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A Spider in the Web: Role of the Palliative Care Nurse Specialist in Uganda—An Ethnographic Field Study

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Abstract

Background: Palliative care is not a priority in developing countries. Hospice Africa Uganda (HAU), where nurses complete a course in clinical palliative care, is considered a model for other African countries. Aim: To explore the role of the palliative care nurse specialist (PCNS) in Uganda. Methods: This ethnographic field study uses observations, interviews, and group interviews. Participants: In total, 20 participants are included in this study. Result: The role of the palliative care nurse specialist is multifaceted. Beyond prescribing drugs, their role is to deliver holistic care. They encounter numerous challenges in their work, but they also have the possibility to improve the quality of the patient’s life.

Keywords
challenges, holistic care, Hospice Africa Uganda, nurses’ role, palliative care, Uganda

Introduction

A considerable body of research is available in the field of palliative care. Researchers have pursued ideas disseminated by Dame Cicely Saunders to study palliative care from both philosophical and empirical perspectives.¹ However, studies in the developing world, and especially in Africa, are few. The fact that only 20% of all 7000 hospices in the world are situated in the developing world might account in part for the paucity of studies.² The World Health Organization (WHO) recommends a high priority for palliative care in developing countries, but most African governments and organizations do not focus on end-of-life care.² The African Palliative Care Organization (APCA) also asserts that palliative care research in Africa is neglected.³ Uganda is the only African country to give palliative care a priority in their National Health Plan² and the first African country to allow nurses to prescribe morphine² after they successfully complete a clinical palliative care course.⁴ Although some quantitative research has been done in the field of palliative care in Uganda, only a few studies have taken a qualitative approach.⁵⁻⁸ None of these focus on the work of nurses. For that reason, among others, more research is needed about the palliative care nurse specialist (PCNS) in Uganda.

Studying the role of the PCNS in Uganda could potentially contribute to the body of knowledge from which other countries might learn. Although all African countries differ, most are in need of starting up or developing a palliative care system. Studies of professions such as the PCNS in Uganda enable other African nurses to learn from the Ugandan experience. As the Ugandan palliative care model is considered a role model for other African countries,² there is a need to better understand the role of palliative care nurses.

Moreover, industrialized countries could be inspired by the Ugandan example of providing good palliative care services and care for patients in their homes while using minimal resources. Kikule⁹ conducted a study aimed at identifying the palliative care needs of terminally ill patients in Uganda. The main results of the study showed that patients in Uganda prefer to die at home, pain-free, without stigma, and remain as independent as possible for as long as possible.⁹ Even in the industrialized world, numerous studies have shown a preference for dying at home.¹⁰⁻¹⁴ Hence, we need to know more about how nurses deliver holistic care, not only in hospitals but also in patients’ homes. In this context, studying the PCNS approach in Uganda could help answer existential questions concerning universal issues in end-of-life care, for example, how to care for someone’s spiritual pain.¹⁵ As Western society becomes increasingly multicultural, nurses need a broader understanding of the problems that patients from different cultures can face at the end of life.

This study aims to explore the role of the palliative care nurse specialist (PCNS) in Uganda within the context of the experiences and challenges that PCNSs face in delivering palliative care.
Methods
A qualitative approach was used to investigate the role and experiences of the PCNS in palliative care.

Ethnography
An ethnographic study was conducted in Kampala District during April and May 2009. Ethnographers used an array of data sources, for example, observations of events, informal and formal interviews, and collection of documents. Ethnographic work takes place in the field, that is, in an everyday context. The study participants are usually small groups, 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. The intention is to explore how the participants view their situation, one another, and themselves. Usually the initial study questions are refined, and possibly even transformed, over time.

Informants included 20 nurses, of whom 3 worked in Mulago Hospital, 11 worked for HAU, and 6 were qualified nurses and students attending HAU’s Clinical Palliative Care (CPC) course. Three of the nurses were male and 17 were female.

Observations
The study included observations during home care visits with the HAU team and ward rounds at Mulago Hospital, where field notes were taken. In total, 19 days were observed. The field notes from this resulted in 30 pages (A4 format) of notes. Home visits lasted about 2 to 4 hours depending on the number of patients visited and the total distance to and between the patients’ homes. Three visits at Mulago Hospital lasted about 4 hours each. Nurses mainly used their local language to communicate with patients and families, and we observed how they interacted with each other. To achieve a better understanding of the situation, we asked probing questions to the nurses afterward.

