

# Nursing care for terminally ill AIDS patients

– A study of palliative care in Namibia

FÖRFATTARE	Emma Andreasson Kristin Berglund
PROGRAM/KURS	Sjuksköterske-programmet OM5250, Examensarbete i omvårdnad VT 2011
OMFATTNING	15 högskolepoäng
HANDLEDARE	Kerstin Segesten
EXAMINATOR	Linda Berg

Institutionen för Vårdvetenskap och hälsa

Sahlgrenska akademien



GÖTEBORGS UNIVERSITET

Titel (engelsk):	Nursing care for terminally ill AIDS patients –A study of palliative care in Namibia
Arbetets art:	Självständigt arbete
Program/kurs/kurskod/	Sjuksköterskeprogrammet, 15 högskolepoäng Examensarbete i omvårdnad, OM 5250
Arbetets omfattning:	15 Högskolepoäng
Sidantal:	25 sidor
Författare:	Emma Andreasson Kristin Berglund
Handledare:	Kerstin Segesten
Examinator:	Linda Berg

---

## ABSTRACT

**Background:** HIV is a retrovirus that attacks cells of the immune system. The final stage of the infection is referred to as AIDS where the immune system is severely weakened and small infections can be fatal. Namibia is heavily affected by the HIV crises in Sub-Saharan Africa and has now reached a prevalence rate of 15.3% among adults. An estimated 200 000 Namibians are living with the infection. The HIV pandemic has increased the need of adequate palliative care in the region. Still, the palliative care in Sub-Saharan Africa including Namibia is poorly developed. The main aim of palliative care should be to improve the quality of life and to meet the patient's needs. Caring for terminal AIDS patients is a challenge and there is a wide spectrum of needs to attend.

**Aim:** The aim of this study is to gain knowledge of how the patients with AIDS in an African country like Namibia, are cared for by the nurses in the palliative stage of their disease.

**Method:** An ethnographic approach has been used to meet the aim of this study. Data has been collected from two medical wards at Katatura Hospital in Windhoek, Namibia during five weeks. Participatory observations took place in the daily nursing work and were supplemented by informal interviews with the nursing staff.

**Result:** The main issues in providing the palliative care in this context formed five categories; *Nursing care of dying patients with AIDS, Where to be cared for, Nurses' attitudes towards the dying patient, Nurses' thoughts about HIV/AIDS and Resources and limitations*. The standard of the hospital and its palliative and medical care is very low. Resources are limited and the dying patients are often left alone and unnoticed. The medical wards are understaffed and this is a source of great frustration for the nurses. The hospital management's supervision of the daily nursing performance is insufficient and there is little or no room for patient complaints. Patients die in the medical wards every day but according to many of the nurses, palliative care does not exist in Katatura Hospital.

## CONTENT

INTRODUCTION .....	1
BACKGROUND .....	1
HIV/AIDS.....	1
Medical facts .....	1
HIV/AIDS Globally.....	2
HIV/AIDS in Namibia .....	2
NAMIBIA.....	3
The country .....	3
Katatura.....	3
Healthcare system .....	3
PALLIATIVE CARE .....	4
Palliative care in Sub-Saharan Africa/Namibia .....	4
Palliative care for HIV/AIDS patients .....	5
THE NURSES .....	6
AIM.....	6
METHOD.....	6
ETNOGRAPHY .....	7
PARTICIPATORY OBSERVATION .....	7
PREJUDICE .....	7
SETTING.....	8
DATA COLLECTION .....	8
ETHICAL ASPECTS .....	9
DATA ANALYSIS .....	9
RESULT .....	9
NURSING CARE OF DYING PATIENTS WITH AIDS .....	10
Meeting the physical needs .....	10
Meeting the emotional and social needs.....	12
Meeting the spiritual needs.....	12
WHERE TO BE CARED FOR .....	13
NURSES' ATTITUDES TOWARDS THE PATIENT.....	14
NURSES' THOUGHTS ABOUT HIV/AIDS.....	16

Nurses' fears .....	16
The stigma of HIV .....	17
RESOURCES AND LIMITATIONS .....	17
CARING FOR PATIENTS WITH AIDS – IDENTIFYING PROPERTIES .....	18
DISCUSSION AND REFLECTION.....	19
METHODOLOGY .....	19
RESULT .....	20
IMPLICATIONS .....	22
REFERENCES .....	24

## INTRODUCTION

Approximately 68% of all HIV infections occur in Sub-Saharan Africa. The World Health Organization (WHO) has set a number of goals called the Millennium Development Goals, which aim to improve life quality and health around the world. The sixth of these goals is to combat diseases such as HIV/AIDS, malaria and tuberculosis. Closing in on that goal would improve the health and living conditions remarkably and have a major positive effect on the whole region [1].

The HIV/AIDS pandemic in Sub-Saharan Africa has increased the need of adequate palliative care in the area. Still, the palliative care in Sub-Saharan Africa, including Namibia, is poorly developed. The needs of the dying patient with AIDS and his or her family are great and include not only pain- and symptom-management and practical care, but also counseling, psychological and spiritual support, financial support for food and shelter, respite and orphan care [2].

This enormous health problem is relatively unfamiliar to health care professionals in our part of the world. We believe this topic to be of great relevance to us as nurses due to the international nature of the profession. This reason, among others, raised our interest in the AIDS situation and resulted in this ethnographic study of palliative care for patients with AIDS in Namibia, a country heavily impacted by the AIDS crisis.

## BACKGROUND

### HIV/AIDS

#### Medical facts

HIV (The human immunodeficiency virus) is a retrovirus that attacks cells of the immune system. It can destroy or impair the function of these cells, leading the immune system to become weaker. As a consequence, the infected person becomes more susceptible to infections. The final stage of the infection is AIDS (acquired immunodeficiency syndrome) where the immune system is severely weakened and small infections can be fatal. AIDS is a broad term for various infections and tumors that can affect a person with an untreated HIV infection. It can take 10-15 years for an HIV-positive person to develop AIDS and antiretroviral treatment can slow down the process even further [3].

The following are examples of infections that commonly affect patients with AIDS:

- Pneumocystis pneumonia (PCP)
- Tuberculosis (TB)
- Infections with tuberculosis-like bacteria
- Yeast infection of the esophagus
- Fungal meningitis
- Toxoplasmosis
- Viral infection of the retina caused by Cytomegalovirus
- Kaposi's sarcoma

- Lymphoma
- Cervical cancer [4]

The HIV-virus spreads in a number of ways. It is transmitted through unprotected sexual intercourse (anal or vaginal), contaminated blood transfusion, sharing of contaminated needles, and between a mother and her child during pregnancy, birth and breastfeeding [3].

As mentioned above, antiretroviral therapy (ART) is used to fight the HIV-virus, which means slowing down the degradation of the cells in the immune system. The standard treatment consists of a combination of at least three drugs that suppress the replication of the virus. This combination is used in order to reduce the likelihood of the virus developing resistance. ART can both reduce mortality and morbidity rates among HIV-infected people, and to improve their quality of life [5].

### **HIV/AIDS Globally**

HIV/AIDS is a global epidemic of large proportions. At the end of 2008 an estimated 33.4 million people were infected with HIV worldwide. The same year, 2.7 million people were newly infected and 2 million died from AIDS including 280 000 children [6]. 7,400 people become infected with HIV every day. Nearly 4 million people are currently receiving treatment, while 9.7 million people are still in need of it. For every two people put on treatment, five more become infected [7].

