop coping skills to survive the period of mourning for the loss of their identity as a healthy person, for the changes that need to occur in their sexual behaviour, i.e. disclosure of the virus to sexual partners, and to deal with their families who mourn the loss of the previous family identity (Macklin 1989:105-107). Promise experienced this stage when, although she still looked and felt healthy, the neighbourhood children knew that she had been diagnosed with HIV and began discriminating against her daughter. Promise knew that she had to protect her from this abuse and in doing so had to accept her identity as 'sick'. She was forced to plan for her daughter's future after her inevitable death. This stage was very difficult for Promise and she told me "I thought about killing myself, I couldn't believe I was really going to die and leave my child with no mother. My sister spoke with me, she said I mustn't be selfish, that I must think about the child. When she said she will take the child I stopped worrying and I made peace with me being sick". Family identity is altered after the diagnosis since one member will be less capable of caring for themselves and family members will have to accept the fact that they will eventually lose this member to a terminal disease and a new family structure with altered roles and boundaries will be created (Macklin

1989:117-119). Many patients with children contemplate the fate of their children as they become more sensitive to the physical symptoms of their disease and the sense of dread that accompanies the changes in their bodies (Macklin 1989:106-108). Lizzie, one of the patients at the Centre, embodied this stage of the disease. When she was diagnosed with HIV, she was devastated and battled to accept that she may never see her child grow up. After she accepted her status, she said that she made plans to ensure that her child, Dumisani, would not be homeless, but since he was also diagnosed with HIV, they both became patients at the Centre.

The next stage is where AIDS-related conditions set in, i.e. patients start to experience symptoms of the disease. Chronic illness occurs with symptoms such as diarrhoea and memory loss. Patients' ability to work may be affected which may mean unemployment and therefore, financial stability is at risk. Ntombi struggled with the decision to tell her family about her diagnosis because she came from a family of graduates and "I was afraid that they would ask me how someone with my qualifications could have been stupid enough to get this disease. I didn't have any option, I had to tell them because I was losing weight and starting to lose concentration at work, everyone saw something was wrong with me. When I told my parents they disowned me. They said that I brought shame to their home and I wasn't welcome anymore. Luckily I had some true friends who stood by me and helped me on the days when I couldn't do things for myself". Many patients in society still maintain secrecy but eventually the symptoms become visible and the need for care becomes more important than the fear of disclosure. Promise, a patient at the Centre, attempted, with her daughter, to maintain some semblance of a 'normal' life, with Promise working for as long as her health would allow her to. Her daughter attended school and life continued until some of the children at the school discovered Promise had AIDS and Promise was forced to admit the truth and submit to professional care. Unfortunately when physical symptoms appear, this pretence is no longer possible.

The patient learns to cope with the symptoms of the disease, develops ways of interacting with the hospital environment and establishes relationships with the health-care team. Eddie found it difficult to relate to the staff at clinics and state facilities because the staff are often extremely busy and do not have sufficient time to explain the details about his condition and how the medication will function to alleviate his symptoms. Eddie said "I don't trust those ones, they speak too much fast, I'm not made to know about what is happening in my body". Eddie said that he developed lesions and constant diarrhoea but he was unsure whether the medication would have an effect on these symptoms or whether they would treat the cause of the symptoms. He had to learn how to interact with medical staff and has learnt how to trust the staff at the Centre due chiefly to the fact that staff have explained to Eddie what HIV AND AIDS is and how they are treating the symptoms of his disease. In addition, the medication has lessened the effect of many of the symptoms such as the diarrhoea. He has accepted that these symptoms are part of the progression of the disease. The Centre's careworkers help patients to adjust to being in a hospital environment by giving them advice about a healthy diet and by telling them about other patients who were following the treatment programme and their improved quality of life. Patients may battle to relinquish their healthy status and the roles they played prior to their illness, i.e. roles where they functioned not as an HIV-positive patient but rather as a parent, sibling, colleague and so forth. Ma Mabel, an outpatient at the anti-retroviral clinic, admitted to resisting the role change because she had always been the strong independent matriarch but had to accept her weakening state and hand some of her responsibilities to her children and other family members. This struggle to accept the sick role may result in patients resisting care from others (Macklin 1989:109-110).

The second last stage is the AIDS diagnosis which is the terminal phase and becomes gradually more debilitating and life threatening. Many role changes are involved for the patient and for family members caring for the patient. Beauty, a patient, admitted that because she spent so much time denying that she was HIV-positive, she had missed the opportunity for anti-retroviral medication to be effective. Beauty gave birth to a baby boy who is also HIV-positive. She was forced to entrust him to her sister to raise when her HIV progressed to full-blown AIDS because she was able to function for weeks without incident but these periods alternated with weeks of secondary illnesses and chronic symptoms like diarrhoea and vomiting. Death may be sudden or after progressive deterioration of the patient's health. There is an atmosphere of anticipatory grief in this stage which may cause some negative feelings for the patient (Macklin 1989:110-113). One of the patients at the Centre, Hennie, was devastated when his doctor told him that the HIV infection had developed into full-blown AIDS. Hennie lost all hope and became suicidal because he felt that he had nothing to live for and was becoming a burden to those caring for him. Hennie struggled to accept that he could no longer be independent and care for himself. His health deteriorated each day until after 106 days of being bed-ridden, death occurred.

The final stage is bereavement and reorganisation where family and friends try to continue a 'normal' life, expecting mental impairment and gradual loss of body function of the patient, while preparing for the patient's death (Macklin 1989:119-120). Medical team members consider the patient's and their family's belief system with regard to treatment of the bodies and type of funeral considered appropriate in order for the death of the patient to be accommodated in a manner to which they can relate. After Benjamin had been bed-ridden for months and had become incontinent and was showing signs of dementia his family was called to the Centre to discuss his imminent death. The family insisted on the body being embalmed and a full mass at the funeral ceremony because they believed that even though he was dying from AIDS they would not be ashamed of him; they wanted to celebrate his life and honour him with a proper

