"AND HERE WE ARE ALLOWED TO DO IT"

AN ETHNOGRAPHIC FIELD STUDY ABOUT THE ROLE OF THE PALLIATIVE CARE NURSES IN UGANDA

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"OCH HÄR FÅR VI LOV ATT GÖRA DET"

EN ETNOGRAFISK FÄLTSTUDIE AV SJUKSKÖTERSKORNAS ROLL INOM PALLIATIV VÅRD I UGANDA

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Nyckelord: holistisk omvårdnad, Hospice Africa Uganda, palliativ vård, sjuksköterskans roll, Uganda, utmaningar.
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Palliative care – end of life care – is not a priority in developing countries. In 1993 Hospice Africa Uganda (HAU) was founded and chosen as a model for other African counties. Among other things nurses are authorised to prescribe morphine and other palliative care drugs after undergoing a nine months clinical palliative care course at HAU. In this ethnographic field study observations, interviews and group interviews are used in order to explore the role of the palliative care nurse specialist in Uganda. In total there are 20 participants involved in this study, who are working at HAU, Mulago hospital and students from the clinical palliative care course. The result of the study reveal that the role of the palliative care nurse specialist is multifaceted. Beyond prescribing drugs their role is to deliver holistic care by taking into consideration the physical, psychosocial and spiritual pain patients and their family can have. They encounter many challenges in their work but they also have the possibility to improve the quality of the patients life.

*Keywords:* challenges, holistic care, Hospice Africa Uganda, nurses role, palliative care, Uganda.
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ACRONYMS

APCA - African Palliative Care Association
CPC course - Clinical Palliative Care course
HAU - Hospice Africa Uganda
ICN - International Council of Nurses
IMF - International Monetary Fund
NGO - Non-Governmental Organisation
OECD - Organisation for Economic Co-Operation and Development
WMA - The World Medical Association
WHO - World Health Organisation
INTRODUCTION

The idea for this study came in 2008 when I heard about the Minor Field Studies program. Since I study nursing science I wanted to focus my study on the knowledge of nurses in the developing world in particular in the field of palliative care. World Health Organisation (WHO) recommends a high priority for palliative care in developing countries, but most African governments and organisations do not focus on end of life care. Only 20 percent of all 7000 hospices in the world are situated in the developing world (Stjernwärd, 2002).

I read about Hospice Africa Uganda (HAU), as a model for palliative care in the African setting. I contacted Dr Anne Merriman, the author of some articles I read and got a positive response from her. Through her I came in contact with my supervisor, Bernadette Basemera at HAU.

Through studying the role of the palliative care nurses in Uganda I hope to be able to add to the body of knowledge from which other countries may learn. African countries for example are all different but most are in need of starting up or developing a palliative care system. The study of professions like nursing in Uganda, which is special in the way that nurses are trained to prescribe morphine, other African nurses can learn from the Ugandans nurses experiences. We in the industrialised countries also have a lot we can learn from Uganda with regards to the provision of good palliative care services using minimal resources.

BACKGROUND

Uganda, its health care system and epidemiology is presented; and a definition of palliative care, hospice and its philosophy is given. Furthermore, an outline of the implementation of African and Ugandan palliative care is drawn. An overview about research in the field of palliative care is given at the end of this section.

Uganda

The east-central former British protectorate Uganda gained independence in 1962 (Mason, 2008) and borders on Kenya, Sudan, Democratic Republic of the Congo, Rwanda, Tanzania and Lake Victoria. During 1971 and 1979 an estimated 300,000 people were murdered under the dictator Idi Amin, who left the country unstable and in economic and social crisis. After his regime the Uganda National Liberation Front (UNLF) led the country to another 8 years of long crisis. The National Resistance Movement took over power and since then the present president Museveni has been in power (Nationalencyklopedin, 2008). The Ugandan constitution was adopted in 1995 (Utrikespolitiska institutet, 2009).

The majority of the population lives in rural areas of the country. There are 40 different ethnic groups living in Uganda. These can be divided according to their language: West Nilotic, which lives in the northern part, East Nilotic in the east part, groups speaking Sudanic languages like lugbari and madi in the north west. The bantu people, living mainly in the south and south west makes out almost two
third of the population. The official language is English, which is spoken by only 10-20 percent of the population (ibid).

The Gross National Product per person is about 300 USD, and 46 percent of the population live on less than one USD per day. In comparison, the Swedish Gross National Product in 2006 was 34,734,94 USD (IMF, 2007). The Ministry of Finance Survey from 1997 determined that the major reason for poverty in Uganda is probably poor health (Afro WHO a, 2008). Due to poor infrastructure only 49 percent of the population have access to health care facilities (Afro WHO b, 2008). Agriculture is the biggest sector of the economy (Utrikespolitiska institutet, 2009).

Freedom of religion is respected and religion is an important part of the Ugandan society. A large part of the population is actively practising their religion. Three quarters of the inhabitants of Uganda are Christians, but different revivalist movements, such as pentecostal, are increasingly popular. Muslims are around ten percent of the population and live mostly in the northern part. A tenth of the Ugandans are estimated to belong to traditional African religions. Many mix Christianity and Islam with traditional religious believes and practices (ibid).

**Uganda’s Health Care System**

In 2005 a total expenditure on health of 130 USD per capita was reported (Unaid/WHO et al, 2008). The health care system is financed with 19 USD per capita by the Ugandan government, but the lion's share comes from the international community. In contrast, Sweden invests 3,202 USD per capita. (OECD, 2008) (Mason, 2008). Uganda spends 1.67 USD per person per year for drugs, which is inadequate. It has been estimated that this should be 4 USD to deliver adequate drugs to the patients. Like in other developing countries there is a gap between rural areas and the capital, Kampala, in the health care system regarding resources for medicine, training and equipment (Mason, 2008).

According to the Ministry of Health in Uganda there are 104 hospitals and 250 health centres. There are 41 training schools and the Uganda National Health Research Organisation, which is the umbrella organisation for eight health research institutes (Uganda Ministry of Health, 2008). Hospice Africa Uganda has three branches in Uganda and there are four more independent hospices in Uganda (HAU b, 2008).

Mulago Hospital, situated in Kampala, is the biggest national referral hospital in the country. It has an annual average inpatient of about 120,000 and attends to over 480,000 outpatients annually and the bed capacity is 1500 (Mulago hospital, 2009).

The lack of trained professionals is a problem, which forces innovative solutions. The density of physicians per 1000 population is 0.08 in Uganda and in comparison 3.5 in Sweden in the year 2005. The density of nurses is 0.55 per 1000 population in Uganda and 10.7 in Sweden (OECD, 2008) (Mason, 2008). There are three medical schools in Uganda with five year courses (Mason, 2008)
and in the nursing schools the training is three years long and includes HIV/AIDS knowledge (Fournier et al, 2007).

Epidemiology
In 2005 the population of Uganda was estimated to be 28 million and in 2004 life expectancy was 49 years (Afro WHO c, 2006). The prevalence of HIV/AIDS has declined from an estimated 14 percent to approximately 6 percent in 2007 (Unaids/WHO et al, 2008). One factor that may have contributed to this reduction is the National Strategic Framework for HIV/AIDS Activities in Uganda which aimed to reduce the HIV prevalence by twenty-five percent and to assuage the consequences of HIV/AIDS (Uganda AIDS Commission, 2004). In 2008 it was estimated that 940,000 were living with HIV in Uganda (Unaids/WHO et al, 2008).

WHO estimated that in 2005 approximately 14,000 people died due to cancer whereby 8,000 were under the age of 70. In the same year 3.7 percent of all deaths were caused by cancer and by 2030 this is projected to be 6.6 percent. In 2002 the most common cancer form among males was prostate cancer and among women cervical cancer (WHO, 2008).

Palliative Care

The World Health Organisation (WHO) defines palliative care for cancer as

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment. Palliative care:

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement” (WHO, 1990 p 11).

Hospice

Taking care of dying people has a long tradition in all over the world. The founder of the modern hospice movement is Dame Cicely Mary Saunders whose aim it was to care for patients at the end of life. Since then, palliative care has developed as a holistic approach to patient care and it is an important pillar in most health care systems (WHO, 2008).
The word *hospice* was introduced in the Middle Ages for a house where they took care of ill or dying pilgrims. In the 19th century the term *hospice* was reused and in 1905 St. Joseph's Hospice was established in London. It was characterized by its connection to the church and non-profit mercifulness work. 1967 St. Christopher's Hospice opened in London on the initiative of Dame Cicely Saunders who earlier worked with dying cancer patients. Her background as a nurse, social worker and physician enabled her to have a multidisciplinary approach to her patients. After World War II the friendship between her and a polish immigrant gave her inspiration. He gave her money to use for a home for terminally ill to spread her idea of holistic end of life care. Interestingly, the basis for the hospice movement are the thoughts, experiences and dreams of one person and not a scientific need-assessment (Beck-Friis & Strang, 2005).