As mentioned in the introduction, 68% of all HIV-infections occur in Sub-Saharan Africa. This region is already burdened with problems such as poverty, food insecurity, indebtedness, gender inequality, gender-based violence, political conflicts, natural disasters, ignorance, fear, stigma and discrimination [8].

Since the epidemic's peak in 1995, the number of new infections has slowly decreased, but the number of people living with the infection has increased, partly due to improved access to HIV treatment. Despite this slightly positive trend, Sub-Saharan Africa remains the region most affected by HIV. For example, in 2008 this area accounted for 91% of new HIV infections among children and 72% of the world's AIDS-related deaths. More than 14 million children were estimated to have lost one or both parents to AIDS [7].

Naturally, an epidemic of this magnitude has impact on the households, communities, companies, public services and national economies in the region. For example, in Swaziland, the average life expectancy fell by half between 1990 and 2007, to 37 years [7].

### **HIV/AIDS in Namibia**

Namibia is severely affected by the HIV/AIDS crisis in Sub-Saharan Africa and has now reached a prevalence rate of 15.3% among adults. An estimated 200 000 people are living with the infection and every year, 5 100 Namibians die from AIDS or HIV. The epidemic has also led to a rapidly growing number of orphans and vulnerable children. 66 000 are now orphaned due to AIDS [7]. The Namibian life expectancy for both sexes is 54 years. Although HIV/AIDS is accountable for 51% of all deaths

in all ages, other common health problems in Namibia are Tuberculosis, Malaria, perinatal conditions and diarrheal diseases [9].

## **NAMIBIA**

### **The country**

Namibia is a sparsely populated country on Africa's south-west coast, bordering South Africa, Botswana, Angola and Zambia. It is a former German colony which has also been occupied by South Africa, but the Namibian population of 2 million has enjoyed more than a decade of stability since achieving independence on the 21<sup>st</sup> of March 1990. The most common livelihoods are mining, fishing, tourism and agricultural industries [10,11].

It is estimated that 27.6% of the population is poor, including 13.8% living in severe poverty [12]. Although Namibia is essentially a desert country with hot and dry climate and sparse and erratic rainfall, it offers contrasting landscapes such as dense bush, open plains, woodland savannah and lush vegetation. The desolate Namib Desert is said to be the oldest in the world. German influences can still be found in the country's good road infrastructure and in most cities' architecture. The capital, Windhoek is situated in the central part of the country and has a population of 223.000 [10,11].

### **Katatura**

Katatura is a Windhoek suburb with approximately 150.000 inhabitants [13]. Just looking at a map of Windhoek, the area appears uninhabited but is the home to half the people of Windhoek. In the early 1900s, during the days of South African mandate and apartheid, all the black Africans working in Windhoek had to live separated from the white population in designated areas in the city. In the 1950s the Windhoek municipal council decided to take back these areas populated by the black, who then where forced to move to a new place. Since they had no say in the matter (violent protests and demonstrations took place) their new settlement got the name Katatura, which can be translated as “we have no permanent place” or “the place we do not want to settle”. Today, Katatura is the poorest and least developed part of Windhoek with tin sheds, mud roads and limited municipal water, power and telephone services [14].

### **Healthcare system**

For every 10.000 inhabitants in Namibia there are three physicians and 30 nurses and midwives [15]. The Namibian healthcare system has a total of 1150 outreach points, 265 clinics, 44 health centers, 34 hospitals (30 district hospitals, three intermediate hospitals and one national referral hospital) and a number of social welfare service points. The total expenditure on health is 8,5% of GDP [12].

Katatura Hospital is one of the two public hospitals in Windhoek. The hospital has departments for medicine, surgery, intensive care, pediatrics, orthopedics, mental care, maternity care, emergency care, tuberculosis treatment and a sexually transmitted disease (STD)-clinic. The main HIV and AIDS care is practiced in the

medical wards [16]. It is well known that only the poorest patients who cannot afford a better alternative come to Katatura Hospital for healthcare. The majority of the patients are Katatura residents.

## **PALLIATIVE CARE**

The World Health Organization (WHO) defines palliative care as:

*“An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*

According to WHO this type of care intends to:

- provide relief from pain and other distressing symptoms
- affirm life and regards dying as a normal process
- neither to hasten nor postpone death
- integrate the psychological and spiritual aspects of patient care
- offer a support system to help patients live as actively as possible until death
- offer a support system to help the family cope during the patients illness and in their own bereavement
- use a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- enhance quality of life, and may also positively influence the course of illness
- be applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications [17].

The advancing palliative disease process is characterized by:

- an incurable condition
- a symptomatic condition, at times rapidly intensifying.
- a progressive state of disease with foreseeable expected time to death [18].

## **Palliative care in Sub-Saharan Africa/Namibia**

The latest numbers of palliative coverage in Namibia are from 2004 and indicate that approximately 50 000 people living with advanced HIV infection received either home based or health facility based care. This was provided by the public sector and non-governmental organizations such as The Catholic church [9].

Sub-Saharan Africa has a great need to focus on a holistic view of palliative care. Evidence shows that the primary need in palliative care is pain management but also psychological, spiritual and social needs are crucial to meet. There is a great need for financial support to address food provision since patients may refuse their medications when they are hungry [2].



## **Palliative care for HIV/AIDS patients**

Most HIV infected patients reach a state of their disease when the immunosuppression increases and the patient develops non-specific problems such as weight-loss, diarrhea and fever. AIDS is diagnosed when the patient develops more opportunistic infections and cancers. Some patients never reach the AIDS stage [19].

Palliative care for patients living with AIDS and HIV has some special features to consider:

- Abrupt changes in the patient's condition can sometimes occur.
- The need of active treatment of palliative nature can be great. A vast range of infections require for example intravenous infusions to reduce symptoms such as pain.
- The disease pattern is constantly changing as well as the treatment.
- A great number of patients are young.
- Patients experience a sense of isolation, stigma and lack of compassion.
- Many patients have complex family issues and social problems such as homelessness [19].

The main aim of palliative care should be to improve the quality of life and meet the patient's needs. For people dying from AIDS, there is a number of needs to fill. By using a holistic perspective it is important to pay attention to physical, emotional, social and existential needs [20].

### ***Physical needs***

As AIDS is a multi-system disease, the physical needs can vary. Caregivers face a great challenge trying to meet the physical needs of terminally ill patients with AIDS, who often suffer from severe symptoms such as frequent diarrhea, total body pain, nausea and vomiting, neuropathy, myopathy, great weight loss, skin lesions and confusion [20].

In order to meet the physical needs of these patients, a highly skilled medical and nursing care is required. It is important to let the patient stay in control of his or her situation, and therefore it is necessary to give information about all available options [20].

### ***Emotional needs***

Patients with AIDS experience a great need of love, acceptance and security when in the palliative stage of their disease. Many of these patients have experienced rejection due to their HIV-infection. Caregivers should be able to fill the patient's need of e.g. hope and honesty, encouragement and motivation and the need for the caregivers' time [20].

### ***Social needs***

To meet the social needs of dying patients with AIDS, it is important to involve social workers. Many of these patients are homeless or in need of adjusted accommodations. The patient might also be a mother caring for a baby. Many

patients experience financial problems and are therefore in need of social services [20].