Interviews
In addition to the observations, 16 interviews were conducted in English. Fifteen of the initial interviews are reported here. Two were excluded due to technical difficulties, but one of these interviews was repeated because the subject’s 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 verbatim. A semistructured topic guide was used, where questions differed slightly from interview to interview. With time, CS (the field researcher) learned to use more follow-up questions and asked questions that she became more interested in during the stay. In total, we conducted 3 interviews with palliative care nurses working at Mulago Hospital, 3 individual interviews with students in the CPC course, and 6 interviews with palliative care nurses working at HAU. The interviews lasted from approximately 30 to 50 minutes.

A focus group interview was planned. According to Polit and Beck, a focus group involves 5 to 10 participants discussing and sharing experiences. However, due to difficulties in assembling this many participants at one time, 2 smaller group interviews in English were held. Each group included 3 participants that had not been interviewed individually before. One group comprised students from the CPC course, and the other included palliative care nurses working at HAU, Kampala. The interview with the students lasted one and a half hours, and the interview with the nurses lasted only 35 minutes due to time constraints of the interviewees.

Ethical Considerations
The declaration of Helsinki and the code of ethics for nurses were respected in this study. Ethical approval was granted by Malmö University and was forwarded to HAU via our supervisor in field, Berna Basemera.

Data Analysis Method
According to Burnard, data analysis starts during or immediately after the data collection period. The research topic emerged slowly in the field, known as “the funnel structure.” The main analysis took part after the data collection period. Themes in the text were identified via several steps: The interviews were transcribed verbatim, whereof half were transcribed directly after the interviews and the rest after the fieldwork. However, field notes were made after each interview, describing the interview situations and any particular items mentioned by the interviewee. All participants were given a code number to guarantee confidentiality. After repeated reading the field notes and interviews in order to know the data, CS summarized topics in the margins. The aim of this so-called “open coding” is to present a summary statement of all themes discussed in the text.

The second step in the analysis involved writing the identified summary words, as identified as patterns or statements on a separate sheet of paper, whereby any duplication could be eliminated. After this reduction in categories, the next step involved identifying similar categories that were grouped together. The material was rewritten and a more focused coding could begin. These final categories were re-identified in the text, marking each category in the text with its own color. Categories of the same color were then cut out and pasted on a new sheet of paper. The following categories were identified: challenges, why diseases, nursing, good death and palliative care, organizational culture, psychosocial care, spiritual care, and holistic care. Categories relevant to the aim of the study were selected and are presented in the results.

Results
Initially, the role of the palliative care nurse is to deliver holistic care to patients and their families. It involves physical, psychosocial, and spiritual care, and the nurses provide...
information, networking, and advocacy as discussed below under the respective headings.

Physical Care

Since it is not easy to counsel someone in pain, it is important to provide physical care before offering counseling. An important tool in physical care is the authorization to prescribe morphine, which the PCNS is authorized to do. This is usually not a role of the nurse in other countries, making Uganda unique.

As morphine is the most important drug for pain control in palliative care, it is difficult to deliver good palliative care when drugs are out of stock, which occurs at Mulago Hospital in Kampala and in some regions in Uganda.

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. (Nurse 9; Note: All of the interview quotations are taken verbatim from the transcribed interviews.)

Another challenge is that some patients cannot afford to buy the drugs prescribed by the nurses if the drugs are not financed by a non-governmental organization (NGO).

Sometimes they have drugs, but they are very expensive. (Nurse 16)

The major focus was on medication but wound care was mentioned as well, in the way it can release psychosocial pain.

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 society. (Nurse 1)

Psychosocial Care

To deliver holistic care, it is important to map the psychosocial concerns of the patient and family to be able to counsel them.

The fact that many health professionals delay in disclosing that patients are terminally ill can cause financial difficulties for the family. By the time the patient comes to palliative care, they are poor, which causes many psychosocial problems. No matter what their financial status, the family will be affected socially. Loss of income has severe consequences for every family.

As long as the patient is terminally ill, that patient is affected economically. (Nurse 15)

Poverty is a challenge in delivering psychosocial care and is one reason why patients might not benefit from radiotherapy. The cost of living in Kampala is high for people from other regions.

Maintaining for patients in Kampala is a big challenge. (Nurse 11)

Generally, as patients contemplate death, they worry about what will happen to their children; especially concerning who will take care of the children and pay their school fees. These worries affect the patient psychologically.

