Caring for the Critically Ill at the End-of-Life

Nurses’ Experiences of Palliative Care in Brazilian ICUs – a Minor Field Study

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Abstract

Background: Critical care is a relatively young speciality with its intention to treat critical illness equally all around the world. Patients admitted to ICUs receive advanced treatments in order to save lives, however some patients will pass away during critical care, which put family members in great physical and emotional distress. It is important to support family needs and keep core principles of palliative care in mind in order for patients and family members to cope with current situation. The need for palliative care is greater than ever, but in most parts of the world it is poorly developed. Brazil struggles with several challenges regarding implementation of a palliative approach within ICU settings. Aim: the aim was to explore nurses’ experiences of palliative care, focusing on family involvement in Brazilian ICUs. Method: semi-structured interviews were analysed using content analysis. Five female nurses were included from one public and one private hospital in the city of Rio de Janeiro, with an average ICU working experience of nine years. Results: three main categories were identified describing nurses’ experiences of palliative care and family involvement: to care for a dignified death, to promote family involvement and areas for future improvement. Discussion: the results reveal that the nurses, even though lack of professional training, believe that palliative care is important for both patient and their family members at the EOL. Brazilian nurses also face several challenges in order to perform palliative care successfully within ICUs. They struggle with strict visiting policy and the perception of nurses being inferior to physicians. There is a wish for acknowledgement of the nursing profession during EOLC in Brazilian ICUs, since nurses spend most time at each patient’s bedside along with their family members.

Keywords: family-centered critical care, palliative care, end-of-life care, ICU, nurses’ experiences, content analysis, minor field study, Brazil
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Without research, palliative care is an art, not a science.

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INTRODUCTION

Patients admitted to Intensive Care Units (ICUs) receive various advanced critical care treatments in order to save lives, but unfortunately some patients will pass away during these circumstances. When having a loved one admitted to an ICU, family members suffers from great physical and emotional distress. Additionally, symptoms of depression among family members are common when having a loved one pass away during critical care. The author of this thesis had a previous interest in palliative care and therefore wanted to continue to explore this subject in the context of critical care, with focus on family involvement. The author was granted a scholarship to undertake a Minor Field Study (MFS) in the city of Rio de Janeiro in Brazil. The scholarship, with the aim to promote international understanding and global knowledge, was administered by the Swedish Council for Higher Education (UHR) and financed by the Swedish International Development Cooperation Agency (SIDA). The Ministry of Health in Brazil has been trying to implement palliative care as a strategy to improve its overall health policy, however Brazil is facing several challenging aspects.

BACKGROUND

Facts on Brazil

With a population of more than 200 million and a geographical area of more than 8 500 000 m², Brazil is the 5th largest country in the world (The Embassy of Sweden 2014, pp. 1-2). It is also the largest country of Latin America, covering 41% of the total area and comprising 34% of Latin America’s total population (Pastrana, De Lima, Wenk Eisenchlas, Monti, Rocafort, & Centeno 2012, p. 4). It is a federal republic presently governed by Dilma Rousseff since 2011. Brasilia is the capital and the official spoken language is Portuguese (Landguiden 2012).

Brazil is a member of the BRIC countries, which is an acronym for Brazil, Russia, India and China. The BRIC countries are the fastest growing emerging markets in the world, and Brazil is presently ranked as the 7th largest economy. Brazil, despite its large economy suffers from varying contrasts (Landguiden 2012). The country is divided in five regions where southeast and south are at the same level as developed countries, while the north, northeast and central west are less developed (Landguiden 2012; Padilha 2008, p. 65). One-fifth of the population is living below the national poverty line with more than 16 million people suffering from extreme poverty (Landguiden 2012).

All Brazilian citizens have constitutional right to free public healthcare, but there are great demographic challenges that make distribution of healthcare unequal. People living in more developed regions (southeast and south) and in big cities have access to more developed healthcare to treat advanced conditions (e.g. trauma, cardiovascular diseases and cancer). In smaller cities and in north and northeast regions, where sanitary conditions are poor, there are more challenges to control transmittable diseases (Padilha 2008, p. 65). Public hospitals vary in quality and are often poor. Lack of resources and staff result in long waits and difficulties to meet healthcare needs of the population.
Private hospitals often meet international standards but require private health insurances (Swedish Ministry of Foreign Affairs 2012, p. 12), which only approximately 55 million citizens have the ability to afford (Padilha 2008, p. 65).

There are both public and private universities in Brazil that offers nursing education. Registered nurses have completed four years of higher education, where critical care nursing is a part of the curriculum. To become a specialist in critical care, nurses must study an additional one and a half year of critical care courses. This is not a mandatory obligation in order for nurses to be able to work in Brazilian ICUs. However, the Brazilian Nursing Council is trying to make critical care education mandatory in order to improve the care of critically ill patients (Padilha 2008, p. 66).

**Palliative care in a global context**

It is a known fact that the world’s population is aging and that the life expectancy is increasing. The most rapid increase in aging is being seen in developing countries, where the population of age 65 and over is estimated to increase by 140% between the years of 2006 and 2030. By the year of 2030 it is estimated that the total population of age 65 and over will increase from today’s 8% to 13%, this leading to social and economic challenges. For example, it has taken France more than a century to double the population of age 65 and over from 7 to 14%, the same demographic aging process will only take two decades in Brazil. For the first time in history the population of age 65 and over will outnumber the population under the age of 5 (National Institute on Aging, National Institute of Health, U.S. Department of Health and Human Services & U.S. Department of State 2007, pp. 2-7).

Medical advances are improving health and longevity, and there is now a shift from infectious and parasitic diseases to the noncommunicable diseases and chronic conditions (National Institute on Aging, National Institute of Health, U.S. Department of Health and Human Services & U.S. Department of State 2007, pp. 8-9). In 2004 there were approximately 58.8 million deaths worldwide where more than 50 % were age 60 and over. The leading cause was cardiovascular diseases, followed by infectious and parasitic diseases, and thirdly cancer (WHO 2008, p. 8).

The aim of palliative care is to improve the quality of life for patients and their family members based on physical, psychosocial and spiritual needs. A palliative approach contains symptom relief, support system for families in order to cope during end-of-life care (EOLC) and bereavement, team approach to meet needs of patients and families and good communication throughout the process. A palliative approach believes that death is a normal process in life and should be introduced early on in the care of ill patients, regardless of curative therapies in order to enhance quality of life (WHO 2015).

Cultural differences can be a challenge to palliative care since there are varieties in how people relate to death and dying. Some cultures, usually from western countries, value autonomy striving to empower patients to be included in decision-making at the end-of-life (EOL). This direct approach towards death and dying can be seen as aggressive and hurtful to patients by other cultures that value beneficence and non-maleficence. These
cultures believe that patients should not be informed about diagnosis and prognosis, that this approach will protect patients from increased emotional and spiritual suffering (Russel Searight & Gafford 2005, p. 516). To discuss the possibility of dying can be seen as destructive and that it eliminates hope. In many countries it is even common to forbid or highly recommended to not discuss diagnosis and prognosis with patients (WHO & WPCA 2014, p. 31).

The global need for palliative care is greater than ever, but unfortunately it is poorly developed in most parts of the world. The World Health Organization (WHO) stresses the importance of education, availability of accurate medication, policy and implementation in order to develop palliative care. Quality palliative care can be found in Europe, Australia and North America. However, in developing countries, where palliative care is needed the most, access is very rare and is just at the beginning of being an option of care. The global number of adults in need of palliative care at the EOL is more than 19 million, where 78% of these adults live in low and middle-income countries (WHO & WPCA, pp. 4-16).

The Economist Intelligence Unit (2010, pp. 11-15) has published a report on quality of death ranking EOLC in 40 countries across the world. A high quality of death can be seen in developed countries, while low quality of death can be seen in developing and BRIC countries. In the overall score of the Quality of Death Index used for ranking United Kingdom is the country to beat, followed by Australia and New Zealand. Brazil ended up as number 38 out of 40 countries, only Uganda and India scored lower. The most important category of this index is the Quality of End-of-Life Care. Indicators included in this specific category are public awareness, training, availability for pain medication, doctor-patient transparency, government attitudes and do not resuscitate (DNR) policy. In this category Brazil is ranked as number 39 out of 40.

**Palliative care in Brazil**

The challenges of today regarding palliative care in Brazil are several. Firstly, lack of knowledge about palliative care among health professionals is common and requires educational programs (Floriani 2008, p. 21). Approximately only 3% of medical schools offer palliative care as part of the curriculum (Pastrana, De Lima, Wenk, Eisenchlas, Monti, Rocafort & Centeno 2012, p. 9). Secondly, quality palliative care requires continuous access to opioids for successful pain control, which can be a challenge because of strict narcotic control policy in Latin America (Floriani 2008, p. 21). Out of the total world population, 80% do not have sufficient access to opioids. Barriers reported by the International Narcotics Control Board (INCB) are for example lack of supply, distribution systems, and fear of law enforcement interventions due to strict regulation on opioid use. Canada, the United States, some European countries, Australia and New Zealand alone consume 90% of the total use of opioid analgesics (WHO & WPCA 2014, pp. 28-29). Thirdly, another inhibiting aspect of implementing palliative care in Brazil is that the relationship between physicians and patients are often being paternalistic. Patients are usually not involved in diagnosis and prognosis, neither in decision-making regarding patient care. Physicians usually approach family members to discuss EOLC matters (Floriani 2008, pp. 21-23).
Successful national development of palliative care also needs established policies and laws. These are fundamental aspects for implementation into healthcare systems (WHO & WPCA 2014, p. 27). Brazil is at the moment lacking national laws for palliative care and there are no resources offered for research and development. There is however a national plan for palliative care, but only connected to cancer and pain programs. The most active members of the Latin American Association for Palliative Care (ALCP) are from Brazil and it is only Brazil of all countries in Latin America who has a national journal about palliative care (Pastrana et al. 2012, pp. 7-11).

Critical care in a global context

Critical care is a relatively young speciality, a multidisciplinary care conducted in ICUs. The intention is to treat critical illness with equal quality all around the world, which is not a reality of today. Most data of critical illness and care are from developed countries, and definitions of an ICU bed vary greatly especially when comparing among developing countries. These are some aspects to why the global burden of critical illness can only be roughly estimated. Challenging aspects in developing countries are lack of critical care educational programs, ICU equipment and availability of ICU beds, as well as poorly developed healthcare infrastructure (Adhikari, Fowler, Bhagwanjee & Rubenfeld 2010, pp. 1339-1341). Transportation of critically ill patients to hospitals with critical care services may not even be an option in developing countries, or if there are hospitals with critical care services the roads may be too unsafe to even be accomplished (Fowler, Adhikari & Bhagwanjee 2008, pp. 2-3).

Global health care spending varies among countries, where the delivery of critical care is the most expensive. Regarding critical care and total global differences there is still little known (Fowler et al. 2008, p. 2). In the meantime, the demand for critical care will only increase worldwide. It is known that critical illness increases with an ageing population. Pandemics, natural disasters, war and terrorism will also increase numbers of critically ill in need of ICU beds. For example, the pandemic of H1N1 influenza caused critical illness among a healthy young population in need of mechanically induced ventilation and high rates of deaths. Natural disasters, such as the Tsunami and the earthquake in Haiti put great pressure on healthcare infrastructure both in developed and developing countries (Adhikari et al. 2010, pp. 1342-1343).

Critical care in Brazil

There are approximately 1425 ICUs among 7863 hospitals in Brazil. Available ICU beds are estimated to be 35 541, representing 7% of total hospital beds. Out of all ICUs, 72% exist in private hospitals where most ICUs (50%) can be found in the southeast region. Each ICU usually consists of 5-14 beds and length of stay varies between 1-6 days. The mortality rate within critical care settings in Brazil is 17%. Registered nurses (university degree) and nursing technicians (high school degree) are working bedside each patient in ICUs. There is a recommendation, legally supported, that there must be at least one nursing technician deposited on every two patients, and one registered nurse for every five patients. Registered nurses are responsible for sustaining critical care therapies as well as prescribe and evaluate nursing care. They also supervise technicians who are delegated to perform less complex nursing skills (Padilha 2008, p. 65-66).

4
Family-centered critical care

Admission to ICUs puts family members in great physical and emotional distress (Al-Mutair, Plummer, O’Brien & Clerehan 2013, pp. 1806-1811). In a Brazilian study it was found that family members experience high levels of anxiety and/or depression when having a loved one admitted to an ICU (Rego Lins Fumis & Deheinzelin 2009, pp. 900-901). Additionally, a French study shows that symptoms of depression are even more common if their loved one passed away during critical care (Pochard, Darmon, Fassier, Bollaert, Cheval, Coloigner, Merouani, Moulront, Pigne, Pingat, Zahar, Schlemmer & Azoulay 2004, p. 93). The aim of family-centered critical care is to identify and understand the needs of critically ill patients and their family members (Hickman & Douglas 2010, p. 81).

Needs of family members of critically ill patients

When supporting families during critical care it is important for health professionals to know about their needs in order for family members to cope with current situation. Support is a multidimensional need including physical, environmental, psycho-spiritual and socio-cultural aspects. Of all health professionals, nurses are the one category being recognised by family members as the most skilled to meet family needs (Al-Mutair et al. 2013, pp. 1806-1811).

Family members stress that the most important needs are assurance and information regarding the prognosis (Al-Mutair et al. 2013, p. 1808). According to a Brazilian study, there can be a challenge for family members to fully understand diagnosis and prognosis, this leading to inaccurate expectations regarding final outcome (Rego Lins Fumis, Nobuko Nishimoto & Deheinzelin 2005, pp. 125-126). Good communication between health professionals and family members are a fundamental need, where sharing information is seen as a great psychosocial support. Inadequate information will only increase levels of anxiety. To not know about their loved one’s condition is more frightening than to be fully informed (Alvarez & Kirby 2006, pp. 614-615).

For family members it is of high value to be physically and emotionally near their loved one, this is often being described as the need of proximity (Al-Mutair et al. 2013, pp. 1806-1811). They want to maintain a physical and emotional connection as a reassurance that their loved one is not alone. Proximity also enables family members to gain a better understanding for the ICU environment, and they become less intimidated by the surroundings. Proximity can also be seen as a fundamental part of the bereavement and healing process (Alvarez et al. 2006, pp. 615-616).

The need of proximity requires liberal visitation policies in order for family members to get physical access to their loved one. There are a lot of aspects influencing visiting policy in ICUs that traditionally has been restrictive. Confidentiality, infection control and the overall culture and attitudes among health professionals will affect visiting policy negatively. However, today it is known that a liberal visiting policy will be beneficial from a family-centered critical care perspective, not the least for children of critically ill patients. To allow children in ICU environments will increase children's...
coping strategies to handle stress and anxiety, they can also feel less guilt and reduces the feeling of being abandoned (Alvarez et al. 2006, pp. 616-617).

Visiting hours in Brazilian ICUs are predominantly restrictive according to a study by José da Silva Ramos, Rego Lins Fumis, Cesar Pontes de Azevedo and Schettino (2014, pp. 341-343). Only 2.6% of participating ICUs offered visiting hours around the clock. Most common policy was to offer two periods of visitation allowing visits to exist up to 60 minutes per period. However, during special circumstances such as EOLC, most ICUs often accepted liberal visiting hours. Presence of children during visiting hours were most likely to be restricted due to an age limit, most commonly excluding children under 12 years of age (José da Silva Ramos et al. 2014, pp. 341-343).

**Needs of family members during end-of-life care**

When being admitted to ICUs patients are often being treated with mechanical ventilation, vasoactive drug infusion and continuously analgesia and sedative infusion in order to save their life. However, some patients are most likely to pass away during critical care treatments, which is why palliative care has become a matter of interest associated with circumstances in ICUs (Chan 2013, pp. 67-68). According to a Brazilian study, patients in ICUs for adults were receiving mechanical ventilation, vasoactive drugs and sedatives/analgesics 24 hours before death. Decisions such as withholding/withdrawing treatment and “do not resuscitate” (DNR) were most likely not to be reported in medical charts. The frequency of withholding or withdrawing treatment was higher in paediatric intensive care units (PICUs). Involving family members in the decision making process was also more common in PICUs (Piva, Lago, Othero, Celiny Garcia, Fiori, Fiori, Alexandre Borges & Dias 2010, pp. 345-346). The environmental factors are complex and health professionals tend to forget about the patient among advanced technical equipment. It is important to keep the core principals of palliative care in mind, even if curative therapies are being provided for patients (Chan 2013, pp. 67-68).

When opting for palliative care at the EOL in ICUs, the patients are often unable to participate in the discussion regarding withdrawal of curative therapies. Physicians usually need to approach family members to gain access to the patient’s living will. Unfortunately, family members are often unaware of their loved one’s preferences regarding medical interventions. Good communication skills are of great importance since disagreements at the EOL can be quite devastating. Conflicts among health professionals and family members at the EOL can lead to depression, anxiety and post-traumatic stress disorders (Soares 2011, pp. 1-2). In a systematic review, Hinkle, Bosslet and Torke (2015, pp. 83-90) focus on factors associated with family satisfaction during EOLC in ICUs. The single most important factor associated with increased Quality of Dying and Death (QODD) is support during their loved one’s critical illness. Other important aspects are family presence at the time of death, and nurses being competent regarding EOLC. Communication with empathic statements can be of great comfort when reassuring family members that they are not being abandoned and that symptom control are being cared for. Family members who value spiritual support felt more satisfied with a spiritual advisor present during the last day of life. Higher satisfaction among family members during the decision-making process was associated
with discussion of their loved one’s living will at the EOL and spiritual needs. Family members also felt more satisfied with shared decision-making when physicians recommend withdrawal of life-prolonging treatments, such as removal of endotracheal tube prior to death, if withdrawal is being well explained and with successful symptom control. Family members felt decreased satisfaction if time of death occurred during full support. From a nursing perspective Souza da Silva, Pereira and Carneiro Mussi (2015, pp. 42-44) stress the importance of continuously updating the family about prognosis and allow them to be physically near the patient at the time of death in an environment as tranquil as possible focusing on maintaining integrity. The authors also enlighten that nurses in ICUs play an important role in providing palliative care of high quality for patients and their family members at the EOL.

**THESIS STATEMENT**

The aim of palliative care is to improve quality of life for patients and their family members based on physical, psychosocial and spiritual needs. Approximately 19 million people worldwide are in need of palliative care at the EOL. However, this option of care is poorly developed in most parts of the world, especially in developing countries where it is needed the most. There can be cultural challenges in performing palliative care in accordance with the definition by WHO due to that people relate to death and dying differently. In Brazil, there are several challenging aspects in how to implement a palliative approach. Mainly there is lack of education and professional training, as well as a paternalistic relationship between physicians and patients. It is a relatively new medical speciality, but with ambitions for implementation as a strategy to improve the overall health policy. In 2010 Brazil was ranked as number 39 out of 40 countries included in a report on quality of death, where the most important indicators among others were training, availability for pain medication and doctor-patient transparency. When critically ill patients are admitted to ICUs family members suffers from high levels of anxiety, and depression are common when having a loved one pass away during critical care. In Brazilian ICUs, the mortality rate is 17% and when withdrawing treatment it is highly important to support family members in order for them to cope with their current situation. To enable proximity can be of great value for family members during bereavement and their healing process. Proximity requires liberal visiting policy, which is known to be strict in Brazilian ICUs. Nurses in ICUs familiar to EOLC in are an important factor associated with family satisfaction, and therefore play an important role in providing quality palliative care in ICU settings. How Brazilian nurses experience palliative care and viewpoints on family access and involvement during EOLC in ICU settings is an area that needs further investigation, in order to identify obstacles and possibilities to be able to care for a dignified death for both patients and their family members.

**AIM**

The aim was to explore nurses’ experiences of palliative care, focusing on family involvement in Brazilian ICUs.
METHOD

The aim of present thesis was to explore nurses’ experiences of palliative care and family involvement in Brazilian ICUs, therefore a qualitative approach was chosen. This approach is derived from holistic traditions (Henricson & Billhult 2012, pp. 132-133) aiming to gain understanding of the whole of various experiences (Polit & Beck 2012, p. 487). For data collection, qualitative interviews were chosen since the aim of qualitative interviews is to gain access to perspectives of participants’ own experiences (Kvale & Brinkmann 2014, pp. 41-47). Inductive content analysis was used for analysis since present thesis was not based on any previous theories or models. The aim of an inductive approach is to analyse textual data unconditionally, and the approach is suitable when textual data is based on participants’ own experiences of chosen subject to study. Data was analysed based on its manifest content, it describes content of apparent textual data and not its hidden message that is known as the latent content (Lundman & Häggren Graneheim 2012, pp. 188-189).

Participants and settings

Before recruiting participants for present thesis, the author visited both hospitals to meet with ICU head managers to get permission to carry through the interviews. Both oral and written information (appendix I) about the study were distributed, written information was in Portuguese (Emanuel, Wendler, Killen & Grady 2004, pp. 934-935). Convenience sampling of participants was used of nurses who worked on the days scheduled for interviews and who were given time off to be interviewed. Head managers helped find nurses suitable for participation, which all had ICU working experience of minimum one year as well as experience of caring for ICU patients at the EOL. Convenience sampling, or a volunteer sample, can be a suitable way of sampling when a study needs to recruit participants working in a specific clinical setting, in this case nurses working in ICUs with minimum of one year working experience (Polit & Beck 2012, p. 516). Five female nurses between the ages of 24 and 45 were included, where of two had leading positions as supervisors of the nursing staff. Working experiences varied from three to twenty-two years, with an average experience of nine years. The interviews were conducted in one public and one private hospital in the city of Rio de Janeiro. In the public hospital interviews were conducted with nurses from one ICU with 15 beds. In the private hospital interviews were conducted with nurses from one ICU with 20 beds, as well as one coronary ICU with 20 beds.

Data collection

Qualitative interviews were used to collect data, with oral and written permission from head managers of each participating ICU, during the participants’ regular working hours. The interviews were semi-structured, since the author wanted to make sure that specific topics were covered during the interviews (Polit & Beck 2012, p. 537). A written topic guide was used (appendix II), moving from general to specific topics and questions to support the author during the interview. The introductory question was “When did you first hear about palliative care?”. The topic guide also included probes for in-depth answers to develop interesting aspects in the participants’ answers (Polit &
Beck 2012, p. 537). Examples of other probes used during the interviews were “Can you please develop that feeling?”, “Can you please tell me more about that?” and “How does that make you feel?” The author started out with a pilot interview, which was transcribed in order to evaluate the written topic guide and the questions before continuing. The author decided after the pilot interview to use an interpreter with the intention of reducing language barriers and to make participants feel more comfortable. The pilot interview was not included for analysis due to language barriers. The author conducted five interviews during September and October 2015, using an interpreter and a Dictaphone. Duration for the interviews varied from 26 to 55 minutes, with the average time of 37 minutes. During transcription of each interview, participants were coded with a letter and number combination to keep their integrity safe.

**Data analysis**

Content analysis was used to analyse collected data. The preparation phase started out by selecting units of analysis, which were five transcribed interviews. The transcripts were read through numerous times in order for the author to gain understanding of the data as a whole. Units of meaning, responding to the aim of present thesis, were then selected (Elo & Kyngäs 2007, p. 109). A unit of meaning is kept together by its content and context. Each unit should not be too large in order not to hold several messages, or too small for the result to become fragmented (Lundman & Häggren Graneheim 2012, p. 190). Thereafter data was organized, started by open coding. The author put notes and headings throughout the text data while it was read through, several times at this point once again. The aim of the headings are to describe all aspects of textual content, and were later gathered onto a coding sheet to start creating subcategories consisting of codes with similar content. Similar subcategories were then grouped together creating higher order headings; generic categories. Similar generic categories were finally grouped as main categories. The abstraction of data kept on going as far as possible (Elo & Kyngäs 2007, pp. 110-111).

<table>
<thead>
<tr>
<th>Unit of meaning</th>