### *Spiritual needs*

Becoming terminally ill from a disease like AIDS often results in reflections about the meaning of life, and for many patients this is a painful process. It is important that the patient can practice their religion and that they have the opportunity to seek spiritual advisors. The caregivers should create a safe, secure and loving environment without any pressure or judgmental attitudes [20].

### **THE NURSES**

The nurse must possess knowledge of the disease, treatment and issues regarding research. They must also have knowledge and understanding of matters such as the stigma of AIDS, death and dying, sexuality and drug addiction. Good listening- and counseling skills are important, as the nurse's role is to be there when needed and to encourage the patient [20].

There are numerous principles of nursing care that should be the same regardless of care setting. For example, the fundamental principle that the patient and his or her family, partner and friends should always be considered central in the care-giving process. The nurse provides care appropriate for every patient's personal needs. The nurse works in partnership with the patient to achieve the patient's goals. The essence of the care provided by the nurse should be to enhance quality of life [20].

### **AIM**

The aim of this study is to gain knowledge of how the patients with AIDS in an African country like Namibia are cared for by the nurses in the palliative stage of their disease.

Guiding questions are:

- What are the main focuses and goals in the caregiving process?
- What are the nurses' attitudes towards the dying patients and their disease?
- What are the nurses' perception of resources and limitations in providing the palliative care?

### **METHOD**

An ethnographic approach, according to Pilhammar Andersson, has been used to meet the aim of this study [21]. Such an approach is considered appropriate when studying phenomena in clinical care, such as unconscious parts of the actors' daily lives, situations and interactions between actors, in this case, nurse and patient, which is why the researcher needs to be present in reality [21].

## **ETHNOGRAPHY**

Ethnographic research may be described as studies of the culture shared by one group of humans with a focus on the interaction between the person and the cultural system of which he or she is a part [21].

We have chosen ethnography because it is based on the idea that human activities and actions are best understood and explained in the setting where they take place. According to ethnography and its theoretical roots, human feelings and actions are directly and indirectly affected by the surroundings and vice versa. Interpretations and definitions of phenomena and situations are individual because people experience situations in different ways, and because the degree of importance and social meaning attached to the situation also is individual [21].

According to Pilhammar Andersson, the purpose of an ethnographic study is not to reflect the culture as the individuals describe it, but to bring out what they have in common, what the participants adhere to. It is then the researcher's job to take a closer look at underlying assumptions, unspoken messages, norms and values, and relate them to visible actions [21]. The ethnographical approach allows us as researchers to break down the everyday work of the nurses in our study, and look closely at what they do and say, why they do and say it and what it means to them, but also what the consequences are for the patients in their care.

## **PARTICIPATORY OBSERVATION**

Participatory observation can be a useful way of collecting data when interviews are, for one reason or another, difficult to carry out [22]. That was the case in this study since hospital regulations made interviews impossible. This convinced us even further that this method was the most suitable for the purpose of the study. We were advised by our contact person to keep our interviewing to a minimal and only ask sporadic questions in a natural setting, and in an informal way. Participatory observation was the most accessible way to the field of interest. By taking the role of students and focusing on participating in the daily nursing tasks, our emic perspective broadened [22]. To validate our interpretations of what we saw and experienced, a number of questions concerning different aspects of the palliative caregiving process, were asked. The questions correlated with the focus of our observations.

The aspects were:

- Nursing tasks in the palliative stage
- The nurses' perceptions on death and the dying patient.
- The nurses' perceptions on resources, priorities and focuses.
- Obstacles and limitations in the palliative care.

## **PREJUDICE**

Neither author had experience of palliative care for patients with AIDS, or experience of hospitals outside Sweden, prior to the onset of this study. Both authors have worked with dying patients and were trained in palliative care, as part of the Nursing Program, but had only superficial knowledge of HIV and AIDS, and on a general level.

## SETTING

This study took place at two medical wards at Katatura State Hospital. One ward with only male patients and one with only female patients. The majority of the patients cared for in these wards are HIV positive and suffer from one or many opportunistic infections. The most common infections are meningitis and tuberculosis. Unfortunately, many of the Namibian HIV positive patients seek healthcare in a late stage of their disease, when opportunistic infections already have occurred.

The majority of these patients are born in the 1970's but both younger and older patients are common. Many patients suffer from malnutrition and are therefore extremely underweight.

As mentioned earlier, Katatura Hospital has very limited resources, and all their facilities are very worn down, especially hygiene facilities such as showers and toilets where soap and toilet paper are rarely seen. The wards are divided into two parts, one with five six-bed rooms where the most stable and least contagious patients are cared for. The other side has five isolation twin-bed rooms where the most contagious and often terminally ill patients stay. The nurse's station is located in the middle of the ward, facing the rooms where the sickest patients stay.

Most members of the staff are Katatura locals. The majority is female but there are some male nurses in both wards. They are all referred to as nurses but their level of education varies. Every nurse has approximately 12 patients to care for and one nurse is in charge of the medications and also responsible for administrating and organizing the daily work.

The workday starts with washing and turning all the patients who are unable to do that themselves. The wash is a full-body wash when the patient is still in bed, and all the sheets are changed, when clean sheets are available. The breakfast arrives at nine in packages which are distributed to all the patients. It contains the same food every day; pap (porridge made from corn flour), two slices of bread, sugar and milk. The food is eaten in bed (often lying down since the patients are sometimes too weak to be able to sit) due to the fact that there is no other place for them to reside. Some nurses feed the patients who are unable to eat by themselves, if they have time. Some nurses do not and the food is then left untouched. After the breakfast the doctors do rounds and then nurses start with observations and measure the patients' blood pressure, temperature, saturation etc. Observations are written down according to a worksheet referred to as SOAP (Subjective, Objective, Assessment, Plan) designed to assess the condition of the patient. The morning procedures are repeated in the afternoon with "SOAP:ing", turning schedules and so on. In the afternoon there is also a chance for the family members to visit the patients, although visiting hours are not very strict and some patients are visited in the morning too.

## DATA COLLECTION

Data has been collected from two medical wards at Katatura hospital during five weeks. Our participatory observations took place in the daily nursing work and were

supplemented by informal interviews with the nursing staff. Since formal interviewing was not an option, the nurses were, while carrying out nursing tasks, asked to answer some questions about caring for terminal patients. Field notes were taken during and after each workday. In some situations it was possible to take field notes in the moment, while in others this was inappropriate and notes were taken afterwards.

## ETHICAL ASPECTS

We were granted permission to perform this study by our contact person, who is responsible for international students at University of Namibia and handles their contact with Katatura Hospital. The study was also approved by the hospital student coordinator who also introduced us and the study in the medical wards.

Following our contact person's advice, we introduced ourselves as students writing an essay when meeting new staff and patients. The student role enabled us to keep a humble approach when meeting participants of the study. By keeping an open attitude, showing eagerness to learn and asking questions as objectively and non-judgmentally as possible, we tried to keep the nurses in a teaching position where they felt they possessed knowledge unique for their position.

All participants were informed about the purpose of the study and had the option to decline participation. The demand of confidentiality was taken into consideration. All participants were kept anonymous and sensitive parts of the data have been depersonalized.

