

# SAHLGRENSKA AKADEMIN INSTITUTIONEN FÖR VÅRDVETENSKAP OCH HÄLSA

# VIETNAMESE AND SWEDISH NURSING STUDENTS' ATTITUDES TO PALLIATIVE CARE.

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# **Foreword**

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## Abstract:

When it comes to taking care of someone who is ill and dying, there are cultural differences regarding the role of the relative and the knowledge and access to palliative care differs between countries. The purpose of this study was to investigate Swedish and Vietnamese nursing students' attitudes to palliative care. The method used was semi-structured interviews, which were performed in Sweden and Vietnam. A total of 17 interviews took place. The results reveal that in Sweden the individual is the main focus whilst in Vietnam it is the family. The decisions in Vietnam are made by the family and in Sweden the participants say that the decision should belong to the patient. The access of palliative care in Vietnam is limited, due to expensive care and therefore, the use of it is unusual compared to Sweden where it is an essential part of health care. In both countries the participants want what is best for their families. More research is needed to gain a wider understanding of different cultures and the attitudes to palliative care. By broadening the knowledge, it will hopefully improve the health care and the different aspects that needs to be considered when it comes to palliative care.

Key words: palliative care, individual, family, Sweden, Vietnam, nursing student, qualitative.

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### 1. Introduction

The World Health Organization (WHO) states that:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organization, n.d "WHO Definition of Palliative Care", par. 1).

From the start, palliative care was only meant for cancer patients but is now more common for other patient groups in need of palliative care. The use of palliative care has been known since the Middle Ages and later came to develop in the twentieth century through writings and lectures. It was emphasized that the patient's needs can vary a lot at the end of life and that it needs to be considered when caring for patients. Even though pain management and symptom control are the main focus within palliative care, it is equally important to create meaningful time. This requires an interaction between many allied parts of the patient's surroundings which can include both palliative care professionals and relatives; whom may have different cultures and experiences (Randall & Downie, 2006).

The aim of this study is to investigate the attitudes nursing students have to palliative care in Sweden and Vietnam. The experiences and approaches to palliative care is something that needs to be considered since it can differ between patients, caregivers, relatives and cultures. In the future we might provide palliative care for patients and their relatives, where some might have different culture background. Therefore, it is important to find out more within this topic to be able to provide good quality clinical care in our future profession.

# 2. Background

#### 2.1 Palliative care

When it comes to palliative care, pain management is one of the most difficult areas. One of the reasons why this can be hard to manage is because pain is often multidimensional. This can be described with the help of Dame Cicely Saunders "total pain" term where the social, spiritual, physical and psychological types of pain are included. The total pain term is common in palliative care and can be a challenge for the health care staff since it is complex. Many different components can be the cause of the pain which can make it hard to manage (Mehta & Chan, 2008). In 1967, Dame Cicely Saunders opened a hospice which was the start of the extensive hospice movement. The reason for the movement was the people's reactions to the inhumane way of dying. Because of this hospice movement, palliative care spread around the world and became fundamental for the health care (Aranda, 1999).

WHO (n.d) states that palliative care is about the patient as well as about creating a peaceful time for the family since a disease often affects them too. Therefore, a supportive system should be offered to make it easier for the family. At the same time, palliative care does not mean that the death should be hasten or postponed, instead it is about not exposing the patient or family to unnecessary suffering. Ternestedt, Österlind, Henoch and Andershed (2012) state that an essential aspect when it comes to palliative care is the relief of suffering. This includes

the relief of symptoms and being aware of how certain health issues can affect the wellness of the patient. Suffering consists of several aspects which are the psychological, social, existential and physical needs and problems the patient might have. By focusing on the relief of suffering, the patient's self-esteem will be maintained and the patient can die as "healthy" as possible.

#### 2.2 Palliative care in Sweden

Since 1970, palliative care has grown gradually and is today an essential part of the Swedish health care. For the last 20 years, it has grown more rapidly and the awareness has increased (Henoch et al., 2016). When the research of palliative care in Sweden developed, four different categories were created; the patient, relationships, caregivers and dignity at the end of life (Ternestedt et al., 2012). In 2009, the first document of guidelines on how to practice palliative care was established. Three years later, a review of Swedish policy document was released, investigating knowledge about palliative care and human rights. From this review, several quality indicators, such as assessment and treatment of pain, were identified and it was discussed how to give the patient the best care possible by using the guidelines. The intent is that through a continuous development of these guidelines, the quality of palliative care will improve even more in Sweden (Lind, Adolfsson, Axelsson & Fürst, 2013).

A model frequently used within palliative care is the 6 S model, which is the theoretical reference frame used in this essay. Ternestedt et al. (2012) state that the 6 S model is based on Dr. Weisman's writings. Weisman stresses the importance of maintaining self-esteem and social relationships of patients at the end of life as well as giving sufficient symptom relief. The development of the model started during the 90's and is focusing on giving the patient a worthy end of their life by receiving health care based on these six areas. Maeda et al. (2016) state that an extensive part of palliative care is symptom relief as well as providing care using a holistic approach. The authors present how palliative care is multidimensional by maintaining relationships and preserving the patient's self-image by continuing their everyday life to the maximum extent possible. These aspects can be seen in the 6 S model where these, among others, are in focus. These aspects need to be in consideration in order to accomplish a worthy death. Ternestedt et al. (2012) explain that the core in the 6 S is person centered care which is about the patient being in the center where the important people for the patient are included. The person centered care is based on the humanistic approach which focuses on how every person is a conscious, social and reflective human throughout their life. It is essential that the patient is viewed from a holistic perspective where the social, existential, spiritual, physical and psychological aspects are included.