funeral. The family had resigned themselves to his death for the most part since he had been sick for years but they required counselling to be able to reconsider their family without Benjamin. Benjamin had told me “I worry my family will be in trouble coz of the HIV, people are scared they will catch it. The clinic send people to talk with my family so they know what to do when I die”. Benjamin had been the breadwinner for his family and was supporting his parents when he was diagnosed. The transition from a family including Benjamin to one excluding Benjamin was made more difficult by the loss of income and terrible financial strain suffered by the family. The Centre had made arrangements to support the family financially, interspersed with assisting various extended family members to find piecemeal employment. Counsellors help the family to plan for the future as it reorganises itself with a new structure, without the patient (cf. Macklin 1989:120-123). It may be difficult to grieve since often the cause of death cannot be discussed openly due to stigmatisation, discrimination and isolation. Family members of patients may feel angry and helpless because they could not protect the patient from the disease (Macklin 1989:113-115). When Promise, a patient at the Centre, realised that she was dying, counsellors at the Centre actively prepared her daughter for her imminent death through both telephonic counselling sessions and by sending her literature on bereavement. Lizzie’s son, Dumisani went through a series of counselling sessions to develop his coping skills since he had never been separated from his mother and it was feared that he would suffer from separation anxiety and traumatic stress when his mother died. Dumisani understood that he too was infected with HIV and this was a comfort to him in that he felt “mommy and me will be together in heaven”.

Patients at the Centre passed through most of the above-mentioned stages before they arrived at the Centre, since they are only admitted to the Centre during the terminal stage. Of the five funerals of adult patients that I attended at the Centre, three of the families insisted that the death certificate should list the secondary disease that ultimately caused their death because

this would circumvent discrimination and stigmatisation for the family within the community. Sthembile's family said that they lived in a small close-knit community and the stigma attached to AIDS would cause them to be excommunicated. Sthembile's husband had not shared his wife's HIV status with the community, he told them "she has cancer and needs to go to a hospital in a big town to get treatment so you will only see her sometimes". Since they had an HIV-negative daughter, he wanted to protect her from the discrimination linked to HIV. "To die from HIV brings shame to the family but if you die from cancer means you die with respect". Meshack's family concurred with this, begging Father Stan to have pneumonia listed as the official cause of death. Meshack was a teacher and a well-respected member of the community and his family wanted "him to be remembered with respect and dignity". Meshack suffered with various secondary infections during his terminal phase but his immune system could not withstand the onslaught from pneumonia during winter. Meshack had contracted the disease from sexual relations with his ex-boyfriend and his family wanted to avoid the stigma of admitting that their son was homosexual. Having a son who was homosexual and HIV-positive "would be a death sentence for the other kids in our family and for his mother and me". Blaming the death on pneumonia ensured that the family was afforded compassion and care during their time of mourning and allowed them to mourn publicly and without shame. They maintained that listing HIV AND AIDS as the cause of death would strip them of their good family reputation and their dignity as well as ostracise them since in their communities where understanding about the causes of AIDS is low, much fear and confusion about the disease occurs.

5.7 Explanations of witchcraft as a perceived cause of HIV among patients at the Centre

Witchcraft can be defined as "manipulation by malicious individuals of powers inherent in persons, spiritual entities, and substances to cause harm to others" (Ashforth 2001:5).

At the Centre five of the twenty adults interviewed and one of the children claimed that witchcraft was the cause of their condition. Fifteen people or half of the sample to whom I spoke at the

antiretroviral clinic said that they associated HIV AND AIDS with invisible forces of witchcraft. The fact that the above-mentioned Centre and clinic patients interpret the symptoms of AIDS as indications of witchcraft correlates with Das and Poole's account of witchcraft (Das & Poole 2004:142–148). They all said that when young people die in the townships the most common explanation is witchcraft since this shifts the 'blame' from the person with HIV AND AIDS to a witch or a person with the grudge against him or her. People who are accused of witchcraft or identified as witches are usually ostracised.

According to Das and Poole (2004:148-149), witchcraft carries with it symptoms of wasting and sores, with victims becoming thin and coughing continuously with intermittent vomiting, all of which are symptoms of HIV AND AIDS, hence the fact that some people believe they are victims of witchcraft. Ntombi believed that because she was a successful business woman and graduate, her neighbour had paid a witch to put a curse on her. "She was always jealous of me, from when we were children; I always had better clothes and nicer boyfriends. I spoke to her last of last year and she said to me that everyone gets what they deserve and I mustn't think I'm high and mighty because things change. I found out from people that we both know that she was seen with a witch and she told some of the girls she took care of me." Not long after that Ntombi had herself tested for HIV and discovered that she was HIV-positive. The patients at the Centre who believed that their disease was caused by witchcraft explained that since they could not see how they had been infected with the virus, it was easy to believe that they had been given poisoned food or that a spirit in their dreams had 'infected' their bodies. Lennox did not believe that he had HIV, despite his sudden weight loss and chronic illnesses. After he was diagnosed as HIV-positive, he took a leave of absence where he visited a powerful healer in the Eastern Cape. He said "the sangoma said he see a curse with me, it come from one that was fired from the job where I work coz he stole stuff and we tell the boss". Lennox desperately clung to the belief that the healer would reverse the curse and he would return to a state of good

health. Up till the day he died, Lennox never relinquished his belief that his disease was as a result of a curse. Their families for the most part, believed that they were victims of witchcraft and were not perceived as HIV AND AIDS sufferers, creating the perception that they were not dangerous since they were not seen to be carriers of HIV. As a consequence they were still regarded as ordinary members of their communities from which they received sympathy and help. Attributing deaths to witchcraft is a means of explaining the epidemic in a way that makes sense to the community (Ashforth 2001:11; Steinberg 2008:2-3).

5.8 Stigmatisation and its management

Stigma and blame may cause AIDS patients to be deprived of valuable familial or community support, causing them to withdraw from the community. At the Centre stigmatisation is deemed unacceptable.

Stigmatisation is often caused by stereotyping of the disease which is constructed by society and usually not based on fact. Stigmatisation consequently means that sufferers of the disease often struggle to get help (Goldin 1994:1359-1366). The victims of HIV AND AIDS are stigmatised because the condition was initially seen as a 'gay disease' or as a disease associated with people with questionable morals, for example, prostitutes and drug addicts. Hence many HIV AND AIDS victims became subjects of discrimination. Some of the home-based workers were afraid that because they were known as careworkers visiting HIV sufferers, they were actually drawing attention to the HIV-positive patients and their families. Merely going to an ARV clinic to be tested for HIV can result in stigmatisation of the individual due to the fear and social stigma attached to HIV AND AIDS (Macklin 1989:104).