## DATA ANALYSIS

During the process of collecting data, we gradually noticed what the nurses wanted to talk about, what they considered to be important and we were eventually able to identify patterns and commonalities in their responses. Our findings eventually formed a number of different categories which gave us an idea of the main issues in providing the palliative care in this context. These categories are *Nursing care of dying patients with AIDS* which describes how the nurses face the different needs of their patients, how they plan the care and what tasks they carry out. *Where to be cared for*, a closer look at the nurses' perception on where it is ideal to be cared for by the end of life and what options are available. *Nurses' attitudes towards the dying patient* which describes how they view the patient and death, and what they find important in approaching a dying patient. *Nurses' thoughts about HIV/AIDS*, how the nurses perceive the general attitudes towards the disease, and how these attitudes affect their daily work. *Resources and limitations* which describes the nurses' opinion on whether the resources are sufficient or not when providing end of life care.

## RESULT

Katatura Hospital has a very distinct care culture and factors such as religion, limited resources and the cultures of different Namibian tribes, are factors contributing to creating that care culture. The high prevalence of HIV infections and the impact they

have on the Namibian society is also a contributing factor. This care culture and how it reflects on the palliative care is the foundation of our study. The aim of this study was to gain knowledge of how the patients with AIDS in an African country like Namibia are cared for by the nurses in the palliative stage of their disease. The purpose was to find out how these Namibian nurses, often born and raised in Katatura, care for the dying patients with AIDS, and what attitudes they have towards the patient and the disease. We also wanted to see what impact the limited resources have on the nurses' chances of providing good palliative care.

## **NURSING CARE OF DYING PATIENTS WITH AIDS**

When entering the medical wards at Katatura Hospital the smell of urine is quite overwhelming. The wards are very worn down with paint peeling of the walls and old stains on walls, floors and ceilings. The toilets and bathrooms disposable for the patients are dirty and missing toilet paper, soap, paper towels etc. Due to the fact that there is no other place for the patients to reside in the ward but in their beds, the mattresses are very well used and therefore very worn down. Many of them have big holes and some of the patients put pillows in these holes in order to smoothen out the bed to be more comfortable. Because many patients are suffering from pulmonary tuberculosis, the staff make sure that windows and doors are open at all times, and therefore the wards are draughty. The floor can be very filthy at times, since any form of cleaning is considered a task only for the cleaners, so if they are not present, food and other trash dropped on the floor is left untouched.

The nurses spend very little time with each patient and oftentimes the patients have to eat and take their medication on their own, even those who are in need of help. There are no bells or help buttons to push, so if the patients need assistance, they have to shout to get the nurses attention. Most of them do not shout.

### **Meeting the physical needs**

#### ***Pain***

Pain relief is used very sparsely in the wards, especially stronger medication like morphine. We have met patients in severe pain who have been given only Paracetamol, if anything. At one time, we took part in the care of a dying woman, who in her last hours appeared very bothered by pain and was not able to find a comfortable position in her bed. We asked the nurse present about pain relief and got the answer: *"It's only because of her disease that she can't lay still."* She did not receive any medication and died in this stage.

In other conversations with the nurses about pain relief and their routines in the matter, we were given answers very different from each other. Some nurses stressed that patients with AIDS have the same need for pain relief as other palliative patients, while others clearly stated that drugs like morphine should only be given to patients with TB and cancer.

*"Morphine is only given to palliative cancer patients and sometimes to TB-patients who coughs blood. AIDS patients can only be given paracetamol, diklofenak and tramadol. They don't get morphine. Sometimes we give the patient sedatives if he or she is anxious."*

When doing the “SOAP:ing”, the nurses always ask if the patient has any complaints. If the patient complains of pain, oftentimes the nurses just write it down in the SOAP-sheet and move on to the next patient. There are rarely any consequences of the information the nurse gets from the patient, whose pain is usually left untreated.

### ***Bedsore and discomfort***

We have observed that many patients have turning sheets in their patient files. The nurses strictly follow these turning sheets and consider it to be a very important task. The patient is even tied to the bed by the arms and legs to prevent him or her from rolling over. Many nurses bring up the subject of bedsore spontaneously when we ask questions about the wellbeing of the patient. When participating in the full-body wash each morning, we have seen many bedsore and observed in what way they are treated. Usually some antibacterial ointment is applied, but the sore is left without any pressure relieving dressings.

### ***Hydration and Nutrition***

We have observed many weak, very ill and underweight patients struggling to eat the meals brought to them by the kitchen staff. Many times, these patients do not have enough energy to even open the plastic wrap on the food packages. The patients who cannot sit up on their own have to eat their meals laying down in the bed, which complicates their eating even further and adds the risk of choking on the food. One morning we were helping one of these weak patients to eat and a nurse walked by outside the room. She asked us if we were feeding him and told us angrily that he could feed himself.

We have noticed that the daily fluid intake of the weak patients is often poor. Usually they are served a glass of milk with every meal, which they drink if they are helped. Running water is available in every room, but for those patients not able to stand up and fetch it from the tap, the three glasses of milk is all they drink in a day. The patients who are unconscious and/or very close to dying can get intravenous fluid and a nasal gastric tube for nutrition replacement.

### ***Other physical problems***

*Respiration:* Many patients are treated with oxygen, but a lot of times, the patient takes off the mask, voluntarily or not, and usually no one is there to put it back on. *Elimination:* Most of the bedbound patients have a urine catheter but the registration of the fluid loss is often poor. When observing the care of a dying woman, we witnessed an example of this. The nurses were concerned about the patient’s lack of urine production. They struggled with getting the i.v. line in, but when they finally succeeded, they did not record the loss of fluid in the catheter bag and it was impossible for us or anyone else to know the next day, if the patient had any urine production or not. Not once during our time in the medical wards have we seen any record of, or heard anyone talk about the loss of faeces. *Oral hygiene:* The oral hygiene is non-existent in the wards. We have only seen two toothbrushes being used, and in those cases, the patients have been very verbal and able to brush their own teeth with only a little assistance.



### **Meeting the emotional and social needs**

When talking to the nurses about palliative care and the different needs of the patients, they always tend to focus on practical issues, symptom management and spiritual concerns. The emotional and social needs of the patient are topics rarely discussed and never brought up spontaneously by the nurses. When asked specifically about these subjects, some of the nurses have an opinion and stress the importance of emotional support.

*“You can’t just go in to a patient and turn him and then leave. Maybe the patient doesn’t have any relatives to come and visit. You must think of what it would be like if it was your father or yourself who were alone.”*

Some of them pointed to the importance of encouragement and taking the time to talk to the patients who do not initiate conversations spontaneously. They also talked about the possibility to call a counselor, a family member or a reverent if the nurses, for some reason, could not talk to the patient themselves.

During our time in the wards, we have tried to get an idea of how the nurses work and what their roll is. We do not recognize the image portrayed above and have not witnessed any longer conversations between nurses and patients, nor have we seen any counselor or reverent present in the ward.

Even though many of the dying patients cared for at Katatura Hospital have great social needs, due to their condition and to their economic situation, these needs are very rarely considered in the palliative care giving process. Nurses have mentioned that there are social workers working at the hospital, available for the patients in need of their assistance. Still, we have not once met a social worker or heard anything about their work in the wards, even though we have met countless of patients in need of social aid. For example, there are patients who are permanent residents in the wards who desperately need help with other living arrangements.