The model consisting of 6 areas can be used to ensure that palliative care is given through a person centered and holistic perspective (Ternestedt et al., 2012). The areas are listed and described below.

- Self-image: Preserving a positive self-image, so patients can be able to live their everyday life as normal as possible.
- Self-determination: Making patients (and relatives) active partners in their care and in the decisions that must be made.
- Social relationships: Encouraging and providing possibilities to maintain social relationships that are important for the patient.

- Symptoms relief: Trying to relieve all physical, emotional, social and existential symptoms that can occur during the course of the disease until life is ended.
- Context: Letting the patient converse about and interpret their life and therefore achieve a feeling of context. This will reflect on the patients existential and spiritual needs.
- Strategies: Acknowledging the patients' possibilities of approaching death in their own way for example by offering a conversation about expectations, fears, their funeral or how they want to be remembered (Ternestedt et al., 2012).

A survey study done by Westerlund et al (2018) presents that the public awareness of palliative care is quite low and that 84 percent of the participants had little or no knowledge of it. Reasons discussed for this lack of knowledge is a general fear of talking about illness and death, where the unknown is frightening and thereby a social taboo. For example, the fear of dying was considered difficult to discuss, even with the closest family members. Younger people had the least awareness and the authors concluded that, by open discussions, the knowledge about palliative care could increase. According to Ternestedt et al. (2012) Sweden is an individualistic society where people tend to themselves, which could hinder these open discussions.

#### 2.3 Palliative care in Vietnam

In 2005, Vietnam's Ministry of Health initiated palliative care, since the Ministry had detected an increased need for it amongst patients suffering from HIV/AIDS and cancer. When initiating this process, it became clear that there was a significant need for support, education and increased knowledge of symptom and pain management. Since then, palliative care has grown within the Vietnamese health care system but still one barrier concerning pain relief is that Vietnam, in general, is a country that has a fear of opioids. This fear has its roots in Vietnamese history and in the laws, opioids are described using pejorative language. This is attributed to a lack of knowledge and results in poor accessibility and usage of opioid analgesics which are often crucial in palliative care (Krakauer, Cham & Khue, 2010).

A study done by Nguyen, Yates and Osborne (2014) investigated Vietnamese nurses' competence and knowledge within the area of palliative care. They found that a majority of nurses do not speak about death with their patients nor do they explain the process of dying to the family members. The reason the participants gave was that this is not their obligation as nurses. The authors discuss that a contributing factor might be that the nurses in Vietnam do not have the amount of time needed for these types of dialogues. Furthermore, the study presents that the nurses do not have enough knowledge concerning psychological and spiritual wellbeing nor about pain and symptom management. Despite this, the knowledge about the principles behind palliative care was found to be quite high. The authors note that there is no training at all on palliative care in Vietnam which can be a reason for the results found (Nguyen, Yates & Osborne, 2014).

In Vietnam where Buddhism is the leading religion, death is considered a natural and certain part of life. Karma is something a Vietnamese Buddhist believes in, which means; what one does in this life will reflect upon them in their next life (Nichols, 1997). In a study by Donovan and Williams (2015) the results present that caring for your ill or elderly family member is considered the right thing to do regardless of the age of the ill person or length of

time providing care. One participant in the study expressed that caring for a family member is something one does without the need to think twice about it. The reason for this act of caring is that the person who is now ill took care them while growing up and now it is time to give something back and take care of them instead. The needs of the family are valued higher than the needs of the individual. Another example, from the same study, was how one participant chose to take care of her sick mother, even though she had to leave school, since she viewed it as her duty to do so. Further, she explained that she did not see this as a sacrifice because she could continue her life after being the caregiver. Caring for your family members is seen as a token of love. Vietnam is a country with a household structure where the man is working outside the home and the woman does the domestic work and takes care of the family. Being a caregiver is hence seen as a natural part of being a woman and a Vietnamese man or boy would usually not help a family member with their personal hygiene. In addition to this, many Vietnamese want to maintain their privacy and do not want help from non-relatives which sometimes results in suffering of the ill (Donovan & Williams, 2015).

## 2.4 The newly graduated nurse

Odland, Sneltvedt and Sörle (2014) describe that the transition from nursing student to nurse is often difficult since they no longer have the supervision they are used to. Many new nurses feel that they lack competence and that there is a gap between what they have learnt in school and the actual practice of nursing. That feeling of not being sufficiently prepared can be shocking as well as dealing with the responsibility nursing entails. At the same time, they were expected to be efficient in their daily duties. Facing patients with grave illness is especially challenging to the newly graduated nurse. It can be difficult to find the right words when speaking to patients and family members as well as to take appropriate action when knowledge and experience is lacking. Cain, Surbone, Elk and Kagawa-Singer (2018) state the patient's cultural background might affect how they view palliative care. Cultural differences are commonly misunderstood, particularly if the health care staff has another background than the patient. This lack of knowledge can result in lower quality regarding the palliative care.