In the 70s the hospice movement spread fast. Cancer care was neglected in many hospitals and hospices developed to fill the need for this. In Great Britain new hospice units were founded with a connection to local hospitals. In the USA the system operates differently; hospices have to meet certain criteria to get economic support. Initially the majority of hospice patients were dying from cancer but increasingly patients with other diagnoses were admitted for hospice care. The idea of hospice is now present on all continents in different forms and organisation models (ibid).

**Hospice philosophy**

Cicely Saunders promoted holistic care with attention to pain and symptom control. She described the concept of ‘total pain’ as having four components, which are:

- physical pain
- psychological pain
- social pain
- spiritual pain (ibid).

She also meant that the nature of human being includes life and death, the whole human being – body, mind and soul – like a part of a family unit with physical and practical needs and it is the task of the palliative care practitioner to satisfy this in the best way possible. Many patients come to a point where active treatment is of no additional benefit but unfortunately they are still often given this “active treatment”. When it is realized that this is not the right way to treat a patient, the physician has to try to control symptoms, but should never reach the point where there is nothing to offer. Care of terminally ill patients demands more from a physician than medical competence. It has to be completed with intuition to come closer to the human reality (Saunders, 1980).

One important component of the care of terminally ill patients is that the patient and the family are seen as the unit of care. The multidisciplinary team has combined experiences and is able to actively manage pain and symptom control, as well as offering psychosocial and spiritual support. A home care system should exist within the local conditions. Support for the family should continue even after bereavement. Registration and analysis should be done frequently to enable
evaluation and improve care. Education in various forms should continue to play an important role in special clinics, but should also be integrated in bigger education centres. Furthermore, you should strive for a mixture of patient recruitment and an easily accessible administration (ibid).

Palliative Care in Africa
The first hospice in Africa opened in 1979 in Zimbabwe and after this South Africa and Kenya followed. Since then Tanzania, Malawi, Nigeria, Ghana, Cameroon, Ethiopia, Botswana, and Lesotho have founded hospices. In 2002 the African Palliative Care Association (APCA) was founded and opened in 2005 an office in Kampala, Uganda. APCA is working with twenty one African countries and publishes a review of Hospice and Palliative Care in Africa (HAU a, 2008). In Sub-Saharan Africa, Uganda is the only country that implemented WHO's foundation measures for palliative care, which are education, drug availability and government policy (WHO, 2008) (Spence et al, 2004).

Hospice Africa Uganda
Several countries in Africa were looking for a similar hospice concept like the one in Nairobi, Kenya. The idea for hospice concept model in Africa was realised in 1993 when Anne Merriman founded Hospice Africa Uganda (HAU). HAU was registered as a charity in UK in 1993 and as an Non-Governmental Organisation (NGO) in 1994 in Uganda. Other African Countries could come to learn how palliative care can work and then implicate education and service according to their own needs. The first patient was seen in January 1993 (HAU a, 2008).

The objectives of HAU are:

1. “To provide an appropriate Palliative Care service to patients with Cancer and/or HIV/AIDS and their families within defined operational areas
2. To enable the provision of Palliative Care services in Uganda, through Advocacy, Education and Training
3. To facilitate the initiation and expansion of Palliative care in Africa by providing an affordable African model” (HAU a, 2008 p 1).

According to Kikule (2003) patients in Uganda wish to die at home and that is why HAU visit patients in their homes or in hospitals and does not offer an inpatient service. Home care is felt to be culturally appropriate as well as affordable. Patients are mostly referred but do also come on self-referral. In the villages specially trained community volunteer workers identify possible patients for the HAU program (HAU a, 2008).

HAU has three branches in Uganda: In Kampala, Little Hospice in Hoima and Mobile Hospice in Mbarara. In 2008 there were 109 members in the Hospice team divided between the three branches. There is support from local as well as from overseas volunteers (ibid).
HAU offers an holistic approach for care to the patient and the family, which means to integrate the physical, social, psychological and spiritual aspects of the patients care. Physical care means pain and symptom control and as part of the social care HAU is offering among other things nutrition and financial support. An example for psychological care is the day care program with occupational therapy. In terms of spiritual care the staff at HAU discuss spiritual needs and pray together with the patient if requested (ibid) (HAU b, 2008).

**Education**

HAU offers short and long courses for different professions and non health professionals (HAU a, 2008).

Since 2004 Uganda allows legally registered nurses and clinical officers to prescribe morphine after undergoing a nine month clinical palliative care specialist training (CPC course) (ibid).

There is even a distance learning diploma in palliative care for health professionals which is affiliated with Makerere University. At Makerere University and Mbarara University of Science and Technology (MUST) palliative care is part of the undergraduate medical curriculum and postgraduate M. Med. programs. There are also elective students from Uganda and international medical and nursing students at HAU (ibid).

**Funding**

HAU charge 5000 Ugandan Shillings (US$ 1.5) for the costs of medicine and care. Less than one third of the patients can pay this amount of money. To care for one patient per week costs US $20 (ibid).

There are different support groups in different countries that fund Hospice in Uganda. Even charity shops and individual donors contribute to the work of HAU (ibid).

**Earlier research**

Generally, there is a lot of research made in the field of palliative care. A search in the database PubMed in August 2009 resulted in 35,804 results with the search words ”palliative care”. By adding the key word ”Africa” the results were reduced to a mere 243 articles and only 36 articles were found by searching with the key words ”palliative care” and ”Uganda”.

However, there is the African Palliative Care Organisation (APCA) with the aims to promote appropriate palliative care throughout Africa. They state that palliative care research in Africa is neglected, which is further illustrated by the above mentioned search. APCA work together with the European Association for Palliative Care (EAPC) and the International Association for Palliative Care (IAPC) on a strategy to develop a global palliative care research initiative, with a special focus on developing countries (APCA,2009).
There are studies ongoing at HAU, which could be interesting in addition to the present one when they are published. However, the following studies carried out earlier in Uganda may have relevance for the results in the actual study.

Kikule (2003) conducted a descriptive cross sectional study with the aim to identify the palliative care needs of terminally ill patients in Uganda. 173 patients with HIV/AIDS or cancer were randomly selected and included in the study population. They were bedridden and part of a home care program in Kampala. The study found that patients in Uganda want to die at home, pain-free, without stigma and as independent as possible for as long as possible (Kikule, 2003).

The aim of Fournier's (2007) qualitative study was to explore the experience and perspective of six nurses caring of AIDS patients at a national referral hospital in Kampala. Ten focus group interviews, in-depth interviews and photovoice were conducted. Fournier's findings showed that nurses meet challenges like poverty, insufficient resources, lack of ongoing education and fear of contagion which lead to moral distress in their work (Fournier et al, 2007).

**AIM**

The aim of the study is to explore the role of the palliative care nurses in Uganda their experiences in delivering palliative care and the challenges they face. In order to achieve this aim the following questions were explored.

- How do nurses describe their role?
- What are the challenges nurses encounter in delivering palliative care?
- What are the psychosocial issues patients can have and what are the nurses’ roles in delivering psychosocial care?
- What are the spiritual issues patients can have and what are the nurses’ roles in delivering spiritual care?

**METHOD**

To find out about the role of the nurse and their experiences in palliative care a qualitative approach was used. According to Polit & Beck (2006) it is suitable to use a qualitative approach in order to understand human experience through the collection and analysis of narrative and subjective data.

**Ethnography**

A ethnographic study was carried out in the period of April and May 2009 in Kampala District.

Ethnographers use a array of sources of data like observations of what happens, listening to informal and formal interviews and collecting documents of different types. Ethnographic work takes place in the field which means in a everyday context (Hammersley & Atkinson, 2007). The studied subject are usually just a small group and the data analysis “involves interpretation of the meanings,
functions and consequences of human actions and institutional practices” and what they mean in the context (Hammersley & Atkinson, 2007 p 3). The intention is to explore how the subjects studied view their situation, one another and themselves. Usually the initial study questions will be refined over time and eventually even transformed (Hammersley & Atkinson, 2007).

**Study Population**

The study population included 20 nurses, three of which worked in Mulago Hospital, 11 worked at HAU and six were qualified nurses and students attending the Clinical Palliative Care (CPC) course at HAU. Three of them were males and 17 were females.