*“If the patient doesn’t have a family to care for them they can die here. We never throw them out of here.”*

### **Meeting the spiritual needs**

Spiritual issues are present in Katatura Hospital since Namibia is a very religious country. The walls of the hospital have posters with religious messages, prayers and texts about life and death. Many of the nurses we talked to like to discuss religion, and spiritual questions are important to most of them. However, not all the nurses share the same beliefs and their view on the spiritual needs of the dying patient and their roll as nurses in the palliative care, varies.

*“We pray with her and tell her that sometimes miracles can happen. You can never give up even if the doctor says it’s over”*

*“We don’t pray with the patient. It doesn’t do any good, but sometimes the patient prays. If there is nothing left to do, there is nothing left to do.”*



This is yet another image of the nurses' work that we do not recognize from the daily nursing work in the wards. We have not seen anyone praying with the dying patients or talking to them about spiritual issues.

Some nurses argue that the spiritual atmosphere in the wards differs, due to the fact that the nurses working there are religious to different extents. They have explained to us that this affects how often prayers with the patients are part of the palliative care. This is something we have detected when comparing the wards to each other, but the spirituality in the most spiritual wards has only been expressed through prayers on the bulletin boards and religious posters on the wall. As mentioned above, we have never observed nurses praying with or for the patients, not even in the most religious of the medical wards.

### **WHERE TO BE CARED FOR**

Dying patients in Katatura Hospital are faced with two different options. The first one is staying in the hospital and receiving care provided by the nurses. The second one is going home and receiving care provided by their family members. Hospices exist in Namibia, but they are privately owned and therefore very expensive, as the rest of the private care. The patients at Katatura Hospital do not have medical insurance and would therefore have to pay for Hospice care, which they are unable to do.

The patients who chose to die at home are totally dependent on their loved ones to care for them. The family receives information on how to care for a dying person from a so called "quality assurance team" at the hospital.

When the family of a dying patient is unwilling or unable to provide home based palliative care, or if the patient has no family, he or she is always allowed to stay in the ward, even for a longer period of time. They can stay there as long as they need to.

*"There are Hospices but no one here can afford to go there since it's very expensive. Many patients are forced to stay here in the hospital because they don't have any relatives, and they can't manage on their own at home, and they can't afford to go someplace where they are cared for. We can contact a social worker but if they have nowhere to go we let them stay here, even if they are discharged. We never throw anyone out."*

Since Katatura is a referral hospital, many patients who choose to go home to die unfortunately end up dying in the ward anyway, waiting for transport to their hometown or village. Many patients have their families far away from Windhoek, and because of poverty their relatives can't afford to come and visit. The nurses have told us many stories about how patients who have been sent home to be cared for by their families, often come back after a couple of days since the family cannot handle the situation.

The opinions on where it is preferable to be cared for by the end of life differ greatly. Some nurses state that it is better to die in the hospital due to a number of practical

reasons. Other nurses argue the importance of family members' support and the familiar surroundings in the home.

*"It's better to die in the hospital. It's more practical since the body can be taken directly from the ward to the morgue."*

*"I think it's best to die at home with your loved ones. When you're dying the most important thing is to feel loved. You should die peacefully with your family close to you, giving you love."*

In some cases the patient stays in the ward and the family members care for them there. In other cases the patient is all alone.

*"Some patients are anxious when they die, some are not. It's 50/50. The patients who don't die comfortably are the ones who miss their family members, the ones who die alone."*

Working in the wards, we have only seen women caring for their family members, washing them, feeding them etc. Men also come to visit, but do not seem to take part in the care. A son of a patient brought food for his father and asked us nurses to feed him while he watched.

*"When family members come to the hospital to care for the patient, we give them a mattress to sleep on. It's mostly women who come and stay here to care for the dying. Mothers, sisters, daughters. Hardly ever men."*

## **NURSES' ATTITUDES TOWARDS THE PATIENT**

As mentioned earlier, Katatura is a hospital for the poor who cannot pay for any medical care and the great majority of the patients and staff are members of the black community. This is a fact known to all parties, which impacts, and sometimes shapes, the way the patients are cared for and determines what care they receive. For example, high technology care such as dialysis is not available to the patients at this hospital, since there is no money to finance such expensive care.

*"Nobody comes to Katatura if they can afford to go someplace else. It's all about the money. In the private hospitals there are mostly whites. White doctors, white nurses, and white patients. People who go there pay for the medicine and for the care. It's very strict and as a nurse, a lot is expected of you. If you make mistakes, forget something or do something wrong, they will report you to the manager. It's much better here."*

The quotation above illustrates our experience of lack of management control in the hospital. We have observed many nurses making mistakes, being negligent or forgetful during our time in the wards. Very rarely did these mistakes result in any actions from the management. Many of them were not even reported to management. The patients did not file any complaints and the matrons are very seldom present in the wards.

We have observed that the nurses often stand in the middle of a six-bed room, talking to each other loudly about a patient, without actually talking *to* the patient. Also the doctors do this during rounds. It has happened that when we have approached nurses at the nurses' station to ask questions about palliative care, the nurse has brought us to a patient room, pointed at the patient and started talking about the fact that he or she is dying and of what disease and given us other very personal information loudly and in front of the patient.

A major part of the nurses' daily assignments is to collect and record the patients' subjective assessment of their own condition. This is part of the so called "SOAP:ing". We have observed that nurses do not spend much time carrying out this task and leave very little room for the patient to describe how he or she is feeling. When helping the nurses with the "SOAP:ing" one morning, we had problems with a patient who did not speak English. Since we could not ask him how he was feeling or if he had any complaints, which are standard questions in the SOAP-worksheet, we asked a nurse who spoke his language to ask the patient in our stead. The answer we received was: *"just write: communication poor. We can't break our heads over just one patient."*

Several days later, another nurse was instructing us on how to do the "SOAP:ing": *"If you don't understand the patient's language you can call me. Or just look at the patient and write how you think he is feeling."*

During our time in the wards we aimed to find out what thoughts the nurses had on the patients' subjective experience of dying and being cared for by the end of life. The questions we asked were very patient-orientated and about the palliative care-giving process. But the answers we received usually revolved around various practicalities and were not answered from the patients' perspective. Despite our many efforts to re-formulate our questions, be more specific, and ask more follow-up questions, this did not change.

When we asked a nurse if anxiety was common among the dying patients in the ward, the answer given to us was:

*"Most of the time, the patients die quietly. Usually, we don't notice when they die."*

The nurses face dying patients and death every day and a large portion of the patients cared for in the medical wards are extremely sick. Some nurses have described how this affects the way they work and their attitudes toward what they are faced with. The nurses have often told us, when we do things the way we would do them in Sweden, to stay strong. We have interpreted this as a try to encourage us in situations where they have felt that we were too emotionally involved.

*"You cannot let it get to you. You have to stay strong at all times. Learn to hold your tears."*

Being present when patients passed away, we made several observations of how the nurses act around the patient. It is not uncommon that a patient dies in a room with five other patients. At one time there were ten nurses, five patients and two family members of another patient, present in the room when the patient died. The room

was very noisy and the nurses spoke loudly to each other, both about the patient and about other things. Cell phones were used and no one pulled the curtains shut around the bed. The mother of the patient was standing by the bed crying loudly and none of the nurses paid any attention to her. When the patient, a woman in her twenties, was declared dead, no one told the mother. She was expected to understand what had happened.

