Familjefokuserad omvårdnad på ett universitetssjukhus i Zambia

En kvalitativ studie om sjuksköterskors erfarenhet av att involvera familjen i vården

Family involvement in care of a relative in a University teaching hospital in Zambia

A qualitative study about nurses’ experience of involving family in care

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Abstract

**Background:** Family nursing care is a big part in health care and the caring of patients. Within the family nursing care the family along with the patient is meant to be seen as a unit. The multicultural society faces the challenge of all different perspectives to coexist. The study shows how family nursing care is perceived and applied in the medicine wards at the university teaching hospital in Lusaka, Zambia.

**Aim:** The purpose was to describe nurses in Zambia experience of involving relatives in care.

**Method:** The study was conducted as a qualitative research with an exploratory design. Semi-structured interviews were used and the data was processed using a qualitative content analysis. The study included eight participants who worked on five different medical wards in Zambia.

**Result:** The relatives had a great role in the care of the patients, the role was mainly about assisting the nurse in the basic care. There were no guidelines regarding the relatives. The nurses involved the relatives by informing and educating them about the procedures, treatments and the condition of the patient. Nurses expressed that relatives should not have such a big role in the care, but they had to involve the relatives because of the lack of time, lack of staff and the burden of disease.

**Conclusion:** The relatives had a great and important role in the hospital, because of the lack of time, lack of staff and the burden of disease. The collaboration between the nurses and the relatives were of great significance, and may be what helped or hindered the nurses’ work.

**Keywords:** Experience, family nursing, nurses and Zambia.
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1. Introduction
We have both taken a course in cultural competence and realized the difficulties with the development of cultural competence, although it has become an important part of nurses’ work. When the opportunity was given to write the bachelor degree in another country, we saw the chance to develop cultural skills for future professional. Then we began to think about an interesting and beneficial subject. During the nursing program one of the courses is about family involvement and we have learned that family nursing has and will most likely continue having a significant role in health care. We noticed that there is more research regarding family nursing within the Swedish health care then in other countries, still we have experienced the difficulties the nurses have with putting the knowledge into practice. This awoke our interest about how other countries apply family nursing in the care of patients and their relatives. We felt that we would achieve the widest perspective of nurses’ experiences regarding family nursing if we chose a country with different conditions than Sweden. By studying nurses' experience in a country with different culture and different conditions, we hope to achieve a greater knowledge regarding family nursing care. Knowledge that can lead to a more effective implementation of family nursing in our future work as nurses.

2. Background
2.1 Family nursing care
Family nursing care is a big part in health care and the caring of patients. A family nursing care means that the family is seen as a resource and are given the opportunity to be involved in the care of their closed ones, with the goal to promote health in the whole family and not just the patient (Benzein, Hagberg & Saveman, 2012). The family have been seen as system based on the notion that human relationships develop as a system where all the parts affect each other, and that the whole is greater than the parts. This in turn means that changes in one part of the system affects the other parts. For example, if a family member gets sick it affects the rest of the family in a comprehensive manner. To see the family as a system, means to focus on the interactions and relationships between family members. All members in the family affect each other, and the relationships are not linear, but rather circular (Benzein, Hagberg & Saveman, 2014). Therefore, the nurses’ role in having a family focused work can be of great significance for promoting health and wellness for the whole family (Benzein et al., 2012).

2.1.1 Family-centered and family-related care
The concept family nursing care can be divided into family-centered and family-related care. By explaining the different concepts, it may be easier to understand the meaning of family nursing care. Family-centered care is a systematic approach and means that the whole family should be seen as a system where all family member represents their part. Family- related care means that the patient or relative should be in the center and the other family members represent the context, which mean that the caregiver should take into account the patients’ social context. These two concepts should be complementing each other and it can be difficult for the nurse to determine which care that are relevant depending on the situation. In today’s health care is it more common with family-related approach but family-centered approach should be carried out more (Benzein et al., 2012).

2.1.2 Family health
According to Blöndal et al. (2014) are a family defined by whoever the person says they are, and the family as a unit is considered to be a client for health care. Benzein et al. (2012) explains that this definition of the family has an emotional base that focuses on the emotional
bond that exists between people. It means that a family consists of a self-defined group of people, who are not related by blood or law, but that feels like a family. Family Health in recent years has been described as an overarching concept for the families’ well-being and function. The health of an individual is intertwined with family health and a larger system consisting of the society and culture. In different cultures, different beliefs dominate about health and illness, which affects individuals and families experience of health. The concept of family health includes both the health of the family as a whole and of the individual family members. The description of health has a direct bearing capacity of the family when viewed from a systematic perspective. This shows the importance of the family as a balanced unit. This ability can also be related to the availability of forces and resources within and outside the family. The family's strengths need to be identified, developed and released in the health promotion work with families (Benzein et al., 2012).

2.1.3 Health promoting family conversations
Bell (2016) describes health promoting family therapeutic conversations as a nursing intervention in family nursing, the past 40 years have we learned that there are benefits with the conversations. Canada, Iceland and Sweden have developed the knowledge about therapeutic conversations. The conversations are sensitive to environment, time available, language, setting, culture and theoretical orientation. Of these skills and concepts was a base identified that can help and enable the nurses to think and see differently. Instead of seeing just the individual to see the interactions and relationships between the individual and the family, but as well among themselves the nurse and family. It is a foundation for the nurse to “do things differently”, that means that the nurse can through health promoting family conversations provide useful care to the family, make an assessment and intervention for the individual and the family. The nurses can also get greater confidence and capacity to lead and participate in challenging and complex conversations with the family in care. But the most important thing is that families have reported that the conversations have been helpful, they experienced it to be healing. There is still a lack of research when It comes to talking and involved the family and therefore are health promoting family conversations not an evidence-based nursing intervention (Bell, 2016).

2.1.4 History of family nursing
The philosophy of care known as family nursing have for more than half a century advocated for a shift from patriarchy and paternalism to dignity, respect, partnership and collaboration with the patients and their families. Family nursing has been endorsed at the highest policy levels in developed countries (Bell, 2013). It has become an accepted practice within some hospital specialities, such as psychiatric nursing, intensive care nursing and pediatric nursing. In the surgical and the acute medical units, the practice of family nursing is described as invisible and undertheorized Family nursing has become a cornerstone to the system of health care globally seen in the 21st century but still it has encountered difficulties in effective implementation (Blöndal et al., 2014).

A review of the research suggests that health care professionals are hindered by lack of time, skills, knowledge and available resources. But also, that nurses feel threatened by a loss of professional authority, power and control (Coyne, Murphy, Costello, O’Neill & Donnellan, 2013). This results in that it is common that the patients and their relatives evaluate their relationship with the health care professionals as difficult, uncaring and intimidating (Bell, 2013).

A strong foundation has been built for family nursing care in Sweden over the last 10 years, but there is a need for nursing researchers, administrators and educators to implement the knowledge into practice (Saveman, 2010). A research, education and clinical practice for
family nursing was established in 1998 at the university of Kalmar, Sweden. The evolution of family nursing at the university has opened the mind of nurses in the Swedish health care system to think more about the family. Still Swedish nurses see the family both as a burden and a resource. An explanation could be that even though there are university courses about family nursing in Sweden, there is a lack of knowledge about how to conduct family nursing into practice. There is also an obstacle of time, both that the nurses feel they do not have enough time for family nursing, and that attitude and paradigm changes take time. There is also a special challenge for the Swedish nurses to work with families from other cultures and countries, as well can the nurses’ own beliefs be an obstacle. Therefore, there are a need of continuously challenge the own constraining beliefs. To provide a national network for educators and researchers of family nursing the university of Kalmar developed a Nordic family-focused conference (Saveman, 2010).

2.2 Zambia
The republic of Zambia is located in the southern part of Africa and is among the most politically stable countries in Africa. Zambia is a lower middle income country with the goal to become a middle-income country in the year of 2030. The burden of disease is high and is mainly characterized by high prevalence and impact of communicable diseases. Particularly malaria, HIV, AIDS and high maternal, neonatal and child morbidities and mortalities. The country is also facing a rapidly increasing burden of non-communicable diseases, including diabetes, cardio-vascular disease, mental health and violence. From the year of 2006 to 2010 has the health sector in Zambia recorded significant progress in the health service delivery and health support systems. Leading to a great improvement in most of the health performance indicators. The sector faces however despite the achievements major challenges. Challenges that includes high burden of disease, inadequate medical staff, inadequate distribution of health infrastructure, equipment and transport. As well as challenges related to health information systems, inadequate financing and identified weaknesses in the health systems governance (Ministry of Health [MoH], u.å.).

2.2.1 Health care in Zambia
The health care delivery system and health services in Zambia were provided mainly through the public and private institutions which were complimented by faith based organizations. The guiding principle in Zambia was the access to cost effective quality health care that is was close to the family as possible. Provided in a caring environment while striving to achieve a universal health coverage (World Health Organization [WHO], 2015).

In Zambia, there is a critical shortage of nurses and even other health care professionals. This means that health care has become affected, an example is the University Teaching Hospital in Lusaka where one nurse can have up to 60. In addition, the nurses themselves feel that poor salary, heavy workloads and harassment by other health professionals are contributing factors to stress (Carter & Snell, 2016).

2.3 The nurses’ role and responsibility
The International Council of Nurses (ICN, 2012) provides guidance for ethical behavior based on societal values and needs. In a changing society, the code will only be meaningful if it is used as a living document of daily care work. Nurses have four fundamental responsibilities: to promote health, prevent disease, restore health and alleviate suffering. The nurse should provide care to individuals, families and the general public as well as coordinate with other professionals. In the healthcare’s nature is respect for human rights, including cultural rights, the right to life and their own choice, to dignity and to be treated with respect. The nurses code of ethics has four areas which summarizes the guidelines for ethical behavior. Area one is about the nurse and the general public where the nurses’ primary professional responsibility
is primarily targeted to people in need of care. In caring work, nurses’ must foster an environment where human rights, values, customs and beliefs of individuals, families and the general public are respected. In area four about the nurse and the coworker, the nurses also has to intervene in an appropriate manner to protect individuals, families and the public when their health is threatened by coworkers or other persons acting (International Council of Nurses, 2012).

Today’s care work has usually a person-related approach, this approach is considered may not be enough. Instead should the nurse strive after a family-centered approach which could become a challenge. The family-centered care is based on a non-hierarchical and systemic relationship which is characterized by reciprocity. Patient and family members should be equally involved and everyone’s skills should have equal importance. It is important that the nurses can see both their own and the families’ strengths and resources. A challenge for the nurses can be to create meetings and dialogues with several people at once. Family-centered approach were described as a prerequisite for promoting family health and well-being. (Benzein et al., 2012).

3. Problem statement
Family nursing has become a cornerstone to the system of health care, but still it has encountered difficulties in effective implementation. Sweden as a multicultural society faces a challenge of making all different perspectives of the families meaning to coexist. By studying a country in Africa’s experience of family nursing a wider knowledge and understanding can be obtained. The study may give other countries an insight of the nurses’ experience in family nursing. By gaining a broader perspective on the nurses’ experiences of family nursing it can facilitate the implementation of the knowledge into practice.

4. Aim
The purpose of the study was to describe nurses’ experience of involving relatives in care in Zambia.

5. Method
5.1 Design
The study was conducted as a qualitative research with an exploratory design.

5.2 Settings
The University Teaching Hospital (UTH) in Lusaka is located in the capital city Lusaka and is the biggest hospital in Zambia.

"The vision of UTH is” to be the centre of excellency for health care in the country and the region by providing innovative treatment interventions through ongoing research”, while the mission statement is “To provide affordable quality health care; function as a referral centre; train health care providers; conduct research to find solutions to existing health problems and for the development of science”."

The aims and objectives of UTH is about that all citizens of the Republic of Zambia should be provided general health care, to train health personnel in medicine, physiotherapy, radiography, nursing and other related paramedical disciplines, to conduct research to be able to establish better management of commonly occurring diseases and to act as a centre of referral for all the medical needs in the country (http://www.uth.gov.zm/).

5.3 Sampling strategy
The study included eight female nurses who worked on five different medical wards at the University teaching hospital in Lusaka with patients that was hospitalized. It would have been
six different medical wards but one was excluded due to that the nurses that worked had no
time for interviews, because of that were two nurses instead of one chosen from another ward.
All nurses had the profession general registered nurse with a work experience of 2-7 years.
The participants were selected by the head nurse of the different wards after receiving the
criteria for the sampling. They were chosen through a purposive sampling. According to
Kristensson (2014) purposive sampling means that all the participants who meet the inclusions
criteria are asked to participate. Inclusion criteria was nurses who had experience with
working together with patients relatives and had worked for more than one year in the health
care.

5.4 Data collection
In-depth interviews were used to collect the data. The interviews were based on semi-
structured form (Appendix 3 and 4) which means that the study had the same questions with
the opportunity to talk freely and to answer follow-up questions. A computer and a tape-
recorder were used for the documentation during the interview. All information required from
the interviews were then transcribed and stored local on a computer.

5.5 Data analysis
The data was analysed using a qualitative content analysis based on semi-structured interviews.
A content analysis is common in the qualitative studies and are used to process large amounts
of text (Kristensson, 2014).

Both authors listened to the recorded interviews and transcribed the content. The texts were
analysed with a structured approach to describe patterns, similarities or differences in the
material.

All the interviews were read to get an overall sense of the texts content. Thoughts about the
content of the text was written down and then the authors met to discuss impressions and
interpretations. The authors identified meaningful units that are related to the aim of the study.
The remaining data was deleted. The meaningful units were condensed into codes. This means
that the text shortens to one or some words summarizing a whole or a part of a meaningful unit
without losing the message. Next, the different codes were read to identify similarities or
differences. The codes that have similarities was summarized into a sub category and formed
into a title that summarizes the codes. Then the subcategories, the codes and texts were read
through again to adjust the categorization further, optionally formed subcategories. Finally,
the categories and subcategories were read through and put in relation to the interviews. By
comparison it was sought to find the overall meaning or significance and then summarize it in
a comprehensive master category or theme. If no overall main category or theme were emerged
the analysis stopped. After completing the analysis, the results were compiled. First the overall
result was described and then a structure at a time. Which meant that the theme or the overall
main category with associated subcategory were described (Kristensson, 2014).

6. Research ethical considerations
A modern trend was the renewed attempt to create a global ethics for research (CODEX,
2016). It was fundamental that the research only could be approved if it could be done with
respect for human dignity, human rights and if the fundamental freedoms were considered in
the ethical review (Lag om etikprövning, SFS 2003:460, § 8). For the study to be put into
practice, an ethical proposal was made and was sent to the Ethics Committee in Zambia for
review. The study received the ethical approval 21 February 2017.

The four ethical principles were intended to provide standards for the relationship between
researchers and research participants. The aim was to provide a basis for the researcher's
reflections and an insight over their responsibilities. The basic individual protection requirement could be categorised in four general main requirements for the research. These were the requirements of information, compliance, confidentiality and use (CODEX, u.a.).

The information requirement meant that the researchers informed the study participants about their role in the project and the conditions that applied to their participation. The study participants should be told that the participation was voluntary and that they had the right to withdraw their participation at any time. The researcher should also collect the participant's consent pursuant according to the consent requirement. Confidentiality requirement meant that those who participated in the survey had the right to independently decide on how long and under what conditions they would attend. It also meant that they could cancel their participation without any negative consequence (CODEX, u.a.). To meet the requirements for information, compliance and confidentiality. Every participant was handed an information sheet before the interview were conducted. The information sheet included a presentation of the authors and the purpose of the study, as well as contact information to the authors and their supervisors if any questions related to the study occurred after the interviews were completed. After the participants had read the information sheet they signed a consent form in which they ensured they understood the purpose of the study and that they could choose to exit the study at any time during the process without having to give a reason why.

According to the use requirement were the study participants not allowed to be exposed to undue pressure or influence in their decision to participate or withdraw their participation (CODEX, u.a.). Participants were not affected by the authors in the decision making to participate in the study, but they may have experienced pressure to participate from the head nurse, as the head nurse chose who would attend. Whether they felt pressured to participate or not, the head nurse influenced who participated in the study. However, could the sample not be controlled by the head nurse when participants were chosen according to those who were available that day. By giving the study participants contact information such as email and phone number to the authors the opportunity were given to leave the decision to end the study in the manner the participants were most comfortable with.

All data were analysed confidentially so that the participants of the study could not be connected to the content or result. Using the local storage on the computer instead of the cloud storage resulted in a higher safety, because the authors could better control so unauthorized people could not access the data. By disconnecting the drives from the network the data were made safe from attacks. To further ensure that the data could not be accessed by unauthorized the data was placed in a folder on the computer that were made invisible and required a password. Only the authors knew the password and the procedure to access the folder.

Data collection retrieved from interviews puts demands on the interviewer regarding the planning, formulation of questions and the interaction to the interviewee. The conductor of the interviews becomes consequently an instrument when the interviewer and the interviewee create meaning about the subject in interaction with each other (Kristensson, 2014). Because the interviewer function as an instrument and the meaning of the subject is created through the interaction between the interviewer and the interviewee, the data could not be handled in an objective manner. This means that if a similar interview would be made by another person the answers would be different.
7. Result
7.1 Nurses experience of collaborating with relatives

7.1.1 Relatives in care
It appeared that the relatives needed to have a greater role in the care because of the limitations the nurses struggled with due to the lack of time and the number of patients. “The relatives have a role because you see the numbers are huge, and there are only two of us. So, we don’t have time. “- Nurse 8

Nurses expressed that the relatives should not have such a big role in the care of the patient, but because of the lack of time and the burden of disease the relatives had to play a greater part in the care. “We involve them and educate them so the patient can go home. “- Nurse 5

7.1.2 Participant in clinical decision making
The relatives played a big role in decision making about treatment and procedures for the patient. Information was given both to the patient and the relatives, then they decided mutually on how the treatment would proceed. “In the decision-making about procedures like lumbar puncture both the patient and the relatives will agree with the procedure. “- Nurse 8

The relatives’ opinion was of great importance especially at times when the patient was not adequate. In cases where the relatives and the patient did not agree considering the treatment the patient was the one who had the decision-making role. “It’s up to the family to decide, but sometimes the families decide in behalf of the patients. For example, with the lumbar puncture. If the patients want it then we go ahead and do the procedure. “- Nurse 5

7.1.3 Source of information about the patient
The nurses explained that the communication between them and the relatives were important. When the patient was not able to speak for themselves, could the relatives accommodate essential information to facilitate the nurses’ work. “Maybe for finding out information, when the patient is not able to talk for themselves. You get some more information from the relatives. “- Nurse 4

The relatives also had a role in notifying the nurses if any changes occurred. Because the nurses cared for a large number of patients they depended on that the relatives could provide information about any changes.

“We do communicate, we tell them to say anything strange with the patient. Please inform us so that the only thing that we need like, we tell them that the only thing we need you here is to just watch over the patient and clean but the rest you leave it to us. If it is any change you have noticed, you call the nurse and the nurse will now what to do. “- Nurse 1

The nurses saw positive aspects with that the relatives could have an extra observing eye and provide important information about the deterioration of the patient. They pointed out that they were in need of the assistance of the relatives when the burden of disease was so great.

7.1.4 Practical bedside assistance
Mainly the relatives observed and informed the nurses about the condition of the patient, but in shortage of time they would assist the nurses in the basic care of the patient. “It’s impossible for us to take care of everybody. That’s why we allow bedsiders to help us with the care of the patients. We need them to help. “- Nurse 1

The relatives helped the nurses with the basic care at the times the nurses did not have time. The nurses also felt that the relatives were there as a support to the patient. They argued that the relatives had a role that was equivalent to the role of an assistant nurse. “Okay mainly
what I will say it is here in Zambia it’s more like they are nursing assistants because we don’t have nursing assistants here. “- Nurse 2

The nurses stated that the relatives sometimes were needed to pay for example procedures, bringing food if the patient did not like the hospital food and also to help the nurses to convince the patients regarding certain treatments.

“The positive aspects. If we have a stubborn patient, they are able to convince the patient. If given an example if the patient don’t want the treatment. They default but if you have a bedsender that understands the important of sticking to the plan, he or she will convince the patient. Many patients default some treatments, so we really need the bedsiders to help for that. “- Nurse 6

7.1.5 Information in educational and home care measures

The nurses involved the relatives by given them information and educating them in the care of the patient. All information was given both to the patient and the relatives. The nurses stressed how important it was to involve and explain the specific procedures for both the patient and the relatives, to avoid misunderstandings. “So, all information is given to the patient is also given to the relatives. “- Nurse 6

The nurses informed and explained the patients’ condition to the relatives so they understood and knew what to do. The nurses both educated the relatives how to care for the patient within the hospital and how to care for the patient in the home after it had been submitted. The information could be regarding for example the disease the patient had and the education was for the care and lifestyle-changes for the patient.

“We go to the patient and we explain the condition of the patient so they understand and now what to do and what they are not supposed to do. Like when they go home what type of food they are supposed to give the patient and what kind of environment they are supposed to be in. “- Nurse 7

7.2 Nurses experience of providing support to relatives

7.2.1 Nurses support to the relatives

The nurses supported the relatives by informing and educating them about the patient’s condition and what they should do. The information and education led to that the relatives’ anxieties were attenuated.

“Well we do actually involve them. Is usually to educate them on the condition if the patients and just so they know what is going on in generally with the patient. To just relive the anxiety, so the fears and the worries that they have. We try to involve them as much as we can. “- Nurse 2

The nurses tried to make time to support the relatives while they were attending to the patients. When they felt that they could not give enough support to the relatives they contacted a counsellor as an extra support. At the hospital area, there was also a chapel for the relatives to go to and seek solace in. Still many of the nurses experienced that they had no or minimum support to the relatives.

7.2.2 Psychosocial consoling

The nurses learned psychosocial consoling in the nursing program, so they were able to console the patient and the relatives. Though many of the nurses felt that they did not have enough time to do so. “Usually, okay we are nurses in our nursing program it involves psychosocial consoling. So, we are able to console the patient. “- Nurse 6
7.3 Nurses experience of the guidelines regarding family nursing

7.3.1 Guidelines for the relatives
There were no guidelines concerning the family nursing, but there were guidelines for the relatives to follow. The relatives could be one by the bedside everyone else had to be outside the ward. The relatives had specific visiting hours, but in times were the patient were critical ill or confused the relatives were allowed to be at the bedside at all times.

“We only allow bedsiders for the patients that are critical ill and the confused patients. Because we fear that they will run away. Because as nurses we are few, so sometimes it is difficult. So, then we allow one relative at the bedside. “- Nurse 5

As a relative you were allowed to be at the bedside attending to the patient if you were at least fifteen of age. There were exceptional cases where the patient did not have relatives over fifteen of age, in those cases children under the age of fifteen could be at the bedside. The reason why children under the age of fifteen were not allowed on the ward were because of the infection risk.

“We have certain rules about visiting hours and how many can be by the bedside. Children up to 15 is not allowed at all on the wards because of the infections risk. Do you want your child to run around here? “- Nurse 8

7.3.2 Difficulties respecting the guidelines
Even if there were guidelines for the relatives the nurses experienced that the relatives had problems to respect and follow the guidelines. The consequence of that guidelines was not followed were that the ward got overcrowded which complicated the nurses work. “But those guidelines are never follow to say the truth, their never followed. There are always three or four people by the bedsiders, they even sleep through the night so it is just hard. “- Nurse 2

7.4 Nurses experience of the negative aspects of involving relatives in the care

7.4.1 Summoners of patient’s complaint against nurses
The nurses experienced that the relatives sometimes compared what they did against other nurses. “The worst thing is when we do procedures, because everything you will do they compare between the nurses, and then they will be refusing. So, it is better to do it without the bedsiders. “- Nurse 8

It resulted in that the nurses felt observed by the relatives and thought it was better if the relatives were outside the ward while they were doing different procedures. Some of the nurses stated that the relatives sometimes had bad attitudes towards them and interfered with what they were doing.

“The attitudes, bad attitudes. That we can’t take care of the of the patient … It’s a challenge, just bad attitudes. Even if you try to explain, that it’s the doctors’ orders. They have bad attitudes. You find that the relatives come in and interfere what we and the doctors are doing. “- Nurse 5

The nurses struggled with the dilemma of allowing the relatives to observe their work or asking them to sit outside the ward while doing procedures. If they allowed the relatives to sit with the procedures, the relatives could interfere and compare their work. In the other side if the relatives were not allowed it could create a lot of questioning and they could accuse the nurses for doing something wrong if an incident occurred while they were not there to observe.

“The positive is that, there is at times were the relatives are not here, the patient collapse and it becomes an issue. What happened? What did you do? When they are
their observing what is happening we usually don’t have these problems. Because they have observed what is going on. But when they are not there it creates a lot of problems and a lot of questioning. “- Nurse 3

The relatives could also create problems through spreading information that the nurses did not take care of the patients if they could sit by the bedside while doing the procedures. “The negative part of it is the information that they take out of there, like that the nurses are not taking care of the patients. “- Nurse 1

7.4.2 Challenges of having relatives by the bedside
The nurses experienced that the relatives often started to control the work that they were doing and when to many relatives were sitting by the bedside the ward got overcrowded. It then became more difficult for the nurses to do their work. “Yeah because it is difficult to work with them, they start controlling and make the place crowded. And it is really difficult to work like that. “- Nurse 4

Relatives could also create more confusions.

“They start filling in more confusion like they have come to take care of the patient and they come drunk and fall asleep. And maybe it is a confused patient the patient end up maybe upstanding. The nurse is maybe really busy and by the time you find out, the patient is already somewhere else. “- Nurse 2

The nurses relied on the relatives to do their part, so if any problem occurred it could take time before the nurses noticed that something was wrong and the problem could get even greater.

7.4.3 Risk of negative influence on patients
The nurses expressed that the relatives’ opinion, beliefs and convincing voices could both be positive and negative. The relatives could help the nurses to convince the patient about a procedure or treatment, but they could also impinge the patient to decline a procedure or treatment that were needed.

“It’s a 50/50 deal. They can help us convince the patient. Here in Zambia lumbar puncture. They don’t understand what type of investigation it is, and with blood transfusion. They don’t want it, they don’t understand the importance of blood transfusion. They say you are going to get HIV from the blood or other diseases from the blood. Or sometimes is about religion. They convince the patient not to get the treatment. “- Nurse 6

It was clear that the nurses had to work hand in hand with the relatives to provide optimal care and create a humble collaboration.

7.4.4 Permanent management of ethical dilemmas
Relatives felt needed to stay with the patient always, so sometimes when privacy were needed the nurses experienced a dilemma. Usually the nurses ask the relatives to sit outside the ward when privacy were needed. It became a challenge because the nurses felt that the relatives took offense, which is because they believed that the relatives wanted and felt obligated to stay with the patient. The risk with allowing the relatives to stay at the bedside during procedures and conversations with the doctors, were that the relatives could disclose private information about other patients outside the hospital.

“The doctor is by the bed and the language they using the relatives is able to hear what they discus about the patient. And if there are neighbours they start disclosing that
information. That they have this illness like HIV. So usually we send them out when the doctor comes. “- Nurse 3

There was also a risk that the patient would be exposed to unauthorized persons if the nurses allowed relatives to stay by the bedside.

7.4.5 Risky collaboration
The nurses also expressed that a negative aspect of allowing relatives by the bedside was because of the infection risks, the relatives risked catching the infection diseases under the process.

“The negative aspects will be that most of them by the time they’re going home. Those relatives would be coming back again, there will be the ones that now is sick because there is a lot of infectious diseases in here. So, they end up you know catching those diseases in the process. “- Nurse 2

It meant that the relatives came back, but that time as a patient instead, which increased the burden of disease.

7.5 Nurses experience of being dependent on relatives
7.5.1 Contact details to the relatives
The nurses felt that they were depended on the relatives to be at hand. Usually one relative sits by the bedside and in the patients file are there a phone number to the next of kin, in case they needed to get in contact with the relatives. Sometimes the nurses could not find a number for the next of kin in the patients file, then they had to rely that there would always be a relative at the bedside or outside the ward. Because that the relatives had a great role in decision making about treatments and procedures it became a challenge for the nurses if the relatives would not be available.

“We usually do have phone numbers on their files, when they come in there is a next of kin. So, it is numbers. But it is not with everyone, on someone's there is nothing there on the files so it is hard to have a backup. Because you don’t know who to call what to do. Mainly we rely on the relatives, unfortunately that is how the system is here. “- Nurse 2

This meant that the relatives had a great responsibility and that the nurses felt uncertainty regarding the relatives’ availability.

7.5.2 The outcome of involvement depends on the level of understanding
It emerged that depending on the level of understanding of the relatives the nurses experienced it differently god to involve the relatives in the care. “Sometimes is good and sometimes it’s bad it depends on the understanding of the relatives… The negative sides are that you tell them how to do it and then they do the wrong thing. “- Nurse 7

The nurses meant that sometimes the relatives did not understand how they should do a certain procedure, which became a challenge for the nurses when they needed to rely on the relatives to assist them in the care. The relatives could also sometimes have difficulties with understanding why and how treatments proceed, this increased the risk that the relatives could convince the patient to refuse a treatment.

8. Result summary
The relatives had a big role in the care of the patients, the nurses compared the relatives’ role in the care with the role of an assistant nurse. Nurses believed that the relatives should not
have such a big role in the care that they had. They had to involve the relatives due to lack of time, lack of staff and the burden of disease.

There were no guidelines regarding the involvement of relatives, but the relatives had guidelines to follow regarding the maximum number allowed, age and visiting hours. Unfortunately, the nurses felt that the relatives did not always followed the guidelines which made the nurses work more difficult and overcrowded the wards.

The nurses involved the relatives by informing and educating them about the procedures, treatments and the condition of the patient. They also tried to offer them the social support they were thought in nursing school while attending to the patients, but because of the lack of time it was a challenge.

The involvement of the relatives in the care of the patients could both be positive and negative. Much depended on the level of understanding that the relatives had, which affected how they collaborated and could provide mutual support.

9. Discussion
9.1 Method discussion
Explorative design intends to explore an area where there is not much previous research (Kristensson, 2014). There was not much research available on the topic that this study focused on. Therefore, the method explorative design was chosen that aimed at research areas that previously had little research.

Reason for the selected research method was that the knowledge obtained could not be generalized. Instead the knowledge was acquired through empirical studies of people's lived experiences. A qualitative research required a smaller population which were an advantage when the number of study participants needed to be met in a short time.

After the data were transcribed it was stored locally on a computer, which provided a better control of who could access the information. The downside of storing data locally were that if a disaster should occur on-site, such as the computer break-down, the data remains safe. The data are because of that secured remotely which means there would be no worry of losing backups of the data.

To strengthen the trustworthiness of the study, Kristenssons (2014) four dimensions were used; credibility, transferability, confirmability and dependability. The credibility was about the veracity of the results, interpretation of the results should not have been established by preconceived ideas and fantasies. The transferability of the study refers to how well the results were valid in other contexts and the assessment was made of the reader. The confirmability were about how well the results were represented in the collected material and in which extent the interpretations and results could be verified. One way to strengthen the study confirmability was to reproduce direct quotes. Dependability were about the results stability, an example to strengthen the dependability was by using an interview guide (Kristensson, 2014). The credibility of the study was strengthened by both authors in common analysed and interpreted the material, because of that the material did not risk being interpreted by one individual's preunderstanding. The analysis process was visualized as clearly as possible to make the interpretation process transparent. However, the selection was not as varied as desired, and the data could have been deeper if not the authors were affected by the lack of time. Transferability was strengthened by describing the studies context and by giving a description of the study participants work experience and profession. Confirmability of the study was strengthened by direct reproduced quotes, so the reader could see how well
the quotes related to the result. Dependability of the study was strengthened by the use of an interview guide. The use of an interview guide meant that all the interviewees were given open questions around the same themes and simplified for the interviewer to keep the focus on the phenomenon that were investigated. Because all four dimensions were used to strengthen the study, the study could be considered to be trustworthy.

The environment the interviews were conducted in were very loud which affected the sound on the tape recorder. This meant that it sometimes was difficult to hear what the interviewee said during the transcription of the interview. The authors then had to listen to the recordings several times and sometimes had to guess words along with the context of the sentence. The authors realized already during the interviews that the sound would be affected by the environment, then the decision was taken to transcribe the content of the interviews on the same day that the interviews were conducted. In order to be able to remember what the interviewees stated for information. A calmer environment was not possible related to understaffing.

The study responded to what was desired to investigate. The authors were given a comprehensive picture of the nurses’ experiences about involving the relatives in care. However, a broader perspective could possibly have been obtained if the desired variation of the genders could have been reached. The interview questions were modified between the interviews, but more time to conduct the study had given the opportunity for another round of interviews that could have provided an even broader and desirable result.

The socially constructed characteristics of men and women such as norms, roles and relationships can be summarized to the concept of gender (World Health Organization [WHO], 2017). On a symbolic level men and women’s characteristics are often seen as opposites. Men can be considered to be more autonomous and individual, while women can be considered to be more focused on relationships (Määttä & Öresland, 2014). Because only women were interviewed there is a possibility that the result of the study would have been different if only men would have been interviewed, or if there was a more variety in terms of gender. Men are usually seen as more action-oriented, while women are seen to be more relationship-oriented. This can lead to that men and women experience the same situation in different ways.

To estimate the extent and cost of relatives’ contribution in care is not simple because there is no clear definition of what it means to provide care. Relatives have always and will most likely always have a central role in the care of patients. Society views and expectations regarding the role of relative changes as the structure of the society changes and develops (Carlsson & Wennman-Larsen, 2009). Having relatives as informal carers can be seen as cost-effective for the health care and society, because the relatives do not receive any money for their work. Relatives are often not educated in nursing which could mean that the care they contribute with could be inadequate, they could also cause more work for the nurse if they for example made mistakes. From the relatives’ perspective, they could instead be affected financially as they may be forced to relinquish work to care for the patient. The relatives can also be affected both physical and mental from the press, stress and infectious diseases in the ward. Based on that the care develops in parallel with the society, it can be a challenge for the nurses to maintain a renewed knowledge. This is one reason that further research is needed in this area, in order to facilitate the nurses work.

9.2 Ethical considerations
The study took place in a country with a culture context that the authors had little knowledge about and therefore there were vital that the authors were humble and showed awareness and
respected the local traditions. A problem that could occur were that the study could be seen as critical of the health care in University Teaching Hospital in Lusaka, Zambia. Healthcare providers may felt that their knowledge was being checked. Remedy for this was clear information about the purpose of the study, to get a better understanding of the subject. In general, the nurses were open and understood the purpose of the study, but in times the authors felt that the nurses hesitated to answer the questions honestly.

Another ethical problem that could occur were with the current participation in the study. For example, study participants could have felt compelled to join or complete the study. Therefore, detailed information both orally and in writing were of great significance and also that the participants did not needed to give a reason to terminate the study. The plan was that the study participants would receive information about the study in well advance on when the interviews would be conducted. Because of the delayed approval of the ethical proposal the authors were short in time, which resulted in that the study participant received the information on the same day that the interviews were conducted.

The study participants were selected by the head nurse of the different wards which leaved room for questioning how voluntary the participation of the study was. A letter with relevant information were handled out to the participants in the study before the interview began. They were also given a document to sign that assured that they were aware of their rights. Before the interview started, was it important that the study participant understood that the interview would be recorded. Measures to make participants aware were a review of the equipment as well as information on how the interview would proceed and leave room for questions. The study participants were provided with the authors contact information if questions and thoughts arose after the interview were completed.

**9.3 Result discussion**

**9.3.1 Nurses experience of collaborating with relatives**

The purpose of the study was to describe the nurses experience of involving relatives in care. Results showed that the nurses were depended on the relatives in the care of the patients because of the limitations lack of time, lack of staff and the burden of disease. In Zambia, were there no assistant nurses so the nurses compared the relatives’ role with the role of an assistant nurse. The nurses further expressed that the relatives’ role should not have been so great but because of the limitations they received an important role. An assumption was that the need for more nurses is a key to limiting the obstacles the nurses experienced regarding lack of time and the burden of disease. More nurses would contribute more time and that the burden of disease would not be as overwhelming.

Results revealed that the relatives mainly were meant to observe and inform the nurses about the condition of the patient, but in the shortage of time they assisted the nurses in the basic care of the patient. According to Powell and Hunt (2013) kinshipnetworks and extended family of reciprocity realistically must be seen as safety nets with holes. Which could mean that the relatives could be seen as safety nets for the nurses, but not without risks. There was not an easy situation for the nurses to commit the responsibility to the relatives and trust that they could live up to the expectations. Simultaneously a great responsibility was put on the relatives, that they may not have sufficient knowledge to handle.

Results showed that the relatives were a great resource when it came to providing important information to the nurses. This improved the conditions of the collaboration between the relatives and the nurses. According to the result could the relatives contribute with important health support to the patient. Studies have showed that the family wanted to be gathered, give
each other comfort and above all be close to the patient. The presence of the families offered them the opportunity to help and be a natural link and mouthpiece between the patient and the staff (Benzein et al., 2014). As the relatives preferred to be close to the patient it simplified for the informative link between the nurses and the relatives.

9.3.2 Nurses experience of providing support to relatives

The nurses tried to support the relatives while they were attending to the patients, but felt that they lacked in time to do so. According to Carlsson and Wenman-Larsen (2014) have being a relative and a caregiver been described as a stressful situation with both physical and psychological consequences. The relatives were facing several challenges for example stress, burnout, costs of the care, they had to rely on the nursing skills and give support for caregivers (Powell & Hunt, 2013). Although the nurses felt that they did not have time to provide support to the relatives, both the nurses and the relatives depended on the other when it came to supporting each other.

Some families could barely afford any recreational space, which enhanced the health disparities between groups of families and contributed to the difference in various social place in society based on class, gender and ethnicity (Rämgård, 2012). In those cases, were they felt inadequate to support the relatives, were there different supports such as counsellors and a chapel for the relatives too seek comfort in. Still many of the nurses experienced that they had no or minimum support to the relatives.

Karlsudd (2012) explains that experience have shown that there were major shortcomings regarding information and collaboration between relatives and nurses in health care. In some cases, a reason for the shortcomings could be the culture the family had. According to Benzein et al. (2012) could a families’ beliefs have an effect on their experience of health. This showed further that the nurses faced big challenges regarding the collaboration and the support to the relatives.

Health promoting family therapeutic conversations is an intervention that Bell (2016) reported to be helpful for the patient and the relatives. But the conversation is sensitive to environment, time, language, settings, culture and theoretical orientation. In this case would it be difficult for the nurses to put health promoting family therapeutic conversations in practice related to the lack of time and the environment. They had the theoretical orientation but that would not be enough.

Family members who want to talk about their situation turn themselves primarily to persons in the social network, not the medical staff (Benzein et al., 2014). This can create challenges for the nurses when it comes to offering support to the relatives. It takes time and resources to create a good relationship so that the relatives can express their feelings and concerns, according to the result will this be the biggest problem area, because nurses felt that they neither had the time or the resources necessary to provide optimal support.

Because of the challenges the nurses faced they felt inadequate to support the relatives. When people train themselves to do good, they create an ethical competence and develop good habits (Öresland & Lützen, 2014). Good habits can be broken, for example of time constraints, lack of space for the patients, different power structures or internal obstacles. Although people are aware of it, they cannot live up to their moral goals (Öresland & Lützen, 2014). Their working conditions made them feel inadequate in the care of patients and their relatives. They have the knowledge and the will to do more than they are capable of doing during their working conditions, they describe it themselves as very difficult. According to Musto and Rodney (2016) moral distress points at a disjuncture between moral choices and
moral actions as a consequence of external constraints. The disjuncture makes the person experience frustration, anger, guilt, and powerlessness as a result (ibid.). This could be connected to when the ideal does not meet the real. Allowing the nurses to be under a moral distress of external constrains that they cannot influence.

The Zambian nurses’ experiences regarding the relatives is similar to what Saveman (2010) described that Swedish nurses’ experiences regarding family nursing. The relatives were considered to be both a burden and a resource. This further shows that regardless of the challenges and conditions the country have, the nurses feel that family nursing knowledge is difficult to put in to practice.

9.3.3 Nurses experience of guidelines regarding family nursing
The result showed that the nurses had no guidelines regarding family nursing. Instead the results showed that the relatives had guidelines they should follow during the time the patient were in the hospital. According to Benzein et al. (2014) are the family centered perspective an unexplored area and the family-centered nursing research is limited in its scope. Reasons for this may be the lack of clear methods of data collection and analysis, and that it requires a special expertise of the researcher to manage a systematic interview situation (Benzein et al., 2014). Although they had no guidelines on how to involve the families, they expressed that the relatives were a resource and that it was important to involve them.

The literature proves that family-focused care is important in the health care and that nurses should strive to have a family-centered approach. The nurses at the medical wards at UTH had to involve the relatives in the care, and were rarely given a chance to reflect on how or when they wanted to involve them. Relatives had to be involved because the nurses lacked in time and had to focus on the medical measures that they could not delegate to the relatives.

The lack of research may be one reason why there were no general guidelines regarding family-nursing, which could have caused difficulties for the nurses with knowing how to involve the relatives. The limitations of lack of time, lack of staff and the burden of disease the nurses struggled with affected the way the nurses involved the relatives.

The nurses struggled with that the guidelines for the relatives were not followed by the relatives. The consequence was that the ward became overcrowded, which complicated the nurses’ work. Although in some situations it could be helpful for the nurses to have more relatives by the bedside, because they could observe and give support to the patient at all time. Which creates a dilemma for nurses when there are both advantages and disadvantages when the relatives did not follow the guidelines. There seemed to be a balance when the family stopped being a resource and instead became a burden for the nurses in the care of the patients.

On occasions was even children under the age of fifteen allowed to sit with the patient when the patient had no other relatives. This shows how dependent the nurses were of the relatives in the care process, but it also shows how obligated the relatives felt to stay with the patient.

9.3.4 Nurses experience of the negative aspects of involving relatives in the care
The results showed that the nurses faced a dilemma when it came to allowing the relatives to sit by the bedside during procedures. Nurses’ decisions were therefore ethical dilemmas where it many time did not exist a right or wrong. All meetings in health care have a moral meaning if someone is in a depended position to the other (Öresland & Lützen, 2014). The relatives could be considered to be in a dependent position to the nurses, because of that have all the meetings between the nurse and the relatives a moral meaning. How the nurses involved the relatives became a factor for making the collaboration to function effectively.
The code of ethics for nurses say that the nurse should take appropriate action to protect, individuals, families and the public when their health is at risk (ICN, 2012). It can be a complex situation when it comes to the dilemma about allowing the relatives to stay at the bedside. There is usually a mutual desire of the family to be there for each other (Benzein et al., 2014). The relatives desire to sit by the bedside at all times can both hinder the nurses in their work and be a risk for themselves. The nurses stated that it was common that relatives captured the infectious diseases on the ward while sitting by the bedside. This resulted in that they came back, but this time as a patient, which increased the burden of disease. The ongoing negative spiral that this caused had an impact on both nurses, relatives, patients and the health care as a whole.

9.3.5 Nurses experience of being dependent on relatives
In the care can the relatives be called carers without taking any regard to whether the relatives have the ability to nurture (Carlsson & Wennman-Larsen, 2014). The nurses expressed that it was a challenge that they had to rely on the relatives to take great responsibility in the care of the patients. How much responsibility the relatives could take and how well they could collaborate with the nurses depended on the relatives’ level of understanding. This can be compared to the relatives’ ability to understand and exercise the care that were needed of them.

The relationship between the family and the nurses may be related to how the family understand the information they receive. Once they understand, they feel accepted and treated well. If on the other hand, they do not understand, the family members can withdraw or act in a way that creates misunderstandings between the family and the nurses. The nurses can experience this as that the family-members are accusing and questioning their work (Benzein et al., 2014). The nurses’ themselves illustrates that the problem of caring was guided to de level of understanding the relatives had regarding nursing care. It was evident in the results that nurses felt observed and questioned in their work, which according to Benzein et al. (2014) could be connected to that the relatives did not understand the given information. The nurses’ limitations related to the lack of time, lack of staff and the burden of disease were obstacles to create better conditions in the care. The information and understanding became crucial for what would be a good collaboration between the nurse and the relatives, or what would be a collaboration filled with misunderstandings, accusations and questions subsidence’s.

The results indicated a mutual relationship with the relatives in order to provide support to each other. According to Benzein et al. (2014) the opportunities to find internal and external resources increased if people share each other’s perspectives. The nurses had a heavy workload and the relatives had a great responsibility in the care of the patients. It was apparent in the results that the nurses were depended on the relatives, because of the dependency the nurses were required to see the care situations from multiple perspectives.

According to Powell and Hunt (2013) it is demanding in both time and energy to provide physical care and there exist serious doubts about the relatives’ ability to meet the caregiving needs. It was not only the nurses who were affected by the lack of time, lack of staff and the burden of disease. The relatives had to carry a heavy workload. In many cases, they had neither the knowledge nor the ability to provide the care that was needed of them. The relatives are therefore dependent on the nurses to give them support, while the nurses are dependent on the relatives’ support in order to provide better care to the patients. Because of that nurses and relatives become dependent on each other to provide the care needed for the patient.
10. Conclusions and clinical implications

10.1 Conclusion
The relatives had a great and important role in the medical awards, they helped and assisted the nurses with the basic care of the patient. Although the relatives should not have the responsibility required of them, the nurses needed them for support. Because of the lack of time, lack of staff and the burden of disease. One conclusion was a great need for more nurses.

The nurses involved the relatives mainly by informing and educating them. This was to be able to get assistance from them and because the relatives were the ones who would take care of the patient after discharge. Collaboration between the nurses and the families were of great significance and may be what helped or hindered the nurses’ work.

10.2 Clinical implications
The study was not generalizable and only pointed to how a small group of nurses perceived the involvement of the relatives in the care. Since the area in general were not very researched it required more future research. What the study could do were to highlight the differences in the involvement of relatives depending on conditions in the country. The result may have been of clinical benefits to nurses who work globally in other countries, so they could apply the knowledge in their work. As well as nurses in Sweden could take advantage of the knowledge in the care of patients from Africa. For the Zambian nurses the study could provide wider knowledge of the facts that nurses in general struggle with the implementation of family nursing in the care.

According to Benzein et al. (2012) is it important that the nurses can see both their own and the families’ strengths and resources. The results of the study could provide a wider perspective of the difficulties nurses faces with implementing the family nursing into practice. It can show that family nursing demands time, patients and knowledge. It is important that the nurses are aware of that family nursing are difficult, but that it can play an important role in the health promoting work for the whole family.

10.3 Suggestion for future research
Research on family nursing are being developed more and more. But still there is not much research with a global spectrum, and much of the research focuses on the involvement of family members in pediatric care. Although research on family nursing has begun to emerge it require more research on the basis of both nurses and relatives' perspective. This is so the research becomes evidence-based and can be used in practice.

Proposals for future research is to investigate why the nurses find it difficult to use the knowledge and put it into practice. There is need for more basic research about family nursing that investigates differences globally. This is to take advantage of other countries' knowledge to contribute to the development of the care, when family members often play a big role in the care. As all countries, more or less will become more multicultural, it is important to understand the conditions and the different perspectives that exist.

The challenge of future research is faced with when it comes to generating knowledge of families in relation to health and illness, is to intensify efforts to develop existing models and methods, or to create new ones, which makes it possible to conduct research with family as a unit. A clear focus of research towards relationships and interactions, and the interventions within and outside the family, is a prerequisite to supporting families' health in an optimal manner (Benzein et al., 2014).
10.4 Acknowledgement
We would like to thank all the nurses for taking the time to share their experiences. The swedish International Development cooperation Agency (Sida) and Minor Field Study (MFS) for the financial support. And a big thank you to our supervisors Dr. Maimbolwa, Dr. Mwape and also to all the others who has helped us to conduct the study. Lastly, we will thank our supervisor Berthollet Bwira Kaboru at the university of Örebro in Sweden.
11. References


12. Appendices

12.1 Appendix 1: Participant information sheet

Dear participants,

We are two nursing students from Örebro University, Sweden. Currently undertaken a study titled Family involvement in care of a relative in a hospital in Lusaka. The study focuses on nurse’s experience of involving relatives in care, which role the relatives have, how the relatives are involved, and what type of measurements or/and guidelines regarding the relatives in care there are. The research will be conducted under the supervision of Dr. Maiwbolwa.

The interview is estimated to take approximately 40-60 minutes and the questions will focus on gaining a deeper insight into family involvement in care. The interview will take place when you are ready and at a place suitable for you. The study will not result in any advantage or disadvantages to you. Taking part in the study is voluntarily and you can withdraw whenever you want without any consequence or having to give a reason why and you still remain on the job.

The interview will be tape recorded. All the data that is provided by you will only be used in accordance with the purpose of the study. All the material will be kept confidential and after the processing is complete all the material on the tape recorder will be deleted. Therefore, participating in the study is anonymous that is we will not ask for your names, initials or address, and no one will be able to identify you in the results of the study when these are published.

If you later on wish to withdraw your consent or have questions concerning the study, you may contact:

Principal supervisor: Dr. Margaret Maimbolwa
Email: mmaimbolwa@yahoo.com
Phone number: +260 97 7800067

Vice chance person: C. Nzala
Research Ethics Committee
Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia
Petra Söderquist

Address: Nygatan 29, 702 11 Örebro
Email: Petra.soderquist@gmail.com
Phone number: +4670 – 56 20 801

Michaela Thuresson

Address: Stallgatan 12, 702 26 Örebro
Email: michaela.thuresson@gmail.com
Phone number: +4673 – 39 40 992
12.2 Appendix 2: Consent form
I understand the purpose of the study, how the data is collected, handled and that it is kept confidential. I also understand that I participate voluntarily and can withdraw at any time without giving a reason why.

I have read and understand this consent form and agree to participate in the study.

Please if any questions about the study or interview feel free to contact us.

Best regards, Petra and Michaela.

___________________  ___________________
Signature of participant                  Date

___________________  ___________________
Signature of the interviewer                  Date

___________________  ___________________
Signature of observer                  Date
12.3 Appendix 3: Interview guide

Presentation of the study and short about the interview

- Time required: approximately 1 hour.
- Topics that was addressed: Approaches and guidelines regarding the involvement of family members in the care of a patient.
- The questions focused on getting a deeper insight into how the families were involved in the care in Zambia.
- A tape recorder was used during the interview and when processing was completed, the contents of the tape was deleted. The processed text was kept inaccessible to unauthorized persons.
- There was time for questions before the interview starts.

Background facts

- Gender
- Age
- Role
- Work experience

Finally

If the interviewee had any questions or anything else they wanted to take up before the interview ended.

Semi-structured interview questions

1. What role in the care do the relatives have?
2. How do you involve the relatives in care?
3. What positive aspects do you see regarding the involvement of relatives in care?
4. What are your guidelines regarding family-focused/family-centered care?
5. What kind of social support do you have regarding the relatives in care?
12.4 Appendix 4: Questionnaire

Background facts

- What profession do you have as a nurse?
- How long have you been working as a nurse?

Semi-structured interview question

- What role in the care do the relatives have?
- How do you involve the relatives in care?
- What positive aspects do you see regarding the involvement of relatives in care?
- What are your guide lines regarding family-focused/ family-centered care?
- What kind of social support do you have regarding the relatives in care?
24th November, 2016

RE: ADMISSION TO THE UNIVERSITY OF ZAMBIA, SCHOOL OF NURSING SCIENCES

This letter is your official admission letter for you to come and study at our university from 16th January 2017 for eight weeks. You will take a course in research during this period which will be coordinated and supervised by Dr Margaret Maimbolwa.

Your research proposal has been received and is currently going through the review process by your supervisors in the School. Reviewers' comments will be sent to you through Dr Berthollet Kaboru Bwira who will then share them with you.

We look forward to hosting you.

Yours sincerely,

Dr Lonia Mwape (PhD)
SHADOW DEAN
RE: ADMISSION TO THE UNIVERSITY OF ZAMBIA, SCHOOL OF NURSING SCIENCES

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We look forward to hosting you.

Yours sincerely,

Dr Lonia Mwape (PhD)
SHADOW DEAN
12.6 Appendix 6: The ethical approval

THE UNIVERSITY OF ZAMBIA
UNZA-SCHOOL OF MEDICINE UNDERGRADUATE RESEARCH ETHICS COMMITTEE

22nd February 2017
Petra Soderkvist and Michaela Thuresson
Nygatan 29
70211 Orebro
Sweden

SUBJECT: REVIEW OF PROPOSAL

Reference is made to your submitted proposal to UNZASOMUREC in February 2017 entitled “Family Involvement in Care of a Relative in a Hospital in Lusaka Zambia.” The committee is satisfied that your proposal meets the minimum ethical and scientific requirements. Therefore, your proposal is approved. Conditions of approval are as follows.

1. The approve only applies to the reviewed proposal only. If any significant changes are made to proposal especially the methodology, you will need review from the committee.

2. Your approval is only for one year.

Yours sincerely,

Chairperson - UNZASOMUREC