**Observations**

The study collection included observations during home care visits with the team of HAU and ward rounds at Mulago hospital, where field notes were taken. In total, nineteen days were observed. The field notes from this resulted in thirty A4 pages of notes. Home visits lasted about two to four hours depending on the number of patients visited and the total distance to and between the patients home. The three visits at Mulago hospital lasted about four hours respectively. Nurses talked mostly in their local language with the patient and their family, and I observed how they interacted with each other. For getting a better understanding of the situation I asked elucidating questions to the nurse afterwards.

**Interviews**

Additionally, sixteen interviews were conducted in English whereby only fifteen interviews are reported here because two were excluded due to technical difficulties. One of the excluded interview was repeated because the subjects opinion was considered interesting for the aim of the study. All interviewees were also observed in their work. All interviews were tape-recorded and transcribed. A semi-structured topic guide was used where questions were little different from interview to interview. After some time I learned to use more follow up questions and to ask questions I got more interested in during my stay. In total there are three interviews with palliative care nurses working at Mulago Hospital, three individual interviews with students in the CPC course and six interviews with palliative care nurses working at HAU. The interviews lasted from approximately 30 minutes up to 50 minutes.

A focus group interview was planned which is according to Polit & Beck (2006) a group of five to ten people discussing and sharing experiences. Because of this a focus group interview was planned, but there were difficulties in gathering this group together at one particular time.

For this reason two smaller group interviews were held, each including three participants who where not interviewed individually before. One with students from the CPC course and one with palliative care nurses working at HAU, Kampala. The interview with the students lasted one and a half hour and the interview with the nurses just 35 minutes due to time constraints of the interviewees.
Ethical considerations

The declaration of Helsinki and the code of ethic for nurses were respected in this study (WMA, 2008) (ICN, 2006). Ethical approval was sought from Malmö University which was additionally sent to HAU via my supervisor, Berna Basemera. She was informed about the procedure of this study. In Uganda, I signed a confidence form to respect the integrity of the patients at HAU. To integrate the three nurses at Mulago Hospital, I asked for permission from the head of department, which was approved.

All participants received oral and written information about the study before the observations and before the interviews. They also received information about their ethical rights, such as informed consent and confidentiality. After making sure that they understood the information and after asking for permission to record the interview, they all signed the informed consent form.

Confidentiality aims to protect the study participants by not linking the provided information to the individuals and never publicly revealing the identity of the participant. Informed consent is based on voluntary participation after informing the subject about possible risks and advantages (Polit & Beck, 2006).

All participants choose the location for the interviews themselves and it was accepted when the interview had to be shortened due to workload, lack of time or any other reasons.

Data Analysis Methods

According to Burnard (2008) data analysis starts during or immediately after the data collection period. The themes in the text were identified by several steps: The interviews were transcribed verbatim, whereby half of them were transcribed directly after the interview and the rest after the fieldwork. However, field notes were made after all interviews about the interview situations and any particular things mentioned by the interviewee. All participants were given a code name to guarantee confidentiality. The collected names are randomly selected and have nothing to do with the sex of the participants. After reading the field notes and interviews I summarized topics at the margins. The aim of this so called open coding is to present a summary statement for all themes discussed in the text (ibid).

The second step of the analysis is to write the identified summarizing words or sentences on an extra sheet of paper, whereby duplications can be eliminated. After this reduction of categories, the next step is to identify similar categories which were grouped together. These final categories were re-identified in the text, where each category is marked in the text by his own colour. According to the same colour, categories were cut out and pasted on a new sheet of paper (ibid).

RESULTS

In this section the results from the interviews, group interviews and observations is presented. Initially a general picture of the role of the nurse is drawn.
Furthermore their patients’ psychosocial and spiritual issues are surveyed and nurses role in psychosocial care is described. The challenges are mapped out at the end of each section.

**Nurses role**

At HAU, nurses do mostly home visits, where a driver takes them and the team to the patients home or the hospital where they lead the care for the patient. They are also clerking and consulting patients who are able to come to the clinical building. In addition, HAU offers day care for patients, where nurses take care of the patients one day a week. They also supervise and educate community volunteers, who go to the villages to identify possible new patients and support patients already on the program. Regular outreach clinics allow patients who live outside the catchment area to access palliative care.

In Mulago hospital the work is different due to the fact that they offer inpatient care. There is a palliative care unit where four nurses cover the departments. There are two doctors on that team and they all have a advisory role in terms of supporting other clinicians in the care of the patient. However, there are tasks that are common for all nurses working in palliative care:

**Holistic care**

The role of the palliative care nurse is to deliver holistic care to the patient and to his or her family. It involves assessing and managing physical, psychological, social and spiritual pain. By doing that, they can improve the quality of their patients life. Jackie and some other respondents answered that it is most important to do pain and symptom control first than offering counselling because it is not easy to counsel somebody in pain.

> “I make sure, if the patient is in pain, she is the patient is pain-free. Any symptom that comes in, I control the symptom. Then I assess the patient holistically. Physical, psychological, social and spiritual.” (Jackie)

Nurses see it as a right to be pain-free and that's why the nurses’ aim is to do so.

> “And really my aim is to make sure that people are also relieved, become free like me. As I am being free, maybe not having pain, doing my activities, they also have that right of doing their own activities.” (Lee)

Quality is considered more important than quantity in holistic palliative care which is illustrated by the opinion of Kelly:

> “We need to see at least four every day, you go for home visits, we see four we see them holistically.” (Kelly)

**Prescribing**

Nurses in Uganda are allowed to prescribe morphine and other palliative care drugs after undergoing the nine month course in palliative care at HAU, which they consider important in order to do their work.
“And then, most important thing is prescription of oral morphine. We the CPCs have been taught to, to prescribe and the Ugandan law had allowed it. Allowed us to prescribe oral morphine.” (Ariel)

The way they describe their own role makes clear that they are proud to have that competence. The following excerpts illustrate the nurse’s perception:

“When we were still in the curative setting as said, we’re not allowed to do certain things, like prescribing the morphine like seeing patients alone, you just write the observations and whatever. Patients were seen by the doctor. If the patient comes to you to see that patient as one person, find them in the. Diagnosis you write them the medication you give the medication the patient is supposed to take and you give a review date. In the curative setting everything is at the doctors. And here the nurses are allowed to do it.” (Cléo)

Prescribing morphine is usually not a nurses role in other countries, which makes Uganda special. The morphine is carried with them when they visit patients in their homes in plastic bottles in different colour according to the concentration.

**Networking**

Nurses interact as spiders in the web. Their work is characterised by networking between the patient and the family but also networking with other professional categories, like doctors, spiritual leaders, social workers and community volunteers. To supervise these community volunteers is one of the responsibilities a nurse have at HAU.

“We nurses are supposed to act as a catalyst between patient, the family and the other team members.” (Charley)

“I serve so many things: I work as a nurse, I work as a doctor and on the other hand I work as a consultant.” (Francis)

Nurses have the legal authority to prescribe, but still they have to discuss within the team about the patients treatment.

“Of course the role of the doctors and nurses are similar. The nurse is supposed to assess is supposed to examine the patient and to prescribe, since we are allowed to prescribe. The roles are cutting across, that's what I think. But the nurse can go more in counselling, to do more of the psychosocial support than the doctors. And even nurses have more time with patients, sometime than the doctors.” (Charley)

If the patient needs treatment or investigations, the nurse can do the referral to the responsible centres.

“The nurse is who sees the patient first. It is my responsibility is that this patient is referred to another place where they can get treatment.” (Jessie)
Advocacy

One of the roles nurses have is to make the people aware of the importance of palliative care. That not only cancer and HIV/AIDS need to be palliated but also to include patients with other diagnoses. They advocate for morphine as an effective analgesic. Advocating also involves removing misconceptions about HAU because many patients think they get cured when they are referred to HAU. From time to time HAU arrange a charity walk, where the HAU staff participate in order to promote palliative care.

"Palliative care this is a new thing. I think it needs to be put in peoples. To make, I mean awareness the public. Here we only look at the cancer and the HIV but there are other chronic illnesses. There are other, not cancer and HIV there are so many others like hypertension. They all need to be palliated /.../. The first thing is the public, because they come and want to know the importance. They really get what it means to palliate, it is new.” (Jessie)

General Challenges

Nurses encounter many challenges in their work. It was obvious that most challenges are administrative, which nurses cannot influence. On the other hand they can empower the responsible person to make changes. Challenges vary from the place of work. Especially nurses from government hospitals face problems due to the health care system infrastructure, whereby nurses working at HAU fear that donors can step out the program which could affect their work. The challenges all nurses, working in palliative care, can face are: the number of patients and the lack of knowledge about palliative care.

Administrative challenges

There is a shortage of institutions offering radiotherapy in the country, which can become an issue for patients from other regions in terms of transport:

“*You find this patient end up not coming so he cannot benefit from radiotherapy.***” (Sidney)

Morphine is one of the most important drugs in palliative care for pain control. It is difficult to deliver good palliative care when drugs are out of stock, which happens often at Mulago hospital.