Only minutes after a patient has died, the nurses remove the clothes and personal belongings and put them in a plastic bag, which is handed to relatives if they are present. Then the patient's arms and legs are tied together tightly and the body is sent to the morgue. In some cases we have seen dead patients, sometimes covered with a blanket and sometimes not, lying in the ward's dressing room for several hours, in clear sight of whoever might walk past the room.

When asking the nurses about what they do for the patients in their last days and hours of life, the answers we were given varied. The following quotes are examples of the nurses' different opinions:

*"We check in on her every now and then and if anything happens we go to her, but there are other patients who can survive so we have other things to do."*

*"You have to do all you can even if it looks like there is no hope and the doctor does nothing."*

### **NURSES' THOUGHTS ABOUT HIV/AIDS**

When talking to the nurses about the subject HIV and AIDS, two main focuses in the conversation have appeared. First, the nurses personal feeling about working with these contagious patients, and second, the nurses experiences and thoughts about attitudes towards HIV in the Namibian society. They also talked about the consequences these attitudes have on the patient's situation.

#### **Nurses' fears**

The majority of the nurses claimed to be comfortable working with the infected patients, although most of them told us they take many safety precautions before carrying out tasks with an elevated risk, such as drawing blood or admitting new patients with TB.

*"If you are scared, if all the nurses are scared, nobody will go to the patient and he or she will be left unattended. You have to think about how you would want to be treated if you were the patient."*

*"I'm not scared anymore now that you know how its spread and that it isn't easy to get infected at work."*

*"I'm very scared and I think a lot about the fact that so many patients I care for are so contagious. I heard about a nurse in South Africa who got HIV from pricking herself when drawing blood. A doctor bumped into her when she was holding the*

*needle. I'm always extremely careful when drawing blood and I always make sure that I'm alone so no one can bump into me. TB is also scary but AIDS is worse.* “

In our perception, during the time we spent in these wards we have not witnessed any of the nurses act out of fear. The same hygiene routines were used for all patients and we rarely heard the nurses mention the HIV status of the patient.

### **The stigma of HIV**

The opinions on whether there is a stigma surrounding this epidemic or not, vary greatly. We have gotten very different answers to that question depending on who was asked. Most nurses claim that not only does the stigma exist, it also has vast consequences for the patient in his or her disease. Some nurses say that there has been a change the last few years and that society is more open and forgiving towards the infected and that the patients have less difficulty talking about their disease.

The nurses who claim that the stigma still exists, describe that the family of the patient sometimes struggle with accepting the disease. The family sometimes cares for the patient but pretends like there is no HIV and focuses on, for example, just the pneumonia, and never tells anyone about the reason for the pneumonia. According to these nurses, some patients don't even tell their wife or husband that they are infected. We were told that many patients have two patient cards, one for the clinic where they go to get their antiviral treatment, and one which they bring when they go to the hospital for other problems. This leads to difficulty finding out from reading the patient file, if the patient is infected or not.

The nurses all describe the patients as unwilling to talk about their disease. That is also the impression we got when working and spending time with the patients in the wards.

*“I don't know why but the terminally ill AIDS patients seem very frustrated. Frustrated about their disease. I don't feel that for example, cancer patients are frustrated. I think they are ashamed, you know, the stigma. A lot of the patients don't even want their relatives to come and visit them. HIV they can bring to themselves. Cancer you don't bring to yourself. It looks like the relatives of cancer patients feel sorry for the patient. They're grieving.* “

We have frequently asked the nurses in the wards if they care for the patients with AIDS differently than they care for other terminal patients. The answer to that question has always been “No” and that is the impression we got during our observations as well. Apart from safety precautions, we have not been able to detect any differences in tasks, attitudes and work performance.

*“We don't treat the AIDS patients differently than other patients. A stigmatic disease doesn't make any difference for the nursing care. The tasks are the same.”*

### **RESOURCES AND LIMITATIONS**

When asking the nurses about their perception of adequate resources and what limitations hinder them in their daily work with the palliative patients, they all had

the same opinion. They stated that the amount of drugs available to them was sufficient but that they were understaffed and therefore experienced shortage of time. They all had wishes about what they could do if the circumstances were different. For example, they wished they had more time to sit by the patients' beds and carry out longer conversations, to be less stressed when feeding the patients and also have time to pray with the patients. They also explained that many patients die alone due to the nurses' lack of time.

*"We don't have enough time. We can have 42 patients of which 15 need extra attention. If I had more time, I would prevent bedsores and be able to feed the patients without feeling stressed because I know other patients are waiting to be fed."*

*"Unfortunately, many patients die alone here because we don't have time to be with the patient. We're in other rooms with other patients and when we come back, the person has died."*

*"We (the nurses) can't give love because we have too much to do. We try to give tender loving care, but it's only when we have students that we have enough time to sit down and talk. "*

We have many times heard the nurses talking about their wish for more time with each patient, as mentioned in the quotes above. The last quoted nurse claims that having students eases their workload and that leaves them more time with the patients. However, this is not the way we have seen it. When we started the study in the wards there were no other students but us. After two weeks, the Namibian nursing students started their internships, which meant that the number of staff in the ward was almost doubled. After a few weeks these new students were working independently and we could see that this addition to the staff made a big difference and the nursing tasks in the morning were finished much earlier than before. However, we could not see that this extra time was ever spent talking, praying or feeding the patients.

Some nurses express frustration about their working situation:

*"Every day you see a dying person. The workload is heavy and it's very stressful. You get irritated and snap at each other. We get very little rest and work a lot of overtime. The salary doesn't cover our expenses. Many of us are frustrated but as long as we stay positive and work well together, the workload feels lighter."*

We spoke to a nurse with insight in administration and organization about palliative care. She told us that no such thing exists in Katatura Hospital due to insufficient economical resources. According to hospital statistics from 2008, 781 deaths occurred in the four medical wards during that year. More than half of these, 467 were due to AIDS.

## **CARING FOR PATIENTS WITH AIDS – IDENTIFYING PROPERTIES**

A few things can be said to summarize the findings in this study of the palliative care in Katatura Hospital. The standard of the hospital and its palliative and medical care

is very low. Resources are limited and the dying patients are often left alone and unnoticed. The medical wards are understaffed and this is a source of great frustration for the nurses. The hospital management's supervision of the daily nursing performance is insufficient and there is little or no room for patient complains. Patients die in these wards every day but according to many of the nurses, palliative care does not exist in Katatura Hospital. We share that opinion.

## **DISCUSSION AND REFLECTION**

### **METHODOLOGY**

The ethnological approach enabled us to get a closer look at the everyday work with the terminal patients in a very special setting. By using participatory observations we became a very welcomed addition to the staff and the nurses were happy to talk to us since we helped them. We were told prior to this study that formal interviewing was not an option, since we were dealing with sensitive matters.

Since our contact person has, through her position at the University of Namibia, connections with Katatura hospital, which is the only teaching hospital, this was our only option. We were advised to perform our study at the medical wards since this is where the majority of the dying patients with AIDS are treated. The hospital has four medical wards. Initially we spent two days in each ward in order to decide which wards were suitable for our study. All four were quite similar but the members of the staff in two of the wards were more welcoming towards us and were therefore more willing to talk to us about these topics. In those two wards selected for our study, some members of the staff declined participation, which we respected. The duration of the study was five weeks, which we believe was enough time to get good insight and the categories saturated.