We chose to interview nursing students since they, like the authors of this essay, soon will graduate and face the challenges that are explained above. We hope that by performing this essay, it will bring forward knowledge about palliative care and probable cultural differences that can later be used when working as a nurse and meeting this patient group.

#### 2.5 Problem definition

Providing palliative care is a complex task even for the experienced nurse and even more so for the newly graduated nurse. The 6 s model can be a guidance in providing high quality care at the end of life through focusing on self-image, self-determination, social relationships, symptom relief, context and strategies. Cultural differences can further add to the complexity of providing palliative care. The meaning of, for example, self-determination and social relationships can differ between a country with an individualistic culture, such as Sweden, and a more family oriented culture like in Vietnam. A lack of understanding of such differences can lead to misinterpretations and unnecessary suffering when caring for a patient in need of palliative care. Nursing students will soon graduate and face these challenges and therefor it is of interest to explore their attitudes to palliative care.

# 3. Aim

The aim with this study is to investigate attitudes to palliative care among nursing students in Vietnam and Sweden.

#### 4. Method

# 4.1 Study design

In this study we are investigating the attitudes Swedish and Vietnamese nursing students' have to palliative care. Since this is our aim, it is suitable for us to do a qualitative study. Most qualitative studies are done through interviews as this method provides a right insight of the subject. The interview method used in this essay was semi-structured interviews, which contains open questions that allows the participant to speak freely and the questions do not have to be in a certain order (Danielson, 2017b).

## 4.2 Selection of participants

Danielson (2017b) states that a decent number of participants is 20 when performing interviews with open questions. While there might a be a loss of participants, it ensures that a fair number of data will be collected. A lower number of participants might result in not enough information, the goal was therefore to recruit ten nursing students in each country. One man and 16 women participated and the interviews were conducted in Sweden and Vietnam.

At Sahlgrenska Academy, Sweden, palliative care is introduced in the third semester of the nursing program. We used the network GUL, which is the platform lecturers and students use, to send out a question to nursing student in semester five for participation in the study. We recruited six students through this and the remaining four participants were recruited from our class, in semester four. This is called a convenience sample where accessibility and geographical factors are taken in consideration. With this type of sample, the participants must have certain characteristics which suits the purpose of the study (Dörnyei, 2007), in this case being a Swedish nursing student. For the Vietnamese students a convenience sampling was yet again conducted. Through our supervisor Mr. Trung in Hanoi, we got in contact with a student in year four whom we interviewed along with two of her classmates. We also contacted a student in year five whom we met in Sweden when she had her exchange at Sahlgrenska Academy. She brought three other students for us to interview.

Taking part in the study was voluntary and every informant had the right to terminate their partake at any time if they wished. The participants were informed that all answers would be anonymous, but not coded, once transcribed. All this information was given orally. In this study certain inclusion criterias were used, which are specific characteristics that the participants hold (Polit & Beck, 2004). Since the aim of this study was to learn about Vietnamese and Swedish nursing students' attitudes, the informants in Vietnam needed to be of Vietnamese origin and the ones in Sweden of Swedish origin. Exclusion criteria can be explained as certain criterias that the participants are not allowed to have (Polit & Beck, 2004). It did not matter if the student had been absent for a semester or what year they were in. We did not exclude anyone because of their level of knowledge since the study is focused on the attitudes of nursing students, not on how much they know about palliative care.

#### 4.3 Data collection

The participants and the authors agreed to a time that was suitable for both parts regarding the interviews. Appendix 1 shows the questions used in the interviews in both countries. The wording of question number nine, see appendix 1, was changed during the study. At first, this question was a closed, only asking whether or not they would take care of their family member when in need of palliative care. During the first interview, the participant did not know what to reply followed but a moment of silence. We then decided to add the last part of the question; "or will you leave that the health care staff?". When this was changed no one else expressed this type of confusion. Some participants answered two questions in one which resulted in us not asking that person every question due to no need for repetition. All interviews were performed individually and were recorded on mobile phones. As the focus was on the participants and their answers, notes were not taken during the interviews.

The interviews in Sweden were executed at Gothenburg university, some at the school café and some in private study rooms. We wanted to perform the interviews at the university, this to have the participants as comfortable as possible and to elaborate freely. Each interview lasted around 10-15 minutes and the main part of the discussion was about the questions asked. We spoke Swedish because it is the mother tongue of the participants and the authors. By doing so it was probably easier for them to answer the questions with the possibility to elaborate without any misunderstandings.

In Hanoi it was not easy to find secluded and quiet areas to perform the interviews as to why we did it in a café and in a dormitory. The interviews were recorded on mobile phone and each lasted around 20-25 minutes. Some part of the interview was a discussion about the differences between Sweden and Vietnam as well as some further explanation of the questions due to the language barrier. Some concerns regarding the need of a translator were discussed, but once conducting there was no apparent need of this. There were some silences where it was clear that the informant did not understand the question, and we had to explain it using other words. Once the interviews were recorded, they were divided between the two authors and transcribed. The reason for the division was because of the timeframe and number of interviews. The authors transcribed the recordings word by word and listened carefully several times. After this, both authors approved the transcriptions.