Seven of the ten black women interviewed at the antiretroviral clinic felt that women with AIDS were more stigmatised than men and more shameful since they felt that there was a different attachment of blame between men and women. These women said they received very little support from their friends and community because of their status and were shunned, whereas their male counterparts with HIV AND AIDS were less stigmatised in the community.

In Sarie's case, Biblical references detailing how prostitution was frowned upon were used by her roommates to justify discrimination against her and to blame her for contracting HIV AND AIDS (cf. Brouhard 1993:17). Sarie was forced to work as a prostitute to support herself after she ran away from an abusive home. After Sarie started working as a prostitute, she moved into a commune-style home. Unfortunately, Sarie's roommates and some of her friends condemned her, with one girl going so far as to tell Sarie that her AIDS diagnosis was divine punishment for immorality because she was a prostitute. Sarie was hesitant to disclose her HIV-positive status to anyone for fear of further discrimination, stigmatisation and isolation, but she eventually did so in order to receive treatment.

5.9 HIV AND AIDS and sexual behaviour

Women have traditionally taken a subordinate role in sexual relationships, making issues of safer sex difficult for them to deal with (Ashforth 2001:3). During my interviews with the patients at the Centre and anti-retroviral clinic outpatients, both male and female, I asked them about their sexual behaviour and beliefs to contextualise the importance of understanding sexual behaviour (see 2.6 above). All of the men interviewed said they preferred engaging in sexual intercourse without using condoms which hindered their sensation. Tumi, one of the outpatients at the anti-retroviral clinic said that "using a condom is like wearing a raincoat, it's not exciting, you don't feel anything. I don't use condoms and my girls don't ask me because they know I will say no to using those things." This testimony provided concurs with findings by Hepworth and

Shernoff (1989:54), namely the belief that condoms are unnatural and that they interfere with sexual satisfaction and reduce sensitivity during intercourse. Mashudu, another clinic outpatient, told me that "I'm the man; I decide when we have sex, where we have sex and how we do it. The woman knows her place; this is for the man to tell her, not the woman to tell the man". These men confirmed that they felt that women should play a subordinate role in sexual matters. Women generally receive the least sympathy and are blamed most when they have HIV AND AIDS (Macklin 1989:209).

I started by asking the women trivial questions about the qualities they liked best about their partners; how they met their partners, and other such non-threatening questions. Once I had gained their trust and they were more comfortable, I asked them more invasive questions. These women were asked how often, if at all, they had talked to their partners about sexual matters. They were asked whether they had ever asked their partners to wear a condom during sexual intercourse. In addition, we discussed how at ease they felt in talking about their sexual needs and concerns with their partners, such as an unwanted pregnancy and sexually transmitted diseases. I also enquired about what they had been taught by their parents and their community about how women should behave sexually to explore whether it was 'acceptable' for them to be sexually assertive or whether they had been taught to be submissive. The views of the majority of these patients and outpatients confirmed Macklin's ideas, viz that women are conditioned during their upbringing, by their partners and their communities to be passive and therefore, they do not demand safer sex practices (Macklin 1989:99). Suzy, a clinic outpatient told me that "my mother never told me about sex except that the man is in charge of sex and the woman must always show she is happy". Dorah, a patient at the Centre confirmed that "the man does not ask his girlfriend what she wants, the man decides what he wants. When they came to tell us at school that we must use condoms if we don't want to have the baby or AIDS, I told my boyfriend to use the condom but he get very very angry and he said he won't be my boyfriend

anymore if I tell him to do that. He tell me that if he has to use the condom he will know I am a slet and I am not faithful to him. I never ask him again”.

As is evident from the information provided by the patients at the Centre and the outpatients, there is historically a difficulty in forcing people to change their sexual behaviour since much of that behaviour is linked to cultural beliefs and practices and hence condom usage is low in such circumstances (cf. Rieder & Ruppelt 1988:206-209). Dorah and Suzy, among others, confirmed that they had traditionally been shy to talk about sexual matters because this was considered a private issue and it was improper for them to discuss issues pertaining to sex but, with the advent of AIDS, they realised that they needed to discuss sexual experiences and perceptions openly, including communication between partners in order for there to be proper understanding of issues that affect their health. Dorah and Suzy have only adopted this open communication subsequent to their diagnosis as HIV-positive and Dorah said that “My new boyfriend we talk about sex, I tell him I am sick and we use the condom. He listen to me and we know we don’t want to be sick so we must use the condom” (cf. Macklin 1989:99, Weisfeld 1991:92-94).

Young female outpatients at the anti-retroviral clinic were informally asked about why so few girls supposedly used condoms during sexual intercourse. Ten out of the fifteen girls said that they were embarrassed to get free condoms from clinics in case they were seen to be loose-moraled women by their families, partners or communities.

Female patients at the Centre and the antiretroviral clinic were asked whether, knowing they were HIV-positive, they would consider having children despite the danger to themselves and the possibility of having HIV-positive children. The majority of female patients at the Centre and clinic outpatients said that a high value was placed on fertility and children by their husbands and boyfriends, and that having children is important because contraception was viewed with

disparagement by their partners. Sophie, a regular visitor to the ARV clinic, knew she was HIV-positive. The clinic staff advised her against having children because of the possibility of the baby being HIV-positive, but Sophie still chose to have a child to please her long-time boyfriend. Sophie told me that “my boyfriend said he would leave me for another woman if I didn’t give him a baby. He wanted a boy child. I hoped to get pregnant with a boy child so I didn’t want to have to get pregnant again. The baby was a girl so he said I must give him more babies until one is a boy”. For women, pregnancy activates and accelerates the disease progress, with many only discovering they are HIV-positive after their babies are diagnosed with HIV (Macklin 1989:101). All except two of the black men interviewed responded to my question about whether or not children are a sign of male virility by saying that they indeed thought so. Tumi told me that “in my culture children show you are a ‘real’ man, the children make the family name keep going and you look better to everyone when you have children.” The men said that children gave them a higher standing in the community.

Some patients, such as Hennie, said that they had not had a proper education. Hennie was forced to abandon school to support his mother and siblings. He felt that his lack of education led to ignorance of how a virus such as HIV is spread. This was also the case with fifteen other adult patients at the Centre, who admitted that had they known how the disease is spread and had they not had misconceptions about HIV AND AIDS, they might have been able to avoid infection. All of the adult patients stated that HIV AND AIDS prevention education was not prevalent in their communities and that HIV AND AIDS was not openly discussed. All come from poorer sections of the community.