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 for my family. (Nurse 11)

The nurse’s role is to assess psychosocial problems and try to facilitate or arrange solutions within the family. Nurses may need to refer patients to other organizations to help relieve patients’ psychosocial symptoms.

So we are there to guide them that where we say there is networking. We have to bring that, we network with other organizations. They can be there to help handle the social issues. (Nurse 11)

Abandoning the terminally ill patient can occur for various reasons, e.g. due to an offensive odor from a wound, or because sexual needs cannot be satisfied within a relationship. As a result, these patients might not have anyone to care for them. The nurse’s role is to find solutions and talk with the parties involved about how they can connect with each other again.

When the patient feels uncomfortable in the family’s house, where he or she has moved into, it becomes the nurse’s 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. Furthermore, nurses bring patients together, e.g. in day care activities. This helps them share ideas and experiences, making them feel that they are not the only ones with a terminal illness, and this can encourage them to press on.

Some patients do not accept their diagnosis and remain in denial until the end. Nurses offer information, but they cannot force information on someone who is unwilling to accept it. However, Nurse 8 describes one way of 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. (Nurse 8)

Nurse 15 suggests that the way to disclose the prognosis to the patient is for the nurse to ask the patient about what they already know about their disease. If there are misconceptions, the nurse corrects these, and makes it clear that even though everyone dies at some point, the person still matters a lot as an individual. The nurse also explains what palliative care can offer them until God decides when it is time to leave this 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. . . . so that shouldn’t scare you . . . The disease had come, what should we do? Controlling pain, controlling symptoms until God decide you . . . you’re ready for palliative care. (Nurse 15)

Nurses consider it important for the patient and their family to have insight about the disease and what is expected to happen. Otherwise, patients can have unrealistically high expectations, or keep looking for a cure that does not exist. They should be well prepared for their death, and this is a role of the nurse.

**Spiritual Care**

According to the respondents, patients can face spiritual pain that caregivers need to assess to deliver holistic care. Isolation was mentioned as a consequence for terminally ill patients who can no longer go to church or other religious institutions.

Like the HIV patients for example, maybe that disease is so much condemned 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. (Nurse 15)

The respondents also reported that patients can spend a long time searching for a cure, and some change religions because they are promised a cure if they convert.

Some of them when they fall sick, they keep changing from one religion to another. Because they have heard that in other religions they pray for people, and they get healed. (Nurse 14)

One way for nurses to counsel patients regarding their existential questions such as “Why me?” would be to engage them in a discussion of faith and emphasize that disease is not a punishment from God. Another way would be to thoroughly examine the cause of existential questions, as illustrated by the following excerpt:

*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.* (Nurse 8)

Assessing spirituality is the starting point for other actions. The respondents noted that if patients change religion while dealing with their disease, it could be a sign of spiritual pain. Spirituality as part of holistic care means that it is difficult to treat patients’ symptoms when they have spiritual pain, for example, if they are still searching for their God. The respondents included praying with a patient as one of the nurses’ roles. Praying together helps the patient address their spiritual pain and helps the nurse cope with caring for terminally ill patients. Although praying with someone of a different faith is also appreciated, patients and nurses are more comfortable with someone of the same faith, for example because they both know special prayers for the sick in their shared religion. Praying offers the patient a sense of 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. (Nurse 11)

Nurses can offer spiritual counseling as patients bargain with God about their disease and why they have it. Lee notes that although nurses cannot answer that question, they can make it clear that it is not God who gives diseases.

Nurses explain to patients that God is not punishing them; it is more a test of faith, and they must see it through.

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 time, but it is not easy. (Nurse 8)

In some cases, nurses can refer the patient to a religious leader, or arrange for a religious leader to visit the patient’s home. Nurses can also help assure that the patient receives 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 Communion, which I can’t do, I can call the responsible spiritual leaders.* (Nurse 5)

Nurses give hope by encouraging patients so they can find spiritual peace, reassuring them that they are not condemned, and that God forgives them. Nurses consider it important for patients to continue praying and not lose hope. By reconciling the patient with their God, the patient can die peacefully.

*You continue, you encourage them to continue praying. Not to blame and not to curse. To draw nearer to God/. . ./ by the time you leave this world, you have tried to reconcile with their God.* (Nurse 12)

It can be challenging to deliver spiritual care because this requires special knowledge, and most nurses are not trained as spiritual leaders. Many religions are found 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. Whereby it needs someone who is trained as a spiritual leader/. . ./. So sometimes you find it very difficult. (Nurse 19)

**Networking and Advocacy**

Nurses interact as “spiders in a web.” Their work is characterized by networking between the patient and the family, but also
networking with other professionals, for example, doctors, spiritual leaders, social workers, and community volunteers.