# 4.4 Data analysis

A qualitative content analysis was used to analyze the data. This method is appropriate to use when the data is collected through interviews (Danielson, 2017b). We chose to do a manifest analysis where the data is processed into categories and subcategories (Fridlund & Mårtensson, 2017). When using the manifest analysis, data is analyzed in a descriptive way and no interpretations are made. This can be compared to a latent analysis where an interpretative approach is used (Danielson, 2017b). It is essential to read and reread the transcriptions to make the analysis as clear as possible in order to not miss essential data. An inductive approach was chosen since the aim of the study was explorative and not based on a specific theoretical understanding (Henricson, 2017b). When using an inductive approach, one should observe a certain phenomenon, in this case attitudes to palliative care, and thereafter describe the phenomenon. Afterwards the author can try to create a conclusion that could be transferable on similar contexts unlike the deductive approach where the authors are creating assumption based on a theory (Priebe & Landström, 2017).

After reading the data, with a few days between every reading, we searched for meaning units to organize all the collected data. We categorized and looked for patterns in the data to find the most important findings. After finding useful units they were condensed to make it ever more perspicuous. Thereafter different codes were created to see what patterns appeared as well as similarities and differences between them. Using these codes, subcategories were found which then formed categories (Danielson, 2017b). This process is presented below in Table 1.

Table 1. Data analysis schedule

| Meaning units  | Condensation                                   | Code     | Subcategory  | Category                  |
|--|--|----------|--|---------------------------|
| "No focus on palliative care in Vietnam so you don't see it often. We don't have the real definition of real palliative care on our system."   | No focus on palliative care in Vietnam.        | Focus    | Knowledge of palliative care                                       | Access to palliative care |
| "In Vietnam we depend of family decision even if the patient is conscious. We ask the family what to do with the patient. But I think we should focus more on the patient because they have the right to decide what should happen to them." | We ask the family what to do with the patient. | Decision | The decision maker   | Family relationship       |
| "If you don't have enough money you can't receive palliative care."  "If the family cannot afford to pay for treatment the patient does not receive any."  | If you have no money you do not get care.      | Money    | The cost of health care – a major difference between the countries | Access to palliative care |

| "I would have tried to care for them as much as I could but you also have to be realistic and might have to get help from a nursing home or similar."  "I want to say that I would. But I would be there in an emotional way and physical but I would leave the everyday-care to health care personnel." | You have to be realistic, might need help from a nursing home. I would be there in an emotional way. | Realistic, help | Big differences<br>when it comes to<br>taking care of a<br>family member<br>in need of<br>palliative care | Family relationship       |
|--|--|-----------------|---|---------------------------|
| "I would like to die in a place where I feel comfortable and happy, if that is a nursing home or my apartment I don't know."  "With my family, in my home, but I wouldn't want to burden my family so it might be better at a hospital and similar."   | With my family at home but have heard good things about hospice.                                     | Family, home    | Final wishes  | Access to palliative care |

#### 4.5 Ethical considerations

When performing a study that includes humans, ethical considerations must be made. This is not needed in an essay on a bachelor level though (SFS 2003:460), therefore we did not apply for an ethics approval. The participants were given oral information about the aim of this study. We did not let the need of data exceed the rights of the participants and the interviews were done respectfully by not forcing anyone to answer if they did not want to. The interviews were done in a way to protect the individuals and confidentiality was of essence, all done in accordance with WMA (2018), the declaration of Helsinki. The subject that was investigated might, for some participants, be sensitive but no informant was required to answer a question they felt was upsetting. The recorded interviews were not coded but anonymous. They were transferred from a mobile to a computer with a password, meaning that no outsider could get hold of them. The transcripts were also kept on the computer, all of this to protect the participants and their anonymity. When the essay is approved, all data collected will be destructed.

## 5. Results

When the data had been analyzed, five subcategories appeared; big differences when it comes to taking care of a family member in need of palliative care, the decision maker, final wishes, knowledge of palliative care and the cost of health care – a major difference between the countries. The first three subcategories created the category family relationship and the last two created access to palliative care. The categories and subcategories are presented below in Table 2.

Table 2. Categories and subcategories

| Category                  | Subcategory  |
|---------------------------|--|
| Family relationship       | Big differences when it comes to taking care of a family member in need of palliative care  The decision maker |
| Access to palliative care | Final wishes  Knowledge of palliative care  The cost of health care – a major difference between the countries |

# 5.1 Family relationship

This category has two subcategories which are big differences when it comes to taking care of a family member in need of palliative care and the decision maker. The participants in both countries explain that they would like to help their family members as much as possible when needed, which is further explained in taking care of a family member. The Swedish students explain that the focus should be on the individual when it comes to palliative care and decisions whilst the Vietnamese keep focusing on the importance of making family decisions. This is further explained in the decision maker.

# 5.1.1 Big differences when it comes to taking care of a family member in need of palliative care

Only two participants in Sweden give an absolute yes when asked if they would care for their family member while in need of palliative care. In Vietnam, on the other hand, every participant say that they would provide care. They explain this by saying that the older generation depend on them and that they want their children to do the same for them when needed. This differs from Sweden where one says:

"I would have tried caring for them as much as I could because I have the competence. But you also need to be realistic, you have your own life and we are living in a society where we are not caring for many generations in the same home as you do in other countries."