5.10 Coping strategies employed by patients prior to arrival at the Centre

Jordan's account (2003:45-52) of the social relationships that form part of an organisation's culture helped me to better understand the friendships and relationships that develop between those infected with HIV. Those who had existing friendships, such as Lizzie and Promise met at places commonly frequented by those with HIV, places that are off the beaten track, such as anti-retroviral clinics and hospices. Promise and Lizzie, met at Centre while waiting to be seen by the counsellors. Lizzie was carrying a picture of Dumisani and Promise struck up a conversation with her, asking her about her son. The two discovered they had much in common, discussing their children and what the future would hold for them. Promise said that "I was alone and scared; I didn't know what would happen to me and my child. Lizzie has also got a child. She knows how hard it is to have HIV and know you won't see your child grow up. We speak together and it gives me peace because she understands my problems and what I'm scared of, she gives advices and she is a good friend to me". This relationship was functional in nature and acted as a coping mechanism to help the friends cope emotionally.

This coping strategy that I discovered, I call the friendship/commiseration strategy. Both Promise and Lizzie employed this strategy. This is where friendships develop between people who share an HIV-positive status since they are able to identify with feelings of the other person and share their experiences. Zelda informed me that such friendships are based on lifestyle changes, common fears, the common need for acceptance and to share the experiences they live with daily with people who are in similar physical and emotional situations. Promise and Lizzie were both mothers and had bonded as a result of this common factor. Promise told me that such friendships are stronger than any others because, except for someone else who experiences the same things, nobody else understands the emotional and physical issues she was experiencing. Lizzie and Promise both believed that their friendship added a positive

component to their lives, and a means of improving their coping skills when they were ill from secondary infections or when they felt sad and lonely.

Some patients, like Hennie and Lennox, told me that before they came to the Centre they had difficulty believing or accepting that they had HIV AND AIDS and thus continued living their lives as usual, without changing their behaviour since they believed that if they pretended they did not have the disease, they might be able to make it go away. This coping strategy constitutes a denial of what is happening in their bodies and their lives. Hennie said that “I thought because I was dying nobody would feel the same about me, the last thing I wanted was people feeling sorry for me so I wanted to pretend that I wasn’t sick and somehow it would all go away”.

Hennie adopted this survival strategy in order to cope. He said that he needed time to process his diagnosis and to accept it before he could share his status with others. Lennox believed that the diagnosis was incorrect and he continued living his life as though nothing had changed. He was afraid to admit that his HIV status had changed because he feared marginalisation.

Other patients at the Centre used medications dispensed by traditional healers to alleviate the effects of HIV AND AIDS. Benjamin, for instance, has faith in traditional medicine. Benjamin wanted to try all possible treatments available that could have an impact on the HIV. Benjamin tried a healthier diet and focused his energy on being positive in order to convince his body that he was not ill and overcome his HIV-positive status. Some patients at the antiretroviral clinic said they relied on antiretroviral drugs to give them the peace of mind and physical boost to continue their daily lives without succumbing to the effects of the disease. Lizzie used what could be described as a holistic approach that changed her lifestyle. A combination of diet and exercise as well as psychological acceptance, acknowledgement of the HIV-positive status and a positive mind set has been developed in the wake of her diagnosis.

For a few patients a 'devil may care' strategy works, i.e. they show the world a façade. Instead of keeping their status a secret, they share their status with anyone who asks them. In an effort to seem as though they have accepted their condition they pretend that they do not care what people say about them or their families. Lebo confided in me that she was HIV-positive. Many of the community members condemned her for bringing this 'curse' to the community, with one of her neighbours actually moving since he feared being infected by Lebo because of his close proximity to her. She forced herself to 'put on a brave face' and be strong for her family because she felt she had brought shame on them and hence she thought she could repay them by feigning that the hurtful looks and comments from community members did not wound her. Promise said that she was not hurt by the fact that some people chose not to be near her or have contact with her because of her HIV status; she simply pretended she did not care. She developed a 'tough exterior' as a defence mechanism to guard herself against further hurt. Promise said coming to the Centre helped to stave off further criticism and intense scrutiny since this helped her to live a 'normal' life where she was not seen as 'different' from the other patients. For patients, the Centre offers what could be called a 'normal' life, where they are accepted and loved despite their HIV status.

What follows is the conclusion to this study. The conclusion will discuss the findings made during the study of the Centre. The difficult circumstances in which the Centre operates as well as whether it meets its objective of caring for terminally ill patients will be contextualised in terms of the organisational culture of the Centre and how it operates as an intrinsic part of the community in which it is situated.

6. CONCLUSION

With the burgeoning number of people infected with HIV AND AIDS in Sub-Saharan Africa, extreme strain has been placed on families to care for these patients. Since in many families afflicted by HIV AND AIDS, there is more than one AIDS sufferer, it becomes impossible in many cases to accommodate these patients in the family. This creates the need for institutions to provide professional care for such patients. This insight provided the impetus for conducting an ethnographic study in order to holistically explore the nature and functioning of an AIDS hospice caring for those in the final stages of AIDS, as well as assisting patients in earlier stages with treatment to enable them to regain their health to function outside the Centre. I focused on the patients and their perspective of their experience of life as an AIDS patient and the treatment they received at the Centre. Secondly, this study considered the importance of the concept of organisational culture in relation to the Centre, the relationships of power between people in authority, and contribution of the Centre's value system to its role of providing care for HIV-positive patients.

Background and rationale

The Centre was studied in its entirety. This included an investigation of its policies and practices, the human resources employed and the communication style used within the Centre in order to ascertain whether it lives up to its aims and objectives of providing quality care and treatment to all patients, amongst other issues. Furthermore, all facets of the Centre, including the antiretroviral clinics, outreach work, primary health care and prevention education workshops were studied as each element contributes to the success or failure of the Centre as a whole. I offset my study against the social, economic and cultural context of AIDS to explain how the patients came to be at the Centre (see 1.1 above). Through interviews, interaction with

and observation of the patients and staff, I was able to shed light on the institutional environment for the patients who are resident there.