We nurses are supposed to act as a catalyst between patient, the family, and the other team members. (Nurse 8)

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. (Nurse 19)

If the patient needs treatment or further investigation, the nurse can make the referral to the appropriate centers.

It is my responsibility is that this patient is referred to another place where they can get treatment. (Informant 3)

One of the roles of the nurse is to inform people of the importance and role of palliative care. They also advocate for morphine as an effective analgesic. Advocating also involves removing any misconceptions about palliative care.

Palliative care, this is a new thing. I think it needs to be put in people’s . . . . I mean awareness of the public. Here we only look at the cancer and the HIV, but there are other chronic illnesses. / . . . / 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. (Nurse 3)

A problem in the African setting, according to the respondents, is that patients delay coming to a hospital until nearly the end of life. Informational programs are necessary to educate people about the importance of timely care, but these too are dependent on funding.

**Discussion**

**Truthworthiness**

*Credibility* refers to confidence in the authenticity of the data. We refer to Lincoln and Guba's *prolonged engagement* as an important step to enhance credibility. During our 7 weeks in the field, we gained an understanding of the culture and language and built a relationship with the informants. Even *persistent observation* of the situations regarding the phenomena increases credibility. During our stay, we attended the home visits and observed the nurses in their work as often as possible. Our observations at Mulago Hospital lasted just 3 days due to time constraints. Another technique is *triangulation*, which involves using multiple methods and perspectives to increase credibility. Several forms of triangulation are available. We chose to use *method triangulation*. Interviews, observations, educational material, and brochures are included in the study.

When we explored the different issues that patients can face at the end of their life, the results reflect the nurse’s perspective. This could be a source of error in that the patients’ voices are not directly heard. *Data source triangulation* would have been a better option, where we would have interviewed patients and nurses about the topic. However, we refrained from interviewing the patients because most do not speak English. We would have needed an interpreter, which is also associated with certain problems. However, the nurses have extensive experience in working in palliative care. Also, the fact that more than one nurse mentioned the issues presented in the results gives substance to the nurses’ perceptions. Other external checks, for example peer debriefing or member checks, were not considered due to the inherent limitations of this small study. Investigator triangulation is something we would have chosen, if it would be possible for practical reasons because it is considered to be good practice. The circumstance that only one author analysed the data might have an impact on the validity. On the other hand, the researcher in field also was the one who did the analysis and thus is familiar with the data. Moreover, the analysing researcher followed the instructions of Burnard very strictly.

*Transferability* indicates that the results can be transferred to other groups or settings (ibid). Most of the respondents are from the Kampala district, which may have different conditions than other parts of Uganda. It is conceivable that the social status of patients is higher in Kampala district, and there are more health institutions to be referred to than in other districts. Hence, the work of the nurses might be different. In addition, most of the respondents work in HAU, an NGO, which is likely to differ from a hospital setting. The group of respondents is homogenous in the sense that they all participated in the same educational program at HAU, and all are equipped with basically 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.

*Dependability* measures the stability of the data over time and under different circumstances. *Stepwise replication* means involving several researchers who collect data separately and, at the end, compare conclusions. Being a single researcher in the field does not allow this kind of advantage, so the results are based on single interpretations. An external reviewer enhances dependability by reexamining the data. The second author further checked our material, hence playing a similar role as in the inquiry audit.

*Confirmability* is a value that indicates the objectivity or neutrality of the data. The *inquiry audit* mentioned above also has a bearing on confirmability when an *audit trail* is used. The methods section presents a systematic description of how we analyzed the data, even if we do not have a formal audit trail. We also retained all of the material so the analyzed steps can be reconstructed.

*Reflexivity* is another aspect that qualitative studies need to consider. It refers to critical discussion of self-reflections, preconceptions, preferences, and bias brought into the study by the researcher. There is the possibility that we might have asked inappropriate questions, or missed important details in our observations because of our unfamiliarity with the clinical environment. However, we underwent a learning process and presumably developed our skills during the course of the study. In transcribing the interviews, we noticed leading questions and tried to avoid them in the subsequent interviews.
Potentially, problems could arise when researchers from a Western context conduct investigations in Uganda since cultural differences could influence the outcome of the study. On the other hand, the staff at HAU are used to interacting with Western volunteers and staff, who visit there regularly.