"*And another thing; the morphine. Sometimes drugs can be out of stock /.../. It happens, you know the hospital can have few drugs, out of drugs and you know the patients are very many. If you have catered for twelve patients and you get twenty, so the drugs get finished quickly.***” (Ariel)

Many respondents mentioned as a challenge that donors can be difficult to find or may not continue their funding, but the number of patients will be the same and they are supposed to offer the same quality of care. They say as well that they have to manage the patient holistically but this can be difficult if they do not have for example finance for social support, even when there is morphine for the physical treatment.
“Then another challenge. I can call it the organisation challenge. Because there are times when the charity organisation and it depends on donors, some times it runs shortage of, patient are many. Patient budget is not enough to the service available need. So if the patient gets not enough of the available need or if the patient is to get supported with nutrition for seven days which can which ends up with nutrition for three days. Because other also need to get. /.../ We assess holistically but in the management most special the social and yeah most special the social. We normally go like sixty percent. But, the physically we are 100 because the drugs are really enough. The drugs are enough.” (Jackie)

Another issue becomes adequate space for work. In some hospitals there is not enough space for a palliative care unit, which may constrain their work.

"And then another thing space. I think my hospital needs enough space for the palliative care unit, not to be, integrated in the HIV department because you find the nurses overtaking the other work and the palliative care patients attended to later...because these patient are more than the other one. If she has space where she can deal with that patient. Then the other part of the work will be easier.” (Sidney)

Even the interviewed nurses in Mulago hospital talked about a shortage of space which leads the hospital to discharge the patients before the treatment is finished, so staff do not spend much time with the patient.

"The challenges on my side. Patients don't take a long time with you because the ward is so congested that this discharged almost without finishing." (Rory)

Transport can be an issue especially because palliative care is mainly home care and the staff need to have transport to go to the patients home. These was mainly mentioned by informants outside Kampala District. Furthermore the question of transport can even become an issue for the patients. For example, they may have to reach hospitals or other organisations where they can get treatment, and be unable to afford transport.

“How are you going there? And know, you find that is a challenge in transport. How am I transport this bags? Will I review the patient today? Tomorrow I go to this one and next day I go to this one. But how should I come to that? Or should I say that the patient should come to the hospital? And again, you never know maybe this patient is having a pain of social, financial status. How is he coming to the hospital? And you know it becomes a conservational issue now.” (Lee)

The number of patients

Other institutions do not deliver services like HAU does and there is a large number of patients that need quality palliative care. Furthermore there are just three branches of HAU all over Uganda. Patients beyond the coverage area will not receive the care. And when the patients do not have access to transport they will not receive palliative care.
“There are still a number of patients who need the quality of care delivered by hospice, ../., some hospitals they deliver palliative care but not the palliative care which is supposed to be delivered by hospice. So when you look around, we only have three branches of Hospice in Uganda, ../., and again it limits distance coverage. ../. If a patient beyond the 20 kilometres, will not receive palliative care. ../. So if the patient is unable to get transport, they will not access palliative care. And you find other times a patient needs home visits. Hospice can't move beyond 20 kilometres. You will not access home visits. The challenges most patients in Uganda they end up dying without receiving palliative care.” (Jackie)

Workload and working condition

The quota of nurses and patients is very low so that nurses face a high workload. Some days can be busy because there are so many patients to see. However, they consider quality more important than quantity in palliative care.

“We are still few, we have workload here. We may not go through all that steps of holistic. We need to see at least four every day, you go for home visits, we see four we see them holistically.” (Kelly)

In the hospital the working condition can be difficult, especially when many patients die and the nurse is the one that has to handle the dead bodies. It can give her/him occupational injuries.

“Here on this ward you have to bed down on the floor. If the patient is lying down, you have to bed down and put and then the beds, pushing them is very difficult. Because pulling a dead body you need to put it in the room, where it is supposed to be. But it is very difficult.” (Rory)

Lack of knowledge about palliative care

One problem in the African setting according to the respondents is that patients come to hospitals almost at the end of life. Enlightenment programs are necessary to educate about the importance, but these are also dependent on funding.

“They still have not really have understood what palliative care is. So we still have to hold program, enlightenment program that's apart, there is no way I can do palliative care successfully without funding so which is the major problem that I am facing now.” (Morgan)

The lack of knowledge about palliative care can lead to misconceptions about palliative care so some patients think it is just for the dying. This affects the nurses when people have doubts about their role.

“Then we need a lot of sensation about palliative care. They think a palliative care is for the dying patients and sometimes they call us, what stresses me a lot, we call when they almost dying, not knowing palliatives care not start beyond the disease. Patients starts getting pain when they should coming.” (Ariel)

Students from the CPP course that go back to their working place face the challenge to train others in palliative care. They have a big task, especially when
there are no other or few trained nurses in the region where they are working. Nurses have to train others to cover some regions.

"For my site the first challenge was there is only one nurse which can be trained in the whole of the region. The first challenge to train another person. One of the nurse was trained before I followed her.” (Sidney)

Other may not be able to incorporate knowledge they teach about palliative care.

"You know giving information is not easy to a person. Sometime when you're in a working place and you have tried to develop some career or you increased your knowledge. Other people have bias, they have bias. Some people may say: I can't listen to what he's talks. And those people don’t expect that how much I am going go give the knowledge to the people, you never know such kind of people may be around, but I wish them also the impact. How much I say I cannot follow what they say.” (Lee)

In some regions in Uganda there are even morphine supply problems that can be a challenge for nurses.

“So the supply of morphine is always a challenge as you seen. The supply of morphine, the lack of morphine.” (Sidney)

One respondent talked about difficulties with information given by pharmacists.

“Those pharmacies, is it called documentation? They don't tell them the way how to take the morphine. Though they need to be guided. The way it is taken.” (Jody)

The lack of knowledge about palliative care may contribute to high expectations among patients and other health professionals. Families that were supported when the patient was still there can expect that the support will continue afterwards. HAU does bereavement afterwards, but the support is mainly intended for the patient.

“The family members they have high expectations 'cause the care they normally receiving. The organisation may support us. Yeah. But at the end, the news they receive are not what they expected. This is really a challenge /.../ They expect much to see or tell them. Now the parent had died, let's take over our one child, supporting one child. It stops with the patient. And according to the palliative care they even say: improving the quality of the patient and family. So to me I normally see that. Once the patient dies, the family is neglected. Because the patient, there is no more patient. They no longer go back to support the family.” (Jackie)

Even students from the palliative care course talked about high expectations, but in this case when they come back to their working place. Colleagues will have high expectations from them and about their knowledge.
“When you go to school, people expect a lot from you. They may think that you are going to bring, /.../ When you reach there, like this, everyone eager to get in touch with you and in a day, maybe you are planning to do something, the days is gone without even doing it because of the population around you.” (Lee)

**Nurses experience in delivering psychosocial care**

Terminal diseases affect the patient and their family socially as well as psychologically. I asked about these issues separately, but it became obvious that social and psychological issues often go hand in hand with each other. Even the treatment of the patient will be affected negatively when there are psychosocial problems according to the philosophy of holistic care. Hence, it is important to map patient’s psychosocial concerns. Existential questions affecting mainly the patient whereby some psychosocial issues like financial issues, children, abandonment, the patient’s housing and sexual problems concern the whole family. According to the respondents common concerns patients can have are:

**Existential questions**

At the end of life existential questions can come up. A patient in denial is a common psychological issue nurses meet in their work. They can even ask, why am I getting this disease?

“They really have these questions in mind. Why me to have this terminal illness?” (Charley)

**Financial issues**

According to the experiences nurses have, patients come in late stages to HAU. Before, they were looking for treatment, which can be expensive for the patient. The fact that many health professionals did not disclose that they are terminally ill can make it even worse. By the time the patient comes to palliative care they are poor which causes a lot of psychosocial problems.

No matter what their financial status is, the family will be affected socially. Loss of income has severe consequences for every family.

“But once someone becomes terminally ill, there is a state where is socially and economically affected. Whether you are poor or you have been rich. You might come, I might be here having a good, being a big person, a director. I have a good house, good chairs but when I fall sick. I don't have longer a job, no work. I am at home. When you come and visit me at home, you sit in good chairs, you see they have this you have that, this one is okay. But, when I am financially affected because I no longer have work, no longer have a job, no longer have a source of income. So it doesn't matter which level the patient has been. As long as the patient is terminally ill, that patient is affected economically.” (Jackie)

**Children**

If there are children in the family patients worry about their care in general after their death. Who will be looking after them when the patient passes away? The patient's loss of income causes trouble for the family. One issue is the payment of school fees after their death. If there is no relative that can support the family
financially, the patient knows that the family will suffer after their death which affects the patient psychologically.