Research methodology

The literature on research methodology acquainted me with the challenges I would face gaining entry to such an institution as well as the importance of achieving rapport with the research participants (see 2.2, 2.3 and 2.4 above). I used the insights gained to build relationships with both the staff involved in the daily functioning of the Centre and to build relationships with the patients whom I interviewed. As mentioned in 2.7 above, having access to patients on a continuous basis allowed for consistency in tracking their progress and the physical and mental stages of their disease. I engaged in an ethnography of the Centre armed with guidelines around research methodologies and an awareness of the challenges facing ethnographers, such that I could uncover issues that would prove valuable in understanding the organisation. The most appropriate methodology for the study was in-depth interviewing since through the interviews an understanding of the meaning of attitudes, beliefs and practices within the organisation could be discerned (see 2.6 above).

The ethnographic method employed was invaluable in uncovering the depth of information that was necessary to understand the Centre and its staff and inhabitants. The social roles and relationships between staff and patients as well as cultural beliefs and behaviour were explored with ethnographic methods in order to holistically evaluate the Centre. This qualitative method was more suitable and relevant for the setting and the type of information required compared to quantitative methods.

Observation was an invaluable method which I employed to gain insight into tensions, alliances and issues that warranted further investigation (see 2.7 above). Body language that alluded to tensions or alliances and symbols such as furniture layout, uniforms and symbolic red ribbons were instrumental in discovering the true meaning behind what was portrayed within the organisation. The study of elements of the culture of the organisation facilitated an understanding of the meaning of symbols and rituals that characterise the organisation. This contributed to a holistic understanding of the values, beliefs and practices that are sanctioned within the organisation.

Functions and goals of the organisation

As a foundation to comprehending the organisational complexities of the Centre, various sources on organisational anthropology were consulted (see 1.3 above). Because the Centre operates as an all-inclusive institution where each patient is treated as an individual and each patient receives customised solutions, the patients expressed their satisfaction with the actual care they received and the manner in which the nursing staff treat them (see 3.2 and 3.3 above). To this end, the Centre involves all stakeholders, namely the Centre staff, patients, family and loved ones of the patients, in the planning and decision making process to determine the best approach and care for the patients, which meant that patients and their family members felt supported and involved in the process. Each patient admitted to the Centre undergoes a psychological examination as well as a physical assessment to ensure his or her mental and physical condition. This process of involving all necessary stakeholders is also applied to decisions regarding appropriate medication, nutrition and exercise routine being devised for patients. In their quest to make certain that patients receive care that is on a par with the care they would receive from their families, the Centre is meeting its goal by engaging the patients on a spiritual, emotional and a physical level and offering them around-the-clock care and support.

The Centre realises how important it is for patients to be seen as individuals and to customise the drug cocktails, treatment and counselling regimes for each patient so that the patient feels understood and cared for. The patients confirmed that the Centre meets the needs of those with HIV and their families in the area. Those who need to know their HIV status are tested for free, in a discreet and non-judgemental manner which encourages people to be tested. The family members of those who are diagnosed with HIV are provided with counselling and guidance about what to expect with the progression of the disease and how to support those with HIV so that both patients and caregivers can be empowered with the necessary information. The Centre offers a safe and caring haven for those in the final stages of AIDS, and services such as counselling, testing and anti-retroviral medication are provided at the anti-retroviral clinic. The anti-retroviral clinic is invaluable to patients who need to collect anti-retroviral medication outside of their own community so that they can avoid the stigma and discrimination associated with HIV AND AIDS (see 3.5 above).

The outreach activities of the Centre extends the reach of the Centre to patients such as Ma Mabel who cannot be physically resident at the Centre, but still require the emotional, spiritual and financial support that those at the Centre are provided with. The homecare programme adds value and meaning to the lives of those who are often abandoned and stigmatised because of their HIV-positive status (see 3.4 above). The educational workshops have incorporated the community by engaging them in debates around HIV AND AIDS and by educating scholars, pregnant women and general citizens about the causes of AIDS in order to minimise the ignorance surrounding AIDS, and to spread information in the hope that this will reduce the stigmatisation attached to HIV AND AIDS (see 3.9 above).

Due to the severe lack of funding for such institutions, the Centre was found to be proactive in sourcing funding from the private sector so that it could continue to meet its goals. The lack of funding is indicative of the scope of the crisis in the country and the dire need for adequate funding for such institutions (see 3.8 above).

Organisational underpinnings – goals, values, structures and relationships

The staff were interviewed and observed to ascertain whether they were committed to the organisational goals and mission. The study found that the nursing staff were closely committed to the organisational objectives and values, while the behaviour of managerial staff suggested that some have hidden agendas, and others operate individualistically due to their positions as overseers of financial and other resources. The two categories of staff have different functions and therefore have different manners in which they conduct their duties, for example the nursing staff require compassion and caring, while managers need financial savvy and an awareness of the potential impact of their financial decisions on the organisation. Since the staff composition remains relatively stable, it was determined that the reason for this is the fact that they identify with the organisation's mission and goals and that a family atmosphere exists at the Centre, where staff feel valued and able to express their opinions and ideas (see 3.14 above).

A large number of the nursing staff were interviewed to fully comprehend the beliefs and values that underlie their behaviour within the organisational context. The nurses were found to embody the values of the founder, namely compassion, dedication and love, which has contributed to the establishment of a flourishing organisation. These values were largely internalised by the nursing staff, and the way in which they care for the patients is the epitome of these values (see 3.3. above).

The leadership displayed by the Father and the Matron in particular was strong in that most staff members largely emulate these leaders and were motivated to follow out any tasks because they were influenced by their leaders. Generally, staff identified with the organisational goals, mission and its values, which they said they had largely internalised because these were modelled for them. While minor internal power struggles were noted (see 3.11 above), overall the Centre functions effectively with a low staff turnover and high satisfaction levels. Staff were well informed about policies and processes as well as about expectations that they need to fulfil. There was also a high degree of transparency with regard to financial matters, which left staff feeling informed about the company's finances and overall financial decisions. The inclusive nature of the management style was partially responsible for the high satisfaction rate of staff (see 3.6 above). Staff had also been recruited based on their suitability for specific positions within a hospice environment and as a result, there has been a low staff turnover. The efficient running of the Centre had a knock-on effect on the patients, with the majority of patients believing that they were receiving individualised and top quality care.

The up-skilling of staff by means of training specific to each staff member's area of responsibility, was found to be a motivation for many staff members since they felt that their training needs were important and being addressed. The up-skilling of staff also contributed towards the high standard of care received by patients, which aided in making the institution one that is run effectively (see 3.9 above).