**Data Gathering**

A language barrier existed between the observer and the nurses that communicated with patients mainly in their local language. However, after the consultation with the patient, the observer asked the nurse to describe the theme of the conversation. The observer wrote this down in field notes.

The language as being not the first language for either the researcher in field nor for the participants might have an effect on the results in terms of a communication barrier. However, all individuals had a good level of language. For the nurses, it is their working language and their way of reasoning and thinking about the concept of palliative care since their education is in English. The researcher was well prepared before going in the field and had the impression that the communication was fluent.

The interviews were guided by the quality criteria from Kvale,

A review of the effectiveness of multidisciplinary teams in cancer care in the United Kingdom reveals scant evidence of the effects on quality of patient care. It is uncertain whether these results are applicable in the Ugandan context, but the effectiveness question needs to be investigated given the shortage of nurses in Uganda.

**Result Discussion**

The findings reveal a profile of the nurses’ role in palliative care in Uganda. These nurses deliver holistic care, integrating the physical, psychosocial, and spiritual factors affecting the patient.

There are always advantages and disadvantages in professions requiring broad sets of skills. It is important for Western countries to recognize this, because we too must consider how to care for patients in their homes by delivering good quality with limited resources. But we must also bear in mind that the findings might not be applicable in different contexts.

The broad competence of the nurse may promote greater continuity of care when one person delivers all aspects of holistic care and needs to view the patient as a whole. Through regular contact with patients, the nurse is familiar with patients’ needs and is therefore in a strong position to assess their problems. Moreover, the nurse must have a high level of knowledge about all the aspects of holistic care. The nurse must be as skilled in assessing physical pain as in assessing spiritual pain, but every nurse does not have these qualifications.

Part of Dame Saunders’ philosophy is to use multidisciplinary teams. However, since Uganda has a shortage of nurses—with a density of 0.55 nurses per 1000 inhabitants—we must question why nurses cannot make home visits more independently. Fournier showed that nurses caring for patients with AIDS at Mulago Hospital encountered challenges of poverty, insufficient resources, lack of continuing education, and the fear of contagion, leading to moral distress. Nurses in our study met mostly patients with cancer and HIV/AIDS in their daily work. The challenge of poverty was also reported in our investigation, but none of the nurses mentioned the fear of contagion when talking about their patients. This might be attributed to the 9-month educational program at HAU that includes HIV/AIDS as a course subject. We find it interesting that the nurses in our study did not report feeling distressed by this, which accentuates the importance of education. The lack of resources was also mentioned in our study, but in terms of administrative challenges, for example, a lack of institutions offering treatment, space, and transport. Some of the social issues that patients face can be traced back to poverty and the absence of a social safety net. Kikule found in her study that 30% mentioned the loss of income resulting from illness as the cause of financial needs. This is why nurses need to integrate social work into their role. The government of Uganda is involved in the morphine supply within the districts of Uganda. In our opinion, a social safety net is as important as the morphine supply, but we are aware that it is expensive for a resource-poor country like Uganda to cover social programs throughout the country.
Nurses developed strategies aimed at helping patients deal with psychosocial issues. Dealing with poverty is a challenging issue for nurses, but they can refer patients to other organizations and support programs. Regarding counseling, however, nurses can make a major difference in the lives of patients and their families. Kikule reported a need for counseling to heal relationships within the family. The nurses involved in the present study had to raise difficult questions and break bad news, for example, disclosing the diagnosis to the patient. The nurse’s role also involves acting as an intermediary between the patient and the family and providing education about sexuality. Counseling requires fewer resources, and nurses have a major opportunity to influence the quality of the patient’s life through counseling. They can offer time with the patient, which has substantial value in palliative care. In Western countries, shortcomings often involve a lack of time with the patients rather than a lack of resources (although Western countries also deal with relative limitations on resources). Here, we have much to learn from Uganda. Spending time with the patient and their family is important to create a relationship, which is the starting point in delivering psychosocial care. When Ugandan nurses break bad news, they counsel patients by giving them time to accept the diagnosis.

Bolmsjö, in a study carried out in a Swedish context, noted that existential questions mainly arise at night, which can be problematic in home care due to the absence of night staff. This was not mentioned in the present study—that is, when existential questions arise in the Ugandan context—and would be an important issue to explore.

Spirituality is also an aspect of the holistic approach in palliative care. Patients can feel isolated by not being part of the church community. They can feel blamed by their spiritual leader, and they can even blame God for having a terminal disease. It is also possible that patients perceive their disease to be a curse from God, and they might even bargain with God to be cured. When searching for a cure, some patients change their religion.