"The children are here, they are not in school. They are still young, no one has grown up to care for this other. So this social issue will also affect his treatment. If there is nobody who can come up and support some who can giving some finance. To carry on with that treatment and then some of them they feel bad seeing the family suffering at that time. When he was still okay was able to work and do everything and the family would live in harmony. Sometimes children are there, they are out of school. And you will find someone says: I wish I can die so that I don't see the things happening. While others say: What can I do to keep my life there, to improve, so that I am able to stand it? And to be able to do something to my family." (Sidney)

Abandonment
A further topic mentioned in the interviews was the family abandoning the terminally ill patient. This can happen for various reasons, e.g. because of an offensive smell from a wound. The family cannot stand being in this environment and abandons the patient. The consequences will be that the patient is not being cared for by anyone.

“Then could be a wound /.../. Those who not really can cure but then the other aspect of it that offensive smell/.../and the other thing is that they can feel uncomfortably in their environment they are in. You just imagine, I mean, coming near to see a patient to the smelling. /../ but there look at the family members and surrounding so many run away from that patient/.../. If the family runs away from the patient that, that mean the patient is not being attended.“ (Charley)

In addition it was mentioned that the patients can be abandoned due to a separation when one partner starts having symptoms that affect their relationship. The following excerpt was taken within the context of cancer of the cervix.

“The majority of them they have broken homes. Because when they start bleeding they separate, most of them are separated from their homes.” (Ariel)

Patients housing
Moving the patient to a family house where he or she does not normally live was reported to affect the patient psychologically according to several respondents. Being in a different environment brings some issues to the patient, which is illustrated by the statement of Cléo:

“You may find a patient which is brought from his own home and being cared for by their relatives that one gets psychological torture because. He has no access to each and everything in the house. He is limited to certain areas and if he wants to do something he's not allowed and sometimes he even has no money to do what. Like even transport if he wants to go to the hospital he is not working he does not have any job and there is no way of to go somewhere. So that one, psychologically tortures the patient.” (Cléo)
Sexual problems
When talking about psychological issues patients can have, the topic sexuality came up. A common example in the interviews was sexual issues in cancer. Cancer of the cervix and cancer of the prostate lead to that both partners in a relationship are affected because sexual needs cannot be satisfied. Separation is a possible consequence.

“Then of the side /.../ of sexuality. Maybe you find a male patient, they can not function the way they used to be and maybe this is a family, there are a couple. I mean they can not stay together, they cannot function the way they used to be.”  
(Jessie)

Nurses role in delivering psychosocial care
Counselling is considered an important role of nurses in palliative care. It can solve psychosocial problems patients and their family can have. But how do nurses meet the patients needs? How do they answer difficult questions patients can have? How do they break bad news? What does counselling involve in the Ugandan context?

How to answer existential questions
One way to meet patients questions like “Why me?” is for nurses to involve faith in a discussion, as shown in the following excerpt.

What do you answer, when they ask you “why me”?  
(Interviewer)

"It is a very tough question actually/.../but usually we try to tell them: You shouldn't blame anybody. Nobody on this earth wants to see you the way you are. And you can also bring in those spirituality bit saying: God is not here to judge you or, it is not a punishment because we as human beings we can face different problems at different times. And some of these problems are the challenges come to test us, how firm are we how faithful are we so that, God will be able to see whether we are able to go through this tough times, but it is not easy. Why me, but me usually it comes back at me but I don't say to the patient...Then I pray. Though we are all individuals. God decides who gets the disease and who is not. Some are there to support the patient like the carers some are health workers to support the patient the illness. He is a kind God who gives us people to support us.”  
(Charley)

“What do you say?”  
(Interviewer)

“For me what I usually do is throw the questions back, asking Why are you asking this question? What makes you ask this question? Tell me more, what exactly is going on in your mind? What are you thinking? Because from what they share with me, we are able to support them.”  
(Charley)

Breaking bad news
Counselling patients in denial need time because accepting the diagnosis is a process. It is not always possible to get the patient to accept the diagnosis at the end, but the nurse’s role is to try her or his best. Some are stuck in denial even all
the way to the end. However, a way of breaking bad news is described by Charley:

“So what happens is give them some time. First of all we have something we call, breaking bad news. You find out whether the patient would like to know. When you tell them and then the patient says no you don't feel that this is the truth, you give them some time to reflect to find out. Then another time, when you go back, you still try to find out how much they know about their diagnosis. Yeah, but there are some patients, they are get stuck in their denial, accept their diagnosis. Some of them, we have to leave them like that, because you can't force information to somebody who is not willing accept.

/.../ Sometimes they don't accept because I have seen very many patients expecting that, like, I will give an example there is a patient who said: I know God is going to cure me from this disease, even on her death bed continuing to say she going to heal. And the end she even refused the morphine, she refused everything, but of course she ended up dying. We tried our very best, but she was stuck in denial and bargaining.” (Charley)

The way Jackie discloses to the patient is that (s)he asks the patient about what they already know about their disease. If there are misconceptions, (s)he rectifies them and makes clear that everybody has to die at some point but the person still matters a lot. The nurse explains as well what palliative care can offer for them until God decides when it is time to leave the world.

“For us, we are here for you. And you still matter a lot, we are ready to do what we can manage until the last moment. /.../ You are not the first person and you are not the last person. And it is not only cancer which kills people. People have died of accidents, people have died of malaria and there are people who going to die...when you... so that shouldn't scare you...It was the disease that has come. The disease had come, what should we do? controlling pain, controlling symptoms until God decide you... you will wasting money.. you ready for palliative care.” (Jackie)

Even giving information concerning the disease may relieve psychosocial issues. They consider it as important that the patient and their family has insight about the disease and what is going to happen, otherwise they have too high expectations.

"I am supposed to give information concerning the patients illness and if they would like to know what is happening with their lives is talking about the diagnosis, the prognosis and the outcome and also give proper information concerning treatment options. /.../ and then patients make their own decisions, not me to make their decision. I am supposed to offer support through counselling.” (Charley)

“Of course you have to tell them, what is going to go, what is going to happen and what will come up. Because by the time they come here, they have to have insight of their problem.” (Kim)
If patients do not have insight into their disease they keep on looking for a cure, with the above described consequences. They should be well prepared for their death and this is the role of the nurses.

"Because when they don't have the insight, they have high expectations. They think maybe when I come to Hospice I get cured. So the first thing you have to ask: Do you know what you're suffering from? Do you have insight of your illness? From there, you'll explain, if you wants to know. Sometimes we get relatives who don't want the patient to know. But we insist because we know what he's going through. Why does the disease not cure? Usually when we as hospice come. We have to make sure."

(Kim)

**Acting as an intermediary**

When the patient is feeling uncomfortable in the family house, it is the nurses role to represent the patient’s interest. The nurse can act as an intermediary between the patient and the family by encouraging them to discuss the issue, attributing no blame.

“What we do, we talk to the patient himself, he tells us the problem then we find a way how to talk to those people who was staying with the patient. We try to discuss with the relatives and to find the way how the patient can be helped. We don't blame them, we don't just go to blame them but it has to be discussed with them and then we find a way how that patient can be helped."

(Cléo)

**Bringing the patient back to the family**

When a patient is abandoned due to an offensively smelling wound, the nurses role is to show how the patient can clean the wound properly so that it does not smell and the family are better able to cope with their care. A different way is to demonstrate that the nurse can stand the smell and be in the surrounding of the patient and by time the family also can come back step by step.

“But at least you can help her how to clean /.../ that wound. How to use some [metronidazole] to reduce that smell. So that she is not isolated from the society, yeah. You can educate her on health on how to keep herself clean.”

(Kim)

Furthermore, HAU offers day care, where the patient can be referred to. The nurses opinion is, that it will help them to share ideas, experiences and make them feel that they are not the only person with a terminal illnesses.

“If it is worried about the illness and he or she thinks she is the only person that is sick, the only person that has that condition, we advise them for day care. Day care when the patient come they spend a day together. They eat together, they drink together. That can really be good. Because the person will appreciate that, they are not alone. Yes, and that will give them courage to go on.”

(Renée)

**Making referrals**

Even if nurses can solve a lot of problems by themselves, they may need to refer patients to other organisations in order to get some relief in patients psychosocial issues.
“And if there is some organisations that can help in some areas but this depends on which kind of care they give of which type of family. So we are there to guide them that where we say there is networking. We have to bring that, we network with other organisations, they can be there to help handle the social issues.” (Sidney)

**Education**

To minimise the sexual problems, nurses role is to talk about how the couple can find ways to each other. I noticed that it was important for the respondents that the couple can stay together by solving their sexual problems caused by the disease. This opinion may be an influence of their faith.