We believe that the informal conversations that took place between us and the nurses while carrying out the tasks in the wards, constituted a more natural setting to discuss these stigmatic topics, and gave us more honest answers than formal interviews with tape-recorders would have. By taking the role as students, we kept a humble position and we believe that this was an advantage since the nurses felt comfortable talking about their own vulnerability. During our time in Namibia, we lived with a Namibian family and spent a lot of time in Katatura and with the people who live there. This has brought us a deeper understanding of where the patients and the nurses come from and of Namibian culture. We view this as an advantage when it comes to understanding what we have seen and experienced in the hospital.

In our opinion, the language barrier has sometimes been an obstacle in our understanding of the nurse-patient relationship. The majority of the patients speak English and we have often been able to find out what has been said. Sometimes we have felt hindered when we have not been able to catch short comments or questions exchanged in different tribe languages.



## RESULT

According to WHO, the purposes and goals in palliative care should be to enhance the quality of life for the dying patient and his/her loved ones. A holistic approach should be applied where spiritual and psychosocial needs should be taken into consideration, as well as the physical needs. Through preventing and treating problems from all these dimensions the caregiver can relieve the patient's suffering [17].

From our point of view, the palliative care in Katatura Hospital leaves much to desire. Every year, almost 500 patients with AIDS die in the medical wards. Still this group of patients is not prioritized and the care is extremely far from the definition created by WHO. The holistic approach is missing, neither the physical, nor the psychosocial environment stimulate an improvement of life quality. Preventive care measures with for example bedsores, constipation and pain are undeveloped. The nurses are practically oriented and the caring tasks they carry out are mainly of physical nature. Issues of other dimensions are oftentimes neglected.

Sims and Moss describe the nurse's important roll in palliative care for patients with AIDS. Some fundamental principles are that the patient and his/her family should be considered central in the care-giving process and that a partnership between the caregiver and the patient should be established, where the main focus is to achieve the patient's goals. Good knowledge and understanding of all aspects of the disease should be required from the nurse, but also good listening- and counseling skills to be able to encourage the patient. Enhancing the quality of life should be the focus. [20].

During our time at Katatura Hospital, we reacted strongly to the attitude the nurses housed towards the patients. In our opinion, they are very task-oriented instead of patient-oriented. The ward has strict routines and all the nurses know what needs to be done each day, but never seem to reflect on why they are following the routine and how their actions benefit the patients. In the result we mentioned "SOAP:ing" and how this task is carried out and how we were instructed to formulate the patient's answers without even talking to the patient. Reading hundreds of SOAP-sheets in the patients' files, we clearly see that most of the nurses just copy what was written the previous day, sometimes without even talking to, or even observing the patient. This is a great example of a routine, which was probably created to benefit the patient, but is now used without much commitment or interest in the patient. The result of the routine is never evaluated and for these reasons the task seems pointless to us.

In the light of what Sims and Moss describe [20], the palliative care for patients with AIDS in Katatura Hospital appears very poor. We have witnessed very little interest from the nurses in what the patients want and need. We get the impression that nurses do not consider their availability to the patients as an important part of their job. They rarely check in on them and the patients have to make a lot of effort to get their attention, since they do not have any bells to ring. Most of them are too weak and/or too quiet to call for assistance. There is not much room for the patients to express their desires and needs. On the rare occasion that a patient speaks up to tell the nurses about his pain or other problems, we have often witnessed irritation among the nurses for being bothered with this. We have also noticed that a lot of times when someone asks the very sick patients how they are, they will say "I'm



fine” or “I have no complaints”. These are patients who clearly are not “fine”, with bad coughs, bedsores or even more serious conditions. We are not sure if these patients say they are fine due to cultural expectations to stay strong, or due to the fact that they detect the nurses lack of interest in how they are actually feeling and decide there is no point to let them know.

We believe that numerous factors contribute in shaping the nurses’ attitudes and actions towards the patients. Most members of the staff are Katatura residents and many of them are underpaid. They work a lot of overtime, and the emotional challenges they face in their everyday work are tough. After spending some time with the nurses, we have gotten the impression that their lives are quite tied economically. They have to work a lot to provide for their families. The majority of them are women and has large responsibilities at home as well. Many of the nurses seem frustrated since it is so difficult for them to change their situation and that they lack influence over their own lives. Their choices are very limited and many of them have experienced a lot of hardship in their own personal lives. Being nurses, they are more or less in control of their patients’ situation and we have experienced that this control is often misused and takes the form of paternalistic care, where the nurses do not involve the patient in decision-making or invite the patient to express opinions about his/her situation.

The care provided in Katatura Hospital takes place in a very special setting, as described in the background. We believe that this affects the nurses’ attitudes towards the patients and shapes the care they receive. These patients do not have any other alternatives, they do not pay for the care and this seems to impact both the patients’ and the nurses’ view of what is to be expected during the care-giving process. The nurses have expressed how they appreciate the lack of control from the management and the forgiving atmosphere in the wards, which allows them to make mistakes without being reported. The patients are often times grateful for whatever care they receive and hardly ever complain about anything.

The medical wards at Katatura Hospital deal with death every day. The patients with AIDS are very sick and the resources to provide good care are limited. Many of the nurses have argued how the working conditions are very trying and tiring and we have gotten the impression that some of them have given up hope on the situation. We have been told to stay strong several times and believe that this approach, not letting the misery get to you, is some form of defense mechanism. We also believe that it is a strategy the nurses use to save time. Getting emotionally involved in each dying patient and their families would be too emotionally draining and too time consuming from their perspective. We described an example of this attitude when nobody paid any attention to a dying girl’s mother who was devastated. Instead of facing the mother and her grief, the nurses all kept their distance and more or less ignored her. Dying patients and their relatives are not a priority for the nurses. They seem to look at these patients as closed cases and choose to put their energy on other patients. As stated in the result, they even told us this.

The nurses do not give themselves or each other time or space to feel or express whatever feelings they might have due to terrible things happening at their place of work. This contributes to a very emotionally shut down working environment, but we also believe that some parts of Namibian culture help forming this environment.

We have been told that some ethnical groups in the country have a tradition of introvert strategies when facing traumas or emotional challenges. This working environment seems to be deeply rooted in the wards and the new employees tend to be shaped by it, not the other way around, despite the fact that palliative care, and the importance of loving nursing skills are topics well discussed in Namibian nursing school.

In our opinion, the nurses possess a great deal of knowledge about AIDS. This is such a common problem in the Namibian society and it is therefore a natural part of the nurses' everyday work. However, it has been hard for us to determine whether their knowledge of the needs of the terminal patients with AIDS is sufficient and adequate or not, since the palliative care is not a priority. We cannot conclude if the lack of palliative care is due to ignorance, shortness of time or just a result of an inhibitive care culture in the wards. However, this is the case with all the patients, and we have not seen any discrimination of the patients with AIDS. Just as the nurses told us, the nursing tasks are the same for all and not determined by the patients' diagnosis. We do believe that AIDS still is a stigmatic subject both in the Namibian society and in the hospital, and the openness about the disease differs from person to person. Even though the attitudes vary, we have not seen it influence the care.