The theme of isolation might have a universal aspect. From a study conducted in Sweden, Sand reported that nonreligious patients expressed an existential loneliness due to isolation, which the spirit of community could possibly remedy.

Nurses’ roles include assessing the spiritual needs of patients and counseling them accordingly. They pray with the patient; they offer spiritual counseling; they refer to a spiritual leader; and they give hope by encouragement. In our opinion, these roles are as unique as prescribing morphine because the nurse is not a spiritual leader and not educated as one. In Uganda, many competing religions try to influence the patient, and even try to convert patients in the final days of life. The interviewees emphasized that nurses should not convert patients, and they would discourage others from doing so at the end of a patient’s life. Ethically, they respect patients’ self-determination and integrity. This can involve a balancing act because nurses have their own spiritual needs, and these values could influence their work. One example in this context concerns the advice nurses give when a couple intends to separate, and the nurse encourages them to stay together. This advice could be influenced by the Christian values of the family as a unit, and nurses should be aware of this when giving advice.

It seems reasonable that nurses should try to visit patients with whom they share the same faith since it promotes trust. Moreover, it could be easier for nurses to counsel someone spiritually if they speak the same language in terms of religion. At HAU and Mulago Hospital, the team prays together in the morning, which probably influences their work. Palliative care is multidisciplinary, according to the philosophy described above, and praying together may promote solidarity within the team. In Western nations such as Sweden, praying is considered part of the private sphere, which could be a reason why we tend to over- or misinterpret the meaning of praying together.

Many patients with cancer enter palliative care in the late stages of their disease. This is possibly a result of the general ignorance about cancer. Selman et al found that patients and caregivers lack information about their condition, and their informational needs are not being attended.

If people knew more about cancer and the importance of early screening, patients would have a chance of cure and possibly avoid the need for palliative care. We were surprised to learn that disclosing the diagnosis to the patient is a role of the nurse. In our opinion, by the time patients enter palliative care they should know what they are suffering from. The reasons why Ugandan medical staff find it difficult to disclose the diagnosis to their patients would be an interesting question to examine in a future study. Patients ask health care staff for information and express gratitude when they receive it from palliative care services, as reported in a study by Selman et al.

By the time some patients present for palliative care, problems have already arisen, for example, separation due to symptoms that cannot be handled within the relationship. It is often more difficult to repair problems than to prevent them. As regards HIV/AIDS, prevalence has declined in Uganda, possibly as a result of the National Strategic Framework. However, the prevalence of cancer does not appear to follow the same positive trend, thus resulting in negative consequences for individuals and society. It is obvious that the Ugandan Ministry of Health needs a similar strategy to impede the consequences of the cancer epidemic in Uganda. Public information and screening programs are needed for early detection and should be offered throughout the country. Cancer of the cervix and prostate are the most common forms of cancer affecting women and men respectively in Uganda. By early detection, the chances of cure in these forms of cancer should increase, causing cancer prevalence to rise with increased life expectancy, even in Uganda. The health care system should prepare for that eventuality. In our opinion, one step is to continue to advocate for palliative care, but not only from HAU. Palliative care is part of the medical program at Makerere University and Mbarara University. It is important that all health professionals acquire knowledge about palliative care so they do not hold patients in a curative setting when earlier referral to palliative care would be more appropriate. We are aware that
from a Western standpoint it is easy to call for greater engagement by the Ministry of Health, but if poor health is the main reason for poverty in Uganda—as indicated by the Ministry of Finance Survey from 1997—then greater engagement in health care should contribute to economic prosperity in the country.

Palliative care nurse specialists advocate for palliative care, morphine, and Hospice African Uganda. Such initiatives are necessary because palliative care is a relatively new service, and many people are unfamiliar with its purpose and scope. Another challenge involves addressing the misconceptions that people have regarding the work of nurses. Further research is needed to address how advocacy influences the work of nurses.

The traditional role of nurses in palliative care is changing, and as change raises new issues and problems, it also raises needs and opportunities to conduct further research.

Conclusion
The role of the PCNS is broad and unique since these nurses are authorized to prescribe morphine and other palliative care drugs after successfully completing a course in clinical palliative care. In this area, the roles of the physician and nurse overlap. The role of the PCNS is special and different to the western palliative care nurses because of this and because they include the spiritual care as for granted.

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