“I normally tell them please penetrated sex is not the only love to a lady or to a man. Yes even the kind words The tender love given to these patients is very important because you know in our African culture someone sleeping with a woman penetrated sex is the only thing the man shows he loves the wife. We try to talk that please give the lady comfort. I normally give them examples.” (Ariel)

**Challenges in delivering psychosocial care**

Challenges in delivering psychosocial are mainly based on poverty. By the time patients come to palliative care, they may be poor because they have spent considerable amounts of money on searching for cure. They cannot pay the recommended fee of 5000 Ugandan shillings to HAU.

“By the time they come to hospice, they have spent a lot of money searching for a cure and the truth. The medical officers don’t tell the truth at the earlier stage. They keep on telling them: Go for this or go for that, instead of advising them on exactly what to do and reassure them of their condition. So for them it takes time to accept that there is no hope for a cure.” (Kelly)

Poverty is also one reason why patients may not benefit from radiotherapy. The cost of living in Kampala are high for people from other regions. Some patients cannot afford buying the drugs that are prescribed by the nurses.

“Maintaining for patients in Kampala is a big challenge.” (Sidney)

“Sometimes they have drugs, but they are very expensive” (Jody)

It is a challenge for nurses when they wish to support the patient and the family but they cannot due to financial boundaries. Their efforts can feel insufficient.

“You really want to help, but financially you can’t support that patient. So it becomes a challenge to you. So you keep on giving comfort, comfort insurance, which is not enough because at time you need money or anything which can help, but we can’t.” (Kim)
Nurses experiences in delivering spiritual care
Since spirituality is part of the holistic care I was interesting in seeing how spirituality influence the patients care and the nurses work. Spirituality was defined as the relationship to God by the majority of the respondents.

Patients spiritual needs
Nurses themselves also have strong spiritual needs. When they are not met, they feel bad and that is why they can put themselves in the shoes of the patient.

“To me, the spiritual needs is important because without having that faith in you. That one is at a certain moment you need to sit and reflect and see how strong are you in your faith. How much do you know God? When you fail to go to the church services because of one thing or the other, you feel affected and when I relate this and see that this patient also is in the same situation I am.” (Sidney)

Social aspects of spiritual problems
When the patient is terminally ill and therefore no longer can go to church or any other religious institution, it means that he or she is no longer part of the community and therefore isolated. Eventually problems cannot be attended, that usually can be relieved within this context.

“Someone is used to go to services at all times when it is time to go for that or when it is necessary. You are not longer able, you're missing something. You're no longer sharing things do with your religion with your group. You are like isolated /.../ and then nobody is coming towards you, to help you, to give you support you with your spiritual needs.” (Sidney)

Blaming
Jackie mentioned that HIV/AIDS patients can be blamed by the spiritual leader, who may be of the opinion that the patient had behaved immorally. This can be a reason why they hesitate to visit the spiritual leader and their spiritual issues are not attended.

“Like the HIV patients for example, maybe that disease is so much condemn through sexual transmission. /.../ And then people are blaming you, you feel even when you go to your spiritual leader they condemn you saying: You have been breaking some of these laws.” (Jackie)

Patients can even blame God for being in this condition.

“The spiritual issues, especially in terms of blaming. Why me? Why me God? Why is this happening to me?That is what I understand by the spiritual.” (Kim)

Curse and bargaining with God
Some patients see the disease as a curse from God and other bargain with God to get cured, even at the end.

“When a patient has a spiritual pain like I will give an example bargaining with God, saying why did they get this disease. If you take it away I will serve you in a
most better place. Yet we know the disease is not going to go away ‘cause it is an incurable illness. And yet this is a spiritual problem the patient is having. So it affects the whole person, human being.” (Charley)

Changing religion
According to nurses experience patients change religion because they spend a long time searching for a cure. Some religious people promise cure if they convert.

“Some of them when they fall sick, they keep changing from one religion to another. Because they have heard that other religions they pray for people, and they get healed. So when somebody was a catholic and fall sick and they tell her there is no more treatment, become a born again.” (Robby)

Jackie talked about one patient that changed faith to “small Gods” because they did not pay church funds. It may be an alternative for the patients to return to their traditional religions when they don't have access to their usual one.

“So we contacted the catechist. /.../ He refused. They have not yet paid church funds. Those people they still believe, what we call [inaudible] they still believe in small Gods.” (Jackie)

Nurses role in delivering spiritual care
In spiritual care nurses can do a lot of small things which can make a big difference for the patient.

”The things looks small, but they can make a huge [accentuated] difference” (Jessie)

Assessment of spirituality
Assessing spirituality is the starting point for any other actions. By asking certain questions the spiritual needs of a patient can be examined. Questions that could be asked according to the spiritual assessment case sheet are:

“What faith are you raised in? To what faith do you now belong? Has the illness changed the way you believe/your relationship with God? Would you like someone to pray for you if so, whom? What gives you hope? Are you at peace with your God? If you do not believe in a God Are you at peace?”(HAU, 2006)

If the patient changed the religion in connection with their disease it may be a sign for spiritual pain according to the respondents. Spirituality as part of holistic care means that it is difficult to treat the patient’s symptoms when the patient has spiritual pain, for example is still searching for his or her God. Kelly talked about a categorization system that can give guideline about the spiritual needs patients can have.

“Someone who is just like a child could be in spiritual stage one and the person who just following (in)structions could be spiritual stage two. The person who is still searching, looking for cure /.../ is put in spiritual stage three. And the person
who is comfortable and doesn't mind whether to die or not, he is going to meet God, that one is in spiritual stage four. And what we have noticed is, people who are searching it is hard to treat their pain and symptoms, we normally keep on” (Kelly)

**Praying**

To pray with a patient is according to the respondents a role that the nurses have. Praying is often requested by the patients, however nurses ask for permission to do so. Even praying with somebody from a different religion is appreciated according to the nurses. Nevertheless they try to have somebody from the same faith when they go to the patients home because the patient is more comfortable and nurses know for example special prayers for the sick in this particular religion. Praying gives the patient some spiritual healing.

“If it is a Muslim and we can't pray in that language. It is only the way we pray, but it is the same God. We share with them and most of them feel happy.” (Sidney)

Praying together helps the patient in their spiritual pain as well as the nurse to cope for caring for terminally ill patients. They can get their strength from praying. Praying was even described as their culture in HAU, where they gather themselves and pray together in the mornings.

“The same thing here in Hospice, it is the culture. As we come begin the duties we have to pray as a group and then we disperse for our work. Then also when we go in the homes of the patients, we visit then we look at them we see them. We do what we are supposed to do. And then after at least we have to say a prayer together.” (Sidney)

**Spiritual counselling**

Nurses can counsel the patient spiritually when patients bargain with God why they got the disease. Lee says that they can not give an answer to that question, but nurses made clear that it is not God who gives diseases. Lee explains what spiritual counselling is in the following excerpt:

“However, we do what we call, spiritual counselling. Counselling is not giving the person an answer. But you give information to somebody to make his or her own decision. So to me, why me? /.../. After digging out the cause, I counsel. I cannot give an answer, because we have answers within yourself. You can give information about the cause, than you choose how you can cope up with the situation. That's what I can do with “why me”. Because I cannot go to God and say: Why this person? It is impossible. It is just a perception that people will have it in mind. It will may not coming from God. A disease I don't think God gives diseases, I doubt that, because diseases have causes and ... factors. So “why me” it is just counselling” (Lee)

Nurses explain to patients that God will not punish them, it is just a test how faithful the patient is and he or she can go through it.
"And you can also bring in those spirituality bits saying: God is not here to judge you or, it is not a punishment because we as human beings we can face different problems at different times. And some of these problems are the challenges come to test us, how firm are we how faithful are we so that, God will be able to see whether we are able to go through this tough times, but it is not easy." (Charley)

**Referring to a spiritual leader**

In some cases nurses can refer the patient to a religious leader or arrange that the religious leader come to the patient’s house. When transport is the problem it can be necessary to arrange transport for the patient to the religious leader. Nurses even help to see that the patient receives the holy communion and the last sacrament.

“I can connect them to the responsible people, the pastor or the priest. But if they need the holy community, which I can't do, I can call the responsible spiritual leaders.” (Renée)

**Encouragement**

When somebody blames the patient or when the patient blames him or herself, nurses give hope by encouraging them that they are not condemned and that God forgives them so that they can find peace spiritually. Nurses consider it important that patients do not lose hope and continue praying. By reconciliating the patient with their god patients can die peacefully.