Some participants in Sweden will take care of their family member in need of palliative care but only to a certain level. They will provide emotional support but will leave the everyday care to health care professionals. The reasons stated for this is that palliative care can be hard work and very demanding. They also say that it is important that the family member is comfortable with them taking care of him or her, otherwise they will not do it. One Vietnamese participant say that the only time she will not care for the family member is when she will have to work. Since she is an only child, she might have to hire someone to take care of the family member during the time she is working, which is understood as the right thing to do when you cannot care for the person yourself.

#### 5.1.2 The decision maker

Many generations live together in Vietnam and the older family members depend on their children to make decisions for them. This also affects the decisions when it comes to palliative care. Only one participant from Vietnam say that the decisions regarding care belongs to the patient since it is their life. The others say that the family should be the one making the decisions and one motivates this by saying:

"The palliative care is about the individual patient but also its effects and impacts the relatives and the family and not only the patient. The mental pain is not only for the patient but for the whole family so their whole family needs to decide palliative care."

Most of the Swedish participants are in agreement that it should always be the patient who makes the decisions. The fact that the family do not always know what is best for their loved one is discussed and one of the participants expresses:

"It should be the patient. I think the family will always want curative treatment even when the patient may not want it. If they will keep treating the patient it might lower the quality of life."

In Vietnam, even when the patient is conscious, the family might not give him/her all the information they have received from the doctor. The reason being that they do not think the patient should decide and accordingly not knowing all the information is in their best interest. The mentality to want what is best for your family member is thus the same in both countries but the Swedish participants keep their focus on the individual by stating that the dying person's wishes are more important to consider than the family members'.

Another similarity between Vietnam and Sweden when it comes to decision making is that it depends on the state the patient is in. Some Swedish participants express that the patient should be the decision maker as long as it is possible and diagnosis has to be considered. If the patient is not sensible enough the decision should belong to the family with support from health care professionals. By doing this, these participants find that the best decision possible can be made. In Vietnam many mention that a patient who is in need of palliative care might not be in the state of mind to make decisions. Therefore, it should be the family who decides instead of the individual.

# 5.2 Access to palliative care

This category has three subcategories which are *final wishes, knowledge of palliative care* and *the cost of health care – a major difference between the countries.* When it comes to final wishes, most participants emphasize the importance of being around loved ones. In Sweden

nursing students have a compulsory course in palliative care, whilst in Vietnam they do not. This is further explained in *knowledge of palliative care*. The cost of health care in Vietnam limits the possibilities and access to palliative care whereas in Sweden this is not discussed.

#### 5.2.1 Final wishes

Some of the participants from Sweden have no wish in where they would like to spend their last days but state that the important thing is that it is in a place where they feel comfortable. In Vietnam, they have similar thoughts where a strong wish to be around their loved ones is expressed. The word peaceful is mentioned, which can be compared to the Swedish participants who speak about the importance of the environment being stress, anxiety and pain free and the importance to not suffer.

One participant from Vietnam mentions that her wish is not to die in a hospital because of the stressful environment. Another say that if she is not close to her family, she would like to spend her final days at a hospital. This is also mentioned in Sweden where hospital was seen as an option if they would be comfortable there. Hospice is mentioned by some as an alternative to hospital, whereas this do not seem to be an option among the Vietnamese participants.

One participant from Sweden mentions that she would prefer to die at a nursing home so that she will not be a burden to her family. This is mentioned repeatedly among the Vietnamese nursing students where there is a strong wish to not burden their families. Yet, the strong bonds within the family is often mentioned and how everyone is taking care of each other is put forward as an ideal by most participants.

#### 5.2.2 Knowledge of palliative care

According to the participants, palliative care is very limited in Vietnam and that there is no focus on it, neither at the nursing program nor at the hospital. Only two of the Vietnamese participants have been in contact with palliative care through school. Whereas in Sweden all the participants have received knowledge on palliative care through school and some also got experience through clinical training. Some participants from Sweden also have personal experience due to family members needing palliative care. One participant from Vietnam answers the question "is there anything you would like to change about palliative care in your country?" with:

"The palliative care is not focused on the mental health. We don't have enough staff to care about that."

All participants from Vietnam agree that palliative care is very important but state that the two palliative departments they know of are not really based on palliative care models. For example, patients might receive pain relief but no emotional or psychological support. They discuss that the Vietnamese health care system needs more knowledge and focus on palliative care. The opinion that palliative care is important is also mentioned by the Swedish participants.

The participants mention that in Sweden there is a compulsory course about palliative care at the nursing. One Swedish student also mentions that another course on palliative care is

offered later in the program. At the nursing program in Vietnam, on the other hand, they take courses on rehabilitation but the focus is still on treatment and cure. Because of this, all the participants in Vietnam express a wish to learn more about palliative care. When asked the question "do you think palliative care is a subject that should be talked about more? If so, why?" one of the participants answers:

"Yes of course! It's a thing that is coming in the near future. As nursing students, we have to learn more and have to do it more in clinical placement and theory."