The staff at the Centre empower patients to access welfare grants that aid their families by providing some financial respite when they have lost breadwinners. Counselling provided by the psychologist allows the patient to express his/her fears and concerns, but is also a means for the patient's family and loved ones to understand the process that the patient goes through and a chance for them to resolve their feelings concerning the illness and the patient and to gain

closure. Counselling, however, is also provided to staff as a means of alleviating burnout from the pressure of working with terminally ill patients. These measures are proactive and show an organisation that cares for not only the patients, but also the staff (see 3.3. above).

The religious values that are evident in the Centre were considered since they influence the manner in which the Centre functions. Overall, Christian beliefs are embodied by staff who show compassion towards the patients. Discrimination against patients in any form is forbidden (see 3.14 above). Many patients experienced discrimination and marginalisation due to their HIV status in their communities prior to entering the Centre and as a result brought that latent fear of rejection with them, making the Centre's counselling a relevant and appropriate means of healing the psychological wounds (see 4.8.2 and 5.8 above). The Centre's beliefs included the preservation of dignity of the individual afflicted with HIV AND AIDS by providing free funerals to those who cannot afford a funeral or for those who have been abandoned.

Treatment and care that patients receive

The patient's perspective or health beliefs are considered, but ultimately the medical treatment that will be given to each patient is explained to him/her, resulting in care that is properly understood by the patient. This inclusive process consequently means that patients are more amenable to accepting treatment and adhering to medication, nutrition and exercise regimes (see 5.3 above). The patient's sick role and the changes in their lives as a result of their diagnosis and ensuing illness are considered as part of their holistic care. Counselling offered addresses problematic issues and resolves concerns such as caring for children after a patient has been admitted to the Centre. In this way an attempt is made to increase the patient's quality of life and their general experience since they can focus on their own treatment and accept their illness, which is in line with the Centre's aims (see 5.5 above). In attempting to understand how the health beliefs of the patients impact their treatment and adherence to treatment, witchcraft

was identified as an alternative explanation used by patients to explain their HIV AND AIDS (see 5.7 above). Witchcraft causes similar symptoms to HIV AND AIDS and hence was seen by some patients as a credible explanation for their diagnosis. In addition, it allowed them to be viewed with sympathy and compassion by the community as opposed to the HIV diagnosis which carries stigma and fear with it.

In line with their goal of putting the patient first and to ensure that patients benefit from services offered both by the Centre and by the Department of Social Welfare, the Centre operates in partnership with the Department to maintain its standards. The Centre attempts to get as many children fostered or adopted as possible, showing their consideration for the best interest of the child (see 4.4 above). This assessment and facilitation is conducted in conjunction with the Department of Social Welfare. By providing schooling for the children at the Centre, their objective of developing patients in all areas is realised. The staff believe that the children should have as balanced and full a life as possible and receive the best education possible (see 4.3 above).

Ultimately the values and beliefs embodied in the Centre remained fairly constant due to its stable workforce. Themes such as lack of family life, lack of a male role model and over-involvement with a patient were identified and explored to contextualise the experiences of the patients (see 4.8.3 above).

Death from AIDS

Death from AIDS was considered since this is the ultimate result of HIV AND AIDS and is a daily reality for the Centre. It was discovered that death from AIDS creates a different situation compared to any other death. Those who have died from AIDS may be considered polluting as opposed to death from other illnesses where the patient receives sympathy and care. The

impact of death on the morale of other patients was considered, also to understand the crisis measures adopted to deal with such situations. Crisis planning was found to address these situations adequately, including the use of counselling. The reaction of communities to people diagnosed with HIV AND AIDS was considered to explore the information provided by informants about discrimination they had suffered before being admitted to the Centre, and the general lack of education regarding HIV AND AIDS, especially in lower income areas. The Centre is poised to provide educational workshops to address these specific issues and to attempt to reduce the misconceptions and myths surrounding HIV AND AIDS in the communities (see 3.9 above).

The part that the Centre plays, not just in the lives of the patients and their loved ones, but also its role in the greater community was found to be invaluable. My study found that the Centre not only lived up to its aim of providing holistic care to those in the final phases of the terminal illness of HIV AND AIDS, but that it exceeds this aim by offering education and understanding of HIV AND AIDS to lessen the fears surrounding the disease, as well as general ignorance about its causes and symptoms.

APPENDICES

Appendix 1:

Field Work: Case Studies

Children:

Princess

Princess is a girl who lives up to her name. She is dressed like a Barbie princess in a pink faerie-like outfit with a plastic silver tiara and wand to match the outfit. She smiles so broadly that the rest of her face seems to disappear behind her white teeth and laughing eyes. Despite the hardship that she has endured, she comes across as a very mature and well-balanced child, with a firm sense of family and priorities. Princess is the motherly-type, always comforting crying infants and entertaining the other children. It was immediately apparent that in her eight and a half years she has been some kind of caregiver or played a supporting role as a caregiver at home. Her story is one of pain, courage and extreme dedication.

When Princess was four and a half years old her father died from AIDS and Princess had to help take care of her twin brothers while her mother worked as a domestic worker. Her mother taught her how to cook and take care of the twins 'in case anything happened to her'. Two years later, when Princess was six and a half, her mother, after lying on her bed for a few months was finally too weak to fight and passed away from AIDS. Princess was scared that her twin brothers would be taken away and that she would never see them again and so she decided not to tell many people that they were orphans. She was forced to grow up before her time and take on adult responsibilities, although she was aided in her caretaking role by her neighbour. Due to the lack of funds and having household chores, Princess was unable to attend school.

This neighbour had reported the case to the Department of Social Welfare whose social workers were aware of Princess but had agreed to wait a while before stepping in since the neighbour was helping the children to cope on a day-to-day basis. The neighbour helped by cooking additional food with her meals to give to the three children. Princess did her part by collecting water, cooking, washing and looking after her brothers on a daily basis, never thinking of her own welfare. "I went to food places and asked for food but when they didn't give me, I took stuff from the bins outside the food places". Princess was determined to keep her family together because "I promised my mama when she was very sick, and I couldn't let her down". She tried to teach her brothers the value of family love and support and even to carry on the traditions that her mother had taught her.

She was brought to the Centre eight months before I first met her after living for two years as the head of the household. She had begun to show symptoms of HIV infection and both Princess and the neighbour realised that they needed help. "I got sores on me like mama had when she was sick, I was scared I was sick coz mama had much pain and she brought up her food when she was eating".