“You continue, you encourage them to continue praying. Not to blame and not to curse. To draw nearer now to God in their situation cause this is a time when you have to pretend and try to be at least by the time you leave this world, you have tried reconcile their God.” (Morgan)

**Challenges in delivering spiritual care**

It can be challenging to deliver spiritual care because it requires special knowledge and nurses are not trained as spiritual leaders. There are many religions in Uganda and it can be difficult to pray with a patient who is not of the same faith.

“It is a challenge. For us we are trained as medical persons here, we are not trained as spiritual workers and the spirituality is something which is very very broad, eh? Whereby it's need someone who is trained as a spiritual leader. So sometimes you find it very difficult.” (Francis)

Younger patients can be difficult to counsel spiritually because they do not open up according to Charley. They can still be searching for a religion which feels right for them and keep on changing from one to another.

“The younger one, I can say the teenagers eight and those up to thirty years of ages, sometimes they don't open up so much concerning their spiritual needs and spiritual problems and find that, most of those age groups searching, moving from on religion or church to another trying to find out the truth. You come and to find out, they will not tell you the truth. Finding you have sometimes conflicting
information. What the patient tells you is different from what one of the relatives tells you. So the age group is one of the problems.” (Charley)

**DISCUSSION**

In this section the method will be discussed by considering trustworthiness, reflexivity, data gathering and ethical consideration. The results will also be discussed.

**Methodical discussion**

In the present chapter the method will be discussed on the basis of terms like trustworthiness and reflexivity. Also problems in the data collection method and in ethical considerations will be illustrated.

**Trustworthiness**

According to Polit & Beck (2006) trustworthiness is used in qualitative research and includes credibility, transferability, dependability and confirmability.

*Credibility* refers to the confidence in authenticity of the data (ibid). Lincoln and Guba consider a *prolonged engagement* as an important step to enhance the credibility. During my seven weeks in the field I gained an understanding of the culture, language and built a relationship with the informants. Even a *persistent observation* of the situations regarding the phenomena increases the credibility. During my stay I attended the home visits and observed the nurses in their work as often as possible. At Mulago hospital the observations lasted just three days due to lack of time. Another technique is *triangulation* which means using multiple methods and perspectives in order to increase the credibility. There are multiple triangulation forms and I have chosen to use the method triangulation. Interviews, observations, education material, brochures are brought into the study. When I asked about the different issues patients can face at the end of their life, the results are based on the nurse’s perspective. It may be a source of error that the patients’ voices are not heard. A data source triangulation would be a better option, where I would have interviewed patients and nurses about the topic. I refrained from interviewing the patients because they usually do not speak English and I would have needed an interpreter, which is also problematic in some points of view. However the nurses have quite a long experience in working in palliative care and the fact that issues mentioned in the presented results are reported from more than one nurse give substance to the nurses perceptions. Other external checks like peer debriefing or member checks were not considered due to the built in limitations of this small study (ibid).

*Transferability* indicates if the results can be transferred to other groups or settings (ibid). Most of the respondents come from the Kampala district and it may have different conditions than other parts of Uganda. It is imaginable that in Kampala district the social status of the patients is higher and there are more health institutions to be referred to than in other districts. The work of the nurses may therefore be different. In addition, the majority of the respondents work in HAU, an NGO, which is likely to be different from a hospital setting. The group
of respondents is homogenous in the way that they all underwent the same education at HAU and they are all equipped with more or less the same knowledge. This may have influenced the way they answered the questions. On the other hand, HAU is the only institution providing palliative care education in the country (HAU a, 2008).

*Dependability* measures how stable the data is over time and under different circumstances. *Stepwise replication* means to involve several researchers, who conduct the data collection separately and at the end the conclusions were compared. Being just one researcher in the field does not allow this kind of advantage, so that the results are based on one single interpretation. Having an external reviewer enhance the dependability in a way that she/he examines the data in additional. My supervisor made a further check on my material and hence takes a similar role as in the *inquiry audit* (ibid).

*Confirmability* is a value that indicates the objectivity or neutrality of the data. The above mentioned *inquiry audit* has also a bearing in confirmability when a *audit trail* is used. Even if I do not have a formal audit trail, a systematic description about how I analysed the data is presented in the method chapter. I also kept all the material where the analysed steps can reconstructed (ibid).

*Reflexivity*

Another aspect that needs to be considered in qualitative studies is *reflexivity*. It means that by critical self-reflection preconceptions, preferences and bias are discussed and then brought into the study by the researcher (ibid). Being an inexperienced researcher may lead to inappropriate questions being asked or I may have missed important details in my observations because of my unfamiliarity with the clinical environment. However, I underwent a learning process and hopefully developed my ability during the time of my study. During transcribing the interviews, I noticed leading questions and tried to avoid them in the subsequent interviews.

Coming from a western context to Uganda may be problematic. Styles of communication and accepted behaviour might be different between cultures. In addition, the fact that I have a different culture frame in contrast to the informants may have influenced the outcome of the study. For example the fact that I am an atheist and my informants are religious may lead me to a different interpretation of especially the spiritual part. I realized that being white in Uganda means attracting a lot of attention in the streets, which may have influence on the interview situation. On the other hand, the staff at HAU are used to white volunteers and staff and I did not have the feeling of being different at HAU. Maybe the circumstance that I was mostly younger than my respondents, had a bigger influence on my study since I realized during my stay in Uganda that age is more respected than in my country.

*Data gathering*

There are several problems when it comes to data gathering in the study. There was a language barrier between me and the nurses talking with the patients, which was mostly in their local language. Hence, the observations were limited to the
actions nurses were performing but I could not interpret the conversations, which
would be interesting in order to discover any discrepancies between what the
informants say in interviews and what they say to the patient.

The interview situation can be discussed from different points of view. First of all
the interview guide was not pilot tested. However over time I figured out what
was interesting to know more about, I found relevant questions after time and
have made notes about the interview situation directly after the interview to
consider details that may influenced the answers I got. By doing this
circumstances can be taken into consideration that may influence the outcome.
One example is that one respondent asked about possible benefits from the
interview. I made clear that the study may just add knowledge to share to other
nurses working in palliative care and not give personal benefits. A further
example I noticed about the interview situation was that when I asked the
respondents to reflect on their own perceptions and opinions that they answered
mostly along the lines of the material of HAU.

When it was time to collect nurses for the focus group several problems appeared.
There was not any problem with the nurses’ willingness to participate but it was
rather problematic to gather them at one day and time that suited everybody. The
day was postponed several times due to lack of time. It may be easier to just
decide a day and time for them, but I considered it more important that the
participation was voluntary. Due to these problems I decided together with my
supervisor in field to have small focus groups, each with three participants rather
than no focus group. This was also the first time somebody other than me decided
who participates in the study. Furthermore it was difficult for me to encourage
them to discuss with each other. It was more like an individual person to person
interview situation, than an interaction between the interviewees.

Information was sought from nurses working under different conditions (at HAU,
at Mulago hospital, and students who do placements in different branches of HAU
and other networking organisations) and different years of experiences and come
from different regions in Uganda.

Ethical considerations
The coding of names do not give a hint of which sex the respondent has, which
might be interesting to know for different reasons. However I decided not to
reveal the respondents sex in order to maintain confidentiality.

Discussion of the results
In this chapter the presented results will be dicussed under the categories: nurses
role in general, nurses role in delivering psychosocial and spiritual care. Last but
not least the earlier presented articles will be discussed in relation to the results of
the present study.

Nurses role in general
The findings document what the nurses’ role looks like in palliative care in
Uganda. They deliver a holistic care integrating the physical, psychological, social
and spiritual factors affecting the patient. As shown in the results nurses believe
that physical pain is not relieved when the patient has psychosocial issues. They have to take into consideration to assess all parts when delivering palliative care. Dame Cicely Saunders’ idea about total pain is highly topical in the field of palliative care in Uganda. That is why HAU offers social programs and day care and different activities for patients and need. One respondent talked about the supply of morphine is not a problem in Kampala district. It is rather challenging that funders can withdraw funding and hence these programs may not be continued. These programs are as important as morphine supply for delivering holistic palliative care and more donors and the Ministry of Health has to be aware of this. Another interesting aspect of holistic care is where it ends. Integrating the family in the concept of care makes sense, both culturally and financially. It was described as challenging from one respondent that the care ends with the death of the patient and as a consequence the family has high expectations from palliative care to be continued. In my opinion the boundaries of palliative care need to be examined in each country. In countries with a safe social security net other institutions can take over the families needs after the death. In Uganda there is a need for institutions that carry out similar programs for families with these needs. According to me it is not reasonable that this is also a task to be fulfilled by palliative care.