This is also evident among the Swedish participants that all mention the wish to have more knowledge and experience of palliative care as well as a need to speak about death and dying in general. Even though the palliative care is more common in Sweden than Vietnam, all participants from both countries express the wish for and need of more knowledge. The reason for this being that the subject is seen as an important part of the health care practices in both countries.

#### 5.2.3 The cost of health care - a major difference between the countries

Getting access to health care and medical treatment is, according to the Vietnamese participants, expensive. Although some have health insurance it does not cover everything and if the family does not have the financial means to pay for treatment the patient will simply not receive it. One participant states that morphine is not given outside the hospitals, but if you have the money you can buy anything, even though the law forbids. The issue of money and finances in relation to health care access is not mentioned by the Swedish participants. The Vietnamese students also mention how the older generation depend on the family financially because they do not work and have no income of their own.

One participant from Vietnam explains that there is not enough health care staff in the hospitals which means that at least one family member must stay there to take care of the patient. This results in less income and a lot of stress for the family and is one of the reasons why a hospital stay might not be an option. This issue is not mentioned in Sweden where the hinders and possibilities for caring for a family member relates to being realistic in terms of time and ability.

# 6. Discussion

#### 6.1 Method discussion

Mårtensson and Fridlund (2017) describe that credibility with regards to qualitative studies implies that researchers should be able to prove to the reader that the knowledge found is reasonable and that the results are valid. This could be achieved by letting a "critical other" review the data. Dependability means that preunderstanding, the effects of this and how the interviews and transcriptions were carried out should be thoroughly described. For the study to have confirmability, the data analysis process should be accurately described, the decisions made explained, and by letting an outside person review the work (Mårtensson & Fridlund, 2017). We strived for dependability and confirmability by explaining and carefully describing every step in the work with the study. Furthermore, we recorded the interviews, transcribed them word by word and both of us read the transcripts multiple times to make sure that our

results correctly reflected the participant's opinions. Our supervisor read our work along the way which further increases confirmability and credibility.

Since the authors are nursing students and have studied palliative care at the nursing program, having a certain preunderstanding on the subject is inevitable. Preunderstanding implies a certain understanding and knowledge about a subject before starting out an actual study. Preunderstanding might also come from life experiences outside of school which makes them even harder to distance oneself from (Priebe & Landström, 2017). Instead of trying to distance oneself from preunderstandings one can be aware and mindful of them which has been taken in consideration throughout the study.

For the result to have transferability, it should be possible to transfer the results on other groups, situations and contexts. The results also need to be described clearly and the study should be considered to have credibility, dependability, confirmability (Mårtensson & Fridlund, 2017). Most of the Vietnamese students had similar opinions as well as the Swedish, which could point to a transferability to other nursing students or maybe even other groups of people in the two countries. But, because we cannot fully say that the study has credibility, dependability and confirmability, it means that it might not be transferable either.

One challenge with a data collection through interviews is to not steer the informant into a certain direction and it is therefore important that the person in charge of the interview is aware of this and reflects throughout the process. Furthermore, it is of essence to question who the most suiting informants are for the subject and if the best method will be used (Elo et al, 2014). Semi-structured interviews were a suiting choice of data collection since it contains open questions and which allowed the participants to speak more freely. This also meant that one does not steer interviewees into a certain direction, which can be considered a strength. The interviews resulted in a rich and informative data on the opinions to palliative care in the two countries, which was also the aim of the study.

Being mindful of ethical aspect is very important when conducting a study based on interviews. We made sure that the participants knew it was voluntary and that they were not forced to answer any questions they felt was of a sensitive nature. Furthermore, we asked them if we could record the interview and made sure they knew that we would not reveal their identity. The sufficient number of participants has to be judged in relation to the aim of the study and when collecting data through semi-structured interviews striving for 20 participants was deemed enough (Danielson, 2017b). We believe that the recruitment process in Sweden was good as it was evident to the participants that is was voluntary to partake. However, as the Vietnamese participants were recruited through a teacher at the school, we cannot be sure that they wanted to partake in the study. We must acknowledge the fact that maybe they could not say no as it was an authoritarian who asked them as well as the possibility of the teacher choosing students that represent a certain opinion. These facts must be considered a weakness regarding the study. Although ten participants were the ambition, there were only seven in Vietnam since the others did not appear. Despite this, a saturation was achieved where certain patterns were detected and no new aspects surfaced (Carlson, 2017). Because of this, there was no need for further interviews.

It was easier not to steer the participants whilst interviewing in Sweden as Swedish was spoken which is the mother tongue of both parts. This meant that the participant was asked

the question and we did not have to explain it further. In Vietnam, even though the participants level of English was good, there were at times confusion. This meant that we had to ask them the question again using different wording, which could be a weakness. Despite this, we consider it a strength that we did not use a translator because we think it made the environment more open being only the three of us partaking in the interview situation.

Another possible weakness could be that we did not perform a pilot interview. Danielson (2017a) explains that a pilot interview is used to confirm that the questions are suitable and if they need to be adjusted. Despite not having performed a pilot interview, we discovered during the first interview that one of the questions had to be changed. It is a strength that we then decided to change the interview guide to make the question clearer for the participants. After completing all interviews, we realized that not every question resulted in useful data. However, these questions are still beneficial since they created a more comfortable and relaxed environment.