The topic of where to die has been well discussed during our time in the medical wards. Opinions part in this matter and we believe this has to do with how the nurses view the patient and their own role in the care-giving process. Some of the nurses have a task-orientated and practical focus in the end of life care, while other nurses have a slightly more spiritual and patient-orientated focus. This could explain why the opinions on where to die are so different. From our experiences of the end of life care in Katatura Hospital, we believe that the answer to this question is different from patient to patient. It depends more on the patient's situation in life with family, economy, and living conditions, than on symptoms, treatment and stage of disease. If the patient has family or friends capable of providing palliative care in the home, this is clearly the better option. If the patient for some reason is all alone, Katatura Hospital and the care provided in the medical wards is preferable.

## **IMPLICATIONS**

We see the need of improved efficiency in the everyday nursing work in the wards. The majority of the nurses have expressed frustration due to limited recourses, especially when it comes to time. That frustration is understandable since each nurse has so many, extremely sick patients to care for. However, from our point of view, the time they do have could be used in a more efficient way. The workday for the nurses follows a very strict time schedule with a set time for each task. The time it takes to finish the tasks differs, depending on how sick the patients are and how many students are in the ward. For example, some days the nurses finish the washing much faster than usual. That leaves them some extra space in the schedule before it is time to continue with the next task. In our opinion, it would benefit the patients greatly if the nurses took the opportunity to spend some extra time with the patients, but the time is usually spent chatting with colleagues at the nurses' station, texting on cell phones etc.

One cannot ignore the fact that Katatura is a hospital with very limited resources and both the staff and the patients suffer because of it. Even if the existing resources were utilized in the best possible way, the care available to the patients would still be unsatisfactory. We share the nurses' frustration over this situation. The hospital is in great need of renovation, upgraded technical equipment and better working conditions for the staff. The patients would benefit from improved management control and increased transparency between the matrons and the staff. This would hopefully mean that mistakes made in the patient care would have consequences, such as evaluation of what went wrong, followed by preventive measures to insure improvements in patient safety. The patients' opinions on the care should be asked for by the management and taken into consideration. Procedures around patient-related work should be reviewed and new routines should be developed to replace the SOAP:ing, which under current circumstances does not fill the purpose it is intended to fill. We also see a great need of improved and updated knowledge and education in palliative care and the needs of the palliative patient.

The palliative patients would benefit from a change of atmosphere in the medical wards. Better opportunities for the staff to ventilate their emotions and thoughts about what they experiences at work, for example, some sort of debriefing, could perhaps open up for that kind of change. It is possible that the nurses would find it easier to begin to open up emotionally to the patients if they knew there was some kind of help available, to cope with whatever they might experience when facing the patients suffering up close. This could help the nurse to see the patient as an individual who he/she can empathize with and get to know, instead of seeing the patient as an object to which he/she cannot relate.

## REFERENCES

1. WHO. MDG 6: combat HIV/AIDS, malaria and other diseases (Electronic). Available from: [http://www.who.int/topics/millennium\\_development\\_goals/diseases/en/index.html](http://www.who.int/topics/millennium_development_goals/diseases/en/index.html). Accessed 2009-02-03
2. The work continues. Palliative care in Sub-Saharan Africa: an appraisal (Electronic). (2004-01-01). Available from: <http://www.theworkcontinues.org/document.asp?id=1524&pageno=>. Accessed 2010-12-17
3. WHO. HIV/AIDS (Electronic). Available from: [http://www.who.int/topics/hiv\\_aids/en/](http://www.who.int/topics/hiv_aids/en/). Accessed 2010-12-16
4. Sjukvårdsrådgivningen. Hiv och aids (Electronic). (2008-11-08). Available from: <http://www.1177.se/Fakta-och-rad/Sjukdomar/Hiv-och-aids/>. Accessed 2010-12-16
5. WHO. Antiretroviral therapy (Electronic) Available from: [http://www.who.int/topics/antiretroviral\\_therapy/en/](http://www.who.int/topics/antiretroviral_therapy/en/). Accessed 2010-12-16
6. WHO. HIV/AIDS online Q&A (Electronic). (July 2010). Available from <http://www.who.int/features/qa/71/en/index.html>. Accessed 2010-09-08
7. UNAIDS. Regions and countries (Electronic). Available from: <http://www.unaids.org/en/CountryResponses/default.asp>. Accessed 2010-09-08
8. WHO Africa. Acquired Immune Deficiency Syndrome (AIDS) (Electronic). Available from: [http://www.afro.who.int/index.php?option=com\\_content&view=article&id=87&Itemid=563](http://www.afro.who.int/index.php?option=com_content&view=article&id=87&Itemid=563). Accessed 2010-09-08
9. International Observatory on End of Life Care. Namibia (Electronic). Available from: [http://www.eolc-observatory.net/global\\_analysis/pdf/namibia\\_country\\_report.pdf](http://www.eolc-observatory.net/global_analysis/pdf/namibia_country_report.pdf). Accessed 2010-09-08
10. Namibia Tourism Board (Electronic). Available from: <http://www.namibiatourism.com.na/>. Accessed 2010-09-08
11. CIA. The World Factbook (Electronic). Available from: <https://www.cia.gov/library/publications/the-world-factbook/geos/wa.html>. Accessed 2010-09-08
12. WHO. Country Cooperation Strategy (Electronic). Available from:

[http://www.who.int/countryfocus/cooperation\\_strategy/ccsbrief\\_nam\\_en.pdf](http://www.who.int/countryfocus/cooperation_strategy/ccsbrief_nam_en.pdf).  
Accessed 2010-12-16

13. Vanda. Katatura idag (electronic). (2008-07-15). Available from:  
[http://www.vantaa.fi/sv/i\\_perusdokumentti.asp?path=109;3751;7426;62495;6710;6725;75103;75132](http://www.vantaa.fi/sv/i_perusdokumentti.asp?path=109;3751;7426;62495;6710;6725;75103;75132). Accessed 2010-03-18
14. Firestone, M D & Karlin, A. Lonely Planet Botswana & Namibia. Victoria. Lonely planet, 2010
15. WHO. Namibia: Health profile (Electronic). Available from:  
<http://www.who.int/gho/countries/nam.pdf>. Accessed 2010-12-16
16. University of Namibia. Guide for international health care students to Namibia (Electronic). (2009). Available from:  
<http://www.unam.na/faculties/nursing/International%20Health%20Care%20Student%20Guide.pdf>. Accessed 2010-12-17
17. WHO. WHO Definition of Palliative Care (Electronic). Available from:  
<http://www.who.int/cancer/palliative/definition/en/>. Accessed 2010-12-16
18. Vg- Regionen. Palliativ vård I livets slut (Electronic). (2007-12-07). Available from:  
<http://www.vgregion.se/upload/Alingsas/Vårdsamverkan/Palliativ%20vård/Lokal%20handlingsplan%20palliativ%20vård%20i%20livets%20slut.pdf>.  
Accessed 2010-12-16
19. Hanratty, J & Higginson, I. Palliativ vård vid terminala sjukdomstillstånd. Lund: Studentlitteratur, 1997.
20. Sims, R & Moss, V A. Palliative care for people with AIDS. London: Hodder Headline PLC, 1995.
21. Pilhammar Andersson, E. Ethnography; field studies of training and supervision in clinical care, I: Fridlund, B & Hildingh, C (Ed). Qualitative Research Methods in the Service of Health. Lund: Studentlitteratur, 2000. s. 195-212.
22. Dahlberg, K. Kvalitativa metoder för vårdvetare. Lund: Studentlitteratur, 1997.