Nurses are allowed to prescribe morphine and other palliative care drugs after undergoing a clinical palliative care course at HAU. This makes the role of the palliative care nurses special in Uganda. By this, the role between the physician and nurse overlap. The traditional role of a nurse in palliative care is changing and this may be problematic and it might interesting to do further research on this field.

Regarding morphine there is the aspect of security in terms of the colour of the drug. There is a risk to mix-up the morphine plastic bottle with the soda bottles especially when children living in the household because they have a similar colour. It may not be the case in Uganda, because there is a warning sign on the bottle but it would be important to consider a different colour in order to minimise the risks. The aspect of security is also important when it comes to advocacy. It may be easier to advocate for drugs when there is a minimised security risk.

The HAU team does home visits and meet in this way the identified need to die at home in Kikules (2003) study. At Mulago hospital palliative care is inpatient care as long as the patient is admitted. Patients can be referred to HAU afterwards but there may be a need for a mobile home care team based at the governmental hospitals around the country. HAU has just three branches with a limited catchment area. On the other hand there are 104 hospitals (Ministry of Health, 2008) in the country, which could cover a bigger geographic area, if they had a mobile hospice team affiliated with the hospitals.

The team at HAU is multidisciplinary which means sometimes several nurses, a physician, students and sometimes a social worker. It is even part of Dame Saunders philosophy to have a multidisciplinary team but the fact that there is a shortage of nurses in Uganda with a density of 0,55 nurses per 1000 (Mason, 2008) inhabitants makes me asking: Why cannot nurses do home visits more
independently? They have the knowledge and the legal competence to do so in my opinion. Isn't it more efficient to strive for a more independent work so that more patients can be attended in terms of a shortage of resources? The problem hospice has is limited resources, especially transport. Teams also go out together to reduce the stress on the individual. In terms of lifelong career of the nurses this must be a high priority.

Nurses advocate for palliative care, morphine and HAU. This work seems necessary because palliative care is still new and a lot of people don't know what it is about. It was furthermore described as challenging that people have misconceptions about the work nurses do. It would be interesting to explore if advocacy has an influence on the work nurses do.

Many cancer patients come in late stages to palliative care. This is possibly a result of the ignorance about cancer. If people would know more about cancer and the importance of early screening, patients would have a chance for cure and not be in need of palliative care. By the time they come, issues have already occurred, for example separation due to symptoms than cannot be handled within the relationship. It is often more difficult to repair issues than to prevent. In the case of HIV/AIDS, the prevalence has reduced in Uganda as a possible results from the National Strategic Framwork that has contributed (Uganda AIDS Commission, 2004). However the prevalence of cancer does not seem to have the same positive development and the consequences for the individuals and the society are fatal. It is obvious that the Ugandan Ministry of Health need a similar strategy to impede the consequences of the cancer epidemic in Uganda. There is a need for enlightenment and screening programs, which should be offered all over the country for early detection. Cancer of the cervix and prostate cancer are the most common cancer forms in Uganda for women and men respectively (WHO, 2008). These forms of cancer might have high chances of cure, by early detection, the cancer prevalence will rise with a increase in life expectancy, even in Uganda and the health care system should be prepared for that. In my opinion, one step is to continue to advocate for palliative care, not only from HAU. Palliative care is part of the medical program at Makerere University and Mbarara University, which is important in the way that all health professionals should gain knowledge about palliative care so that they do not hold back on the patients in the curative setting and instead refer them earlier to palliative care. I am aware of that it is always easy to demand a higher engagement of the Ministry of Health from a western point of view, but on the other hand if poor health is the main reason for poverty in Uganda according to the Ministry of Finance Survey from 1997 (Afro WHOa, 2008) and a higher engagement may contribute to a economical prosperity of the country.

The qualitative study of Fournier (2007) showed that nurses caring for AIDS patients at Mulago hospital encounter challenges like poverty, insufficient resources, lack of ongoing education and the fear of contagion which lead to moral distress. Nurses in my study meet mostly cancer and HIV/AIDS patients in their daily work. The challenge of poverty was even reported in my study, whereby no nurse mentioned the fear of contagion when talking about their patients. This could be a result of education through the nine month course at
HAU where HIV/AIDS is part of the program. I find it interesting that nurses in my study do not feel disstressed by this which accentuate the importance of education. The lack of resources was also mentioned in my study but in terms of administrative challenges like a lack of institutions offering treatment, space, transport.

*Nurses role in psychosocial care*

Social and psychological issues often go hand in hand with each other. Common psychosocial issues patients can have are existential questions, financial issues due to the loss of income, the support of children, abandonment, and the patients’ environment that can be problematic. Especially in the terms of cancer, sexual problems can occur. Some social issues patients can have can be traced back to the fact that families are poor and that there is a lack of a social safety net. Kikule (2003) concluded in her study that 30 percent mentioned loss of income because of the illness which causes financial needs. That is why nurses have to integrate social work in their role. HAU offers financial support, nutritional support, a school fees program that can reduce some of these problems. It is problematic that these programs are based on funds and that funders can withdraw, but the need of the patients and their families is still there. The government of Uganda is involved in the morphine supply within the districts of Uganda. In my opinion a social safety net is as important as morphine supply, but I am aware of that it is expensive for a resource poor country like Uganda to cover social programs all over the country.

From experiences nurses developed strategies of how they can help patients in psychosocial issues. In terms of poverty the nurses are challenged, but they can refer to other organisations and supporting programs. But in counselling nurses can make a big difference for the lives of the patients and their families. Kikule (2003) reported that there is a need for counselling to heal the relationships within the family. In addition to that nurses in the present study bring up difficult questions and break bad news, like disclosing the diagnosis for the patient. It involves also acting as an intermediary between the patient and the family and educating about sexuality. Counselling requires fewer resources and nurses have a big chance to influence the quality of the patients life via counselling them. They can offer time with the patient, which is of great value in palliative care. In Sweden there is rather a lack of time with the patients than a lack of resources (although within Sweden, a relative limitation on resources is present) and here we have a lot to learn from Uganda. Spending time with the patient and their family is important in order to create a relationship, which is the starting point in delivering psychosocial care. When the Ugandan nurses break bad news they counsel patients by giving them time to accept the diagnosis.

I was surprised that disclosing the diagnosis to the patient is a role nurses have. By the time they come to palliative care, they should know what they are suffering of in my opinion. The reason why medical people have difficulties in disclosing to their patient is interesting to examine in a future study.
Nurse role in spiritual care

Spirituality is also an aspect of the holistic approach in palliative care. Patients can feel isolated by not being in the community that the church offers. They can feel blamed by their spiritual leader and they can even blame God for having a terminal disease. Another possible issue is that the patient can see the disease as a curse from God and he or she can even bargain with God to get cured. When looking for a cure, patients can even change religion.

Here the nurses role is to assess the spiritual needs of the patients and counsel them accordingly. They pray with the patient, they do spiritual counselling, they refer to the spiritual leader and they give hope by encouragement. These roles are even as special as prescribing morphine in my opinion because the nurse is not a spiritual leader and not educated as one. In Uganda there are many religions that try to have an influence on the patient and try to convert him or her even on the last days of their life. They highlighted in the interviews that nurses should not convert the patients and that they would discourage others to do so at the end of the patients life. Ethically, they respect the patients self-determination and integrity. This can be a balancing act because nurses have own spiritual needs and these values could influence their work. One example is the advice nurses give when a couple is going to separate and they encourage them to stay together. This advice may be influenced by the Christian value of the family as a unit and nurses should be aware of this when giving advice.

It seemed reasonable that the nurses try to visit the patient in the same faith like themselves because it creates trust and it may be easier to counsel someone spiritually when you speak the same language in terms of religion. At HAU and Mulago hospital the team prays together in the morning which likely has an influence on their work. Palliative care is multidisciplinary according to the above described philosophy and praying together may create an solidarity within the team. In the western country, like in Sweden praying is rather part of the private sphere and this may contribute to the fact that I over- or misinterpret the meaning of praying together.

CONCLUSION

From the present ethnografic study we conclude that the role nurses have in palliative care in Uganda is multifaceted and encountered by many challenges but also many possiblities to improve the quality of life for the patients and their families. Furthermore we gain a better understanding of usual psychosocial and spiritual needs patients in Uganda can have. Nurse's specific role in delivering psychosocial and spiritual care and the respective challenges are described. The main theme in this study is that palliative care demands more from a nurse in Uganda than nursing care. They have to implement holistic care by taking into consideration the physical, psychosocial and spiritual pain patients and their families can have. With the step of allowing the Ugandan palliative care nurses to prescribe morphine and other palliative care drugs, they can manage the physical pain themselves and have in this way the possibility to manage the patient holistically themselves. A result of that one single profession having multiple tasks
is that they have a better overview of what is happening to the patient and can easily make changes for the improvement of the patient's life.

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