#### 6.2 Result discussion

The aim of this study was to investigate the attitudes that nursing students in Sweden and Vietnam have to palliative care and the main finding were that in Vietnam the family is in focus whilst in Sweden it is the individual. Differences were found between the countries when it comes to knowledge of and accessibility to palliative care.

#### 6.2.1 Family relationship

In both countries, the family was important to the participants and they were willing to provide their family members with palliative care. This willingness was expressed differently between the countries though. In Sweden the focus was on the individual, where most participants said that the patient should be the decision maker. The Vietnamese, on the other hand, expressed that the family is a unit as they depend on each other and live together over generations and thus should make decisions together. Another difference found was that only two of the Swedish but all the Vietnamese participants would provide care for their ill family member at the end of life. One participant said that she wanted her children to do the same for her. As explained by Donovan and Williams (2015), doing so is considered the right and natural thing to do within Vietnamese culture. The family unit is valued higher than the individual and caring for an elderly or ill family member is justified since they took care of them while growing up. Doing so is also seen as the ultimate expression of love towards the other person.

One Swedish participant said that we do not have a society where we provide care for each other in such a way. Ternestedt et al. (2012) state that the patient and family members can be more satisfied if palliative care can be provided at home but that it also implies responsibility for family, for example regarding symptom control. Such advanced caring responsibilities can be seen as strenuous. Taking care of a family member who needs palliative care results in both positive and negative feelings; being close to the patient is seen as positive whilst the mental and physical stress is difficult to handle. In a study by Linderholm and Friedrichsen (2010) family caregivers were interviewed about their experiences of taking care of their family member. They found that doing so was seen the morally correct thing to do and sometimes as an obligation. A feeling of being overwhelmed because of all the duties it was also expressed since the family member becomes a caregiver. This role includes a lot of

responsibility and puts pressure on the family. They also mentioned the essentiality of having good relationships between formal caregivers, the ill person and the family members. Some positive aspects of being a family caregiver were also found, such as thankfulness and being able to spend valuable time with their loved ones (Linderholm & Friedrichsen, 2010).

Nguyen (2015) describes that when an important decision is to be made in Vietnam, the family is included in the process as you must consider the effects it may have on the family. Although the decision might regard the individual's health, they do not believe in autonomy since collectivity is emphasized. Donovan and Williams (2015) support this as they state that decisions are a family matter where care setting, treatments and lastly funeral arrangements are included. The participants in our study mentioned the family multiple times where only one expressed that it should be the individual that decides. Regionala cancercentrum i samverkan (Regional cancer centers in collaboration) (2016) explain that a big part of palliative care in Sweden is about the patient's right to make their own decisions about the care they receive. However, it is equally as important to involve the family member in the dialogue to optimize well-being. This is of great importance since palliative care does not only affect the patient but the family as a whole. The patient might end up not being able to communicate or express their needs and wishes, as to why the staff need to know who the decision maker is at this stage. This was expressed by the participants in Sweden; the individual should decide since it is their life. Despite the difference between the two countries, the participants in Sweden and Vietnam had similarities in their answer as to who the decision maker should be. This was if/when the patient is not in the state of mind to make decisions, then it should be the family.

#### 6.2.2 Access to palliative care

The result showed that several factors contribute to the differences in accessibility of palliative care. Matters such as cost, lack of health care staff and knowledge are limiting the possibilities to obtain palliative care in Vietnam. In Sweden, it is commonly used and easily accessible (Westerlund et al., 2018) and for the past 40 years, palliative care has grown rapidly (Henoch et al., 2016). Westerlund et al. (2018) state that despite the development, the knowledge is fairly low amongst the general public. The study presented that awareness was higher amongst people working in health care or those with a higher level of university education. One reason presented was that accessibility to knowledge of palliative care is limited. Discussions about the subject are not common where a social taboo of talking about death could be a reason. The authors present strategies to increase the general knowledge of palliative care such as information in schools, informative websites and speaking of the topic to make it more visible.

In Vietnam, palliative care has only been active since 2005 and the possibilities are limited (Krakauer, Cham & Khue, 2010). In a study by Green, Kinh and Khue (2006) the lack of health care staff is considered a reason of not receiving palliative care. Takaskima et al. (2017) explain that the lack of health care staff is an urgent issue in Vietnam, palliative being one of the most crucial areas. Thus, there is a shortage of training and knowledge in several areas where resources are limiting. This contributes to lower quality of care and the overcrowded hospitals are limiting the improvement. This can be confirmed by Nguyen, Yates and Osborne (2014) who present that nurses do not receive education regarding palliative care which can be a reason for the low awareness and knowledge about the subject. The same study showed that >51 percent of the nurses' daily tasks focused on caring for

patients in need of palliative care which makes the knowledge more essential. Neither do the nurses have the knowledge needed about the spiritual and psychological areas of palliative care. This fact can be recognized in a study by Green, Kinh and Khue (2006) where nurses treating patients suffering from HIV/AIDS and cancer were interviewed. It was revealed that only 26 percent knew strategies on how to manage pain. The did not have access to the medicine needed for this type of pain management nor did they have education about pain relief and suffering. Furthermore, amongst this patient group emotional suffering is extremely common, however the support is not great. Many things need to be emphasized for palliative care to reach a level of decent quality. National guidelines are needed, opioids should be easier to access, education needs to expand and the availability of palliative care must improve. Green, Kinh and Khue (2006) state that palliative care education should be part of the basic nurse education. Our participants expressed that they do not learn about palliative care, they focus on the rehabilitation and how to cure the patient. The students expressed that they wish palliative care would become more accessible because of the importance they believe it has.