Since the twins are HIV-negative, they are living with a foster family who were only allowed to take the children on the condition that they take both boys and that they bring the brothers regularly to visit Princess. "I miss seeing them every day and being their 'mama' but my mama is looking from heaven and she loves us and she sees the twins and me are happy". Her identity is strongly linked to her role as 'mother' and caregiver, and as being part of a family since she played these roles for so long.

She believes that the love and care she gave her brothers will stay with them forever, long after she has passed away to be with her mother. "I didn't want people to be scared of the twins coz I'm sick"; Princess feared that people would be repulsed and afraid of her because of her HIV status and that they would judge her brothers in the same way even though they are HIV-negative. Therefore she decided to keep her status a secret and live as a family with her brothers for as long as she could. At the Centre schooling is going well and she is a fast learner, "I like to write stories and I like it when teacher shows us knitting and playing on the jungle gym is fun". Her brothers attend a playschool where nobody knows the situation from whence they come and hence nobody judges them unfairly or discriminates against them.

Sarie

The person that tugs most at my heart strings is a devastatingly thin girl sitting in a crumpled heap on a foam-padded blanket in the front of the playroom. The blanket is strategically placed so that she can enjoy the sun and watch the goings-ons of the general complex. She can no longer read, she can no longer bath or even move unaided. She has to be carried as her legs are too weak and thin to carry her and her arms are too weak and her muscles too deteriorated to pull herself up. She cannot even feed herself as this requires more strength than she has. She told me "I wish I can kill myself, I just don't have the guts to do it". She has been this weak for the past hundred and six days and she says "If I knew it would hurt this much and I wouldn't be able to do nothing for myself I would've killed myself and saved everyone the effort".

Sarie is fourteen years old and is wearing adult nappies for incontinence. She was previously in a state-run institution until it closed due to a lack of funding. Sarie shows me photographs from when she was nine years old. She was a beautiful girl with long golden manes of hair, blue eyes and a very mature body for a nine year old. I asked her why she was wearing make-up and she said "my father made me to wear the make-up, he used to touch me and do other things that

weren't right, things that a father shouldn't do to his daughter". One day Sarie's mother, who had endured physical abuse from Sarie's father purchased a 9mm pistol and shot her husband (she shot him six times). The mother received a sentence of life imprisonment for premeditated murder aggravated by the fact that she shot him six times.

Sarie was placed in foster care by the court but "I hated it, the people didn't care about me, they just wanted to use me to get money from the government". After a few months she ran away and started living on the streets of Randburg. She quickly became addicted to 'crack' cocaine to survive the hellish existence on the streets. She needed money to pay to support her habit and that's when she met Jean Claude, a Nigerian man who promised her the world if she agreed to work for him. Sarie worked as a child prostitute at the old Randburg Waterfront. "Most of the men thought I was sixteen because I wear lots of make-up and I have big boobs". What Sarie did not know was that two undercover detectives had infiltrated their 'gang' and after gathering sufficient evidence the detectives arrested Jean Claude for child prostitution and child pornography. The girls were sent for HIV testing and Sarie's test was positive. She was placed at The House of Mercy drug and alcohol rehabilitation centre where she was given intensive therapy, both physically and psychologically. She recovered from the addiction but the psychological scars seem much deeper and more difficult to heal.

When speaking about her family life she bears the branding of someone who lived with the culture of violence, i.e. her father was perpetually physically and verbally abusing her mother and when Sarie tried to intervene "he used to hit me with his fist and strangle me with his hands and he always told me how useless I am". A few months before her mother killed her father, he began sexually molesting Sarie, which was the final straw that drove her mother to kill her father. Sarie feels as though "it was my fault, she shot him because of me, she wanted to stop him hurting me but now she's in jail because of me". Sarie carries guilt because she feels

responsible for her mother's situation. She grew up in a family where women were abused, disrespected and used to fulfil the man's every whim. All Sarie ever knew was the culture of abuse and violence.

She harbours a great deal of anger, mistrust and guilt, the concept of family is negative since her family stripped her of her dignity, trust and self-confidence. Sarie describes her family life as "happy family by day, hell by night". Sarie said that her family was not religiously-inclined and "I don't believe there is a God because he wouldn't make people suffer like this". Sarie has managed to trust a few of the nurses and politely makes conversation with the children but she feels that "I am just waiting to die so I can have some peace for myself".

Adults:

Lizzie

Lizzie is resident in the adult ward at the Centre. She is chronically ill with full-blown AIDS. When Lizzie met her husband they were very much in love and got married after only eight months of knowing each other. The couple had a son after a year of marriage. Dumisani is two and a half years old. He is a child that laughs a lot and is exceptionally friendly, even being happy for a stranger to hold him and pull faces at him.

Lizzie's husband became lethargic and ill. "He always told me that he couldn't help me in the house because he was tired and when he wasn't tired he had the cold or flu, I thought something is wrong". Eventually he had to acknowledge that he had AIDS. He knew that he was infected when he married Lizzie but never had the courtesy to tell her. She was devastated. "I didn't know what to think. I loved this man but he didn't love me because he lied to me and made me to get AIDS too, I knew I must test for AIDS and test the child also". Lizzie went to a hospital and had herself and Dumisani tested for HIV and the initial test result was positive for

both mother and son. Lizzie went in disguise to the antiretroviral clinic to obtain medication for herself and Dumisani. She did not disclose her status to anyone for the first few months, which was a lonely and draining period in her life, "I didn't want to tell no one because where I live the people are scared for ones who are sick with AIDS, they don't want to see you or be your friend, they walk on the other side of the road if they see you". Eventually her husband was taken to a state hospital with pneumonia as a secondary infection.

Lizzie disclosed her status to her employer who was very understanding. When she started to develop lesions on her face and lose a great deal of weight, the parents of the children at the crèche whom she was looking after began to ask questions and they discovered that she was HIV-positive. Many of the parents complained and as a result Lizzie was retrenched. "I was very sad to leave the job because I gave care to the children and the children loved me. They made me feel happy and like my job is important". She became very weak and now has full-blown AIDS. Dumisani is happy that his mother is so close at hand, even though she is weak and he has to be taken to her as she is now incapacitated. "I teach him to talk nicely and how to read the books but he only wants to hear stories all the time so I tell him about the farm in the Eastern Cape where I lived when I was little like him". He is cared for by the nurses and staff, all of which seems to make him a secure and happy child. The problem is that his mother does not have long to live and he will feel a large sense of loss when she dies. Her death will be difficult for him to deal with because his mother has never left him and because he does not understand their illness.

As is experienced by many patients, Lizzie mistrusts institutions (cf. Weisfeld 1991:85). She has always harboured a deep-seated fear of institutions, which meant that for her, coming to the Centre was worse than a death sentence. "When I was a girl we didn't go to hospitals, we got the natural medicines from the sangoma; a good sangoma could make any problem better". She

also knew that her grandmother had been admitted to hospital with what seemed like a minor ailment and had died in hospital with little or no explanation given for the circumstances surrounding her death. Lizzie says that when ailments struck, her mother used to take her to an indigenous practitioner, and if the condition was deemed more severe, Lizzie was sent to a more powerful healer for treatment. "The sickness didn't always go away like the sangoma said but we went to other sangomas, one with more power, one that everyone in the village knew could heal everything and they made the sickness better. I always knew sangomas and natural medicine made me better and made the pain go away when I was hurt, but the big hospitals and funny little pills are for white people". Lizzie admitted that she had little knowledge about medication and the procedures followed in such institutions, which resulted in her having a lack of faith.

Now, after being in the Centre for some time, Lizzie feels that "the nurses and doctor are very good to me, they care about me and making me feel better". She says her fears have been allayed as she now understands more about scientific medicine and hospitals. For Lizzie it has been a difficult process to overcome her fears, but because Dr Ngumbe took the time to explain to her what each symptom was and how it would be treated, as well as the possible side-effects of her medication, she said she was able to comprehend her condition and what lay ahead for her.

Lizzie says that as a mother, she is worried about her child because he will outlive her and she is not sure that he will comprehend what has happened to her. She says: "I can't look into the mirror, I always looked pretty, I always made my hair to be nice and my face with lipstick and now I have sores and I wear bed clothes during the day, I feel like it isn't me, the lady looking back at me isn't me". She has not become accustomed to the feeling of helplessness yet. She is slowly accepting her patient role and status as a terminally ill person, but with acceptance

eventually peace and relief will also come. Lizzie takes comfort from the fact that her son will be well cared for by the Centre and that he too will pass away and they will once again “be together in the life hereafter”.

Lizzie is helping her son to depend more on the nurses and he refers to the nurses as his ‘aunties’ which will help him to make the transition when his mother passes away.

Appendix 2:

Interviews with outpatients at the ARV Clinic

The participants ranged from a drug-addicted marketing executive with higher education to a single mother and teenagers. Their causes of infection were the following: unsterilized needles, unprotected sex and a blood transfusion. Thirty people, varying in ages from 13 years to 60 plus years of age, were interviewed over a period of one month on varying days. Informants who volunteered information and agreed to answer all the questions honestly were chosen.

Participants were asked if they were opposed to the interview beforehand. Those with no objections were interviewed and assured of confidentiality and anonymity. Of the people I spoke to, 25 had been diagnosed with HIV while the remaining 5 were visiting the clinic to be tested.

Each participant provided their education level, occupation, sexual orientation and general background so that I could classify the information I received by category and draw some general conclusions based on economic background, gender, education levels and sexual orientation (see 2.6 above).

The participants generally agreed that HIV AND AIDS does exist and most of them were able to name at least one cause of HIV. Some of the black participants, such as Dorah, confirmed that they had believed, before visiting the ARV clinic, that AIDS was sent by a witch and that it could be cured by a healer, but most had been enlightened when they came to the clinic and realised

that they were suffering from HIV AND AIDS. Dorah admitted that her relatives and community members still believed that witchcraft caused her disease and she was loathe to correct them because she was in a position to receive sympathy as opposed to stigma and isolation (see 5.7 above).

There was a general awareness among ARV clinic frequenters that increased use of condoms or abstinence would help to reduce the spread of AIDS, but only half of the men and two thirds of the women to whom I spoke said that they used condoms on a regular basis (see 5.9 above). Many of the men, such as Tumi and Mashudu felt that condoms lessened sensation and hence avoided using condoms to enjoy sexual intercourse more.

Word of mouth is the most common method of communication between people as regards the antiretroviral clinic and the medication dispensed there. Some patients had heard about the clinic via newspaper articles in the *Boksburg Advertiser*. The clinic guarantees absolute discretion and confidentiality, which motivates people to attend it. Outpatients like Suzy said that the clinic was popular and recommended by people in her community because of its professional stance and the anonymity afforded to the outpatients. Suzy said that when she suspected that she might have HIV she was afraid to ask others where she could be tested and receive treatment if she needed it because she feared being discriminated against because of the stigma attached to HIV AND AIDS.

Consensus among clinic frequenters was that due to the stigma of HIV AND AIDS and the fear of discrimination in their communities, they would not divulge their HIV-positive status to anyone but trustworthy and accepting friends and family (see 5.8 above). Charity had struggled with the decision to reveal her HIV-positive status because she had experienced discrimination and marginalisation in the past as a result of her drug abuse and this made her wary of experiencing

such isolation again. The general feeling is that antiretroviral drugs should be dispensed at all state and private hospitals since many outpatients have to travel far to receive their medication because only certain facilities offer anti-retroviral medication. There was a general feeling among the interviewees that before they were diagnosed with HIV, they were afraid of people with AIDS because they felt that they could contract the disease from them by casual contact or they were unsure about how the disease was spread.

They agreed that they would have benefited from knowing their HIV status sooner and that if there were more mobile clinics it would have been less humiliating for them than having to go to state hospitals where there is little time for counselling upon diagnosis. Julius told me: "I didn't want anyone to see me at the clinic because people talk and now they think you have AIDS even when you maybe don't have it". People are more likely to be identified at state hospitals and stigmatised in their communities.

There seems to be a general trend towards greater awareness of HIV AND AIDS, yet in this information driven era there are still myths and misconceptions surrounding AIDS. Only half of the people to whom I spoke realised that people with AIDS normally die from secondary infections such as pneumonia and not from AIDS itself. Most of the participants felt that their children would develop better if they were placed with family members rather than in foster care or adoptive homes. Ma Mabel said that "the children with HIV must have a chance to be with a family and be like other children."

Some outpatients like Charity feel that women who are HIV-positive and discover they are pregnant should "make the baby go away coz it will suffer and die like its mother". They have limited life-spans, with many becoming orphans when their parents have passed away from AIDS.

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