The results in our study showed that receiving care in Vietnam is expensive and the treatment needed might not be received. The participants mentioned that at times, a hospital visit is not an option because of this. This is presented in a study done by Meyerhoefer, Sahl and Younger (2007) where it is states that the high cost when seeking care in Vietnam has made the access more limited. Thus, it has created a disadvantageous health care system for those with less money. The reason for the high cost is primarily that the financial support received from the public sector is not adequate. The health of every individual affects the economy in the country which makes it even more essential in lower income countries, such as Vietnam. The same study indicated that poor people are higher users of private clinics as these usually are cheaper while wealthier people visit the hospital. Suggestion presented to improve these areas was to reduce the health care cost to increase the quality of care which might be a question of higher taxes (Meyerhoefer, Sahl & Younger, 2007).

In a study performed in Sweden by Harstäde and Andershed (2006) it was presented that trust, participation and safety was emphasized when speaking of the final days of life. Since these three aspects were the definition of a decent place to die, the place of where was not really highlighted, which was a finding in our study. If a place had to be mentioned, a majority in the study said hospital rather than at home where safety was central. Green, Kinh and Khue (2006) conducted a study in Vietnam where they interviewed cancer patients and the results showed that 67 percent expressed a wish of receiving palliative care at a hospital. One reason was regarding the security and the possibility to receive care any time of the day which might not be possible at home. Only a few participants had the wish to receive treatment in other facilities such as hospice. The results in our study showed that in both countries, most participants had a strong wish of being around their loved ones in their last days as well as it being stress free.

The Swedish participants mentioned how they do not want to suffer when in their final days of life, which was not discussed by the Vietnamese. This might be because suffering and the symptom relief is big part of the palliative care in Sweden as well as person centered care. The relief of symptoms is one of the areas in the 6 S model which is inspired by Dr. Weisman (Ternestedt et al., 2012). Since the Vietnamese nursing students expressed that they do not learn about the mental and emotional part of caring, it could possibly result in unnecessary

suffering for the patient. After listening to the participants in Vietnam, we understood that they do not learn about palliative but have a desire to do so. If they were to learn about palliative care from a holistic perspective as Ternestedt et al. (2012) explain, the patient could be relieved of their suffering. This because caring for the patient from a holistic perspective means seeing the patient as a whole and thereby relieving them of symptoms such as pain.

# 6.3 Implications for nursing

The results are useful for health care staff as it gives an insight on how palliative care can differ between cultures. Hopefully it can be used in practical work when caring for a patient with a different cultural background as they will have more knowledge in the area. There are differences between families as to at what extent they should be involved in the care. This might be because of the patient's wishes or culture and must be considered when working within health care. We think that it is of great importance that health care staff are aware and have knowledge of how cultural differences could be expressed. By doing this, they would respect the patient, family and give the best care possible. Through this study, the reader can learn about how palliative care is thought of in two different countries and receive a better understanding.

#### 6.4 Further research

To obtain more knowledge of palliative care will broaden our competence as nurses as we might encounter patients in need of palliative care. Therefore, we believe that further research in other contexts is needed since it is a wide subject with many aspects. By interviewing patients, family members and nurses with different cultural backgrounds it would result in further understanding of palliative care.

# 7. Conclusion

In Vietnam family is the priority and they take care of each other because the health care and society are structured in that way. Palliative care is not easily accessible in Vietnam since it is not common and because receiving care is expensive. Despite this, they care for their loved ones and there is no doubt that they would not. Swedish culture, on the other hand, means that whilst the family members want the best for their family, most would not take care of their loved ones when in need of palliative care. Ternestedt et al. (2012) explain that Sweden is an individualistic society where people tend to themselves, which might be why they are not as close to their families in Sweden as they are in Vietnam. Since everyone can receive good quality care, they do not have to care for their families in ways they are not comfortable with.

This study can be used to gain a deeper insight of cultural differences and that everyone is not able to receive care when they are ill. The findings made would need more research for further conclusions regarding the topic.

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# 9. Appendix 1 Interview questionnaire

- What is your opinion on palliative care?
- At what extent have you studied palliative care at the nursing program?
- What did you know about palliative care before you started studying?
- Do you think the family or the individual should be the decision maker when it comes to palliative care and why?
- Do you think palliative care is a subject that should be talked about more? If so, why?
- Have you been in contact with palliative care been while working/at internship? If so, in what way?
- How do you think the patients experience the palliative care they get?
- Is there anything you would change about the palliative care in your country? If so, what?
- Will you take care of your family members when they are in need of palliative care or will you leave that to health care staff?
- When your life is coming to an end, how would you like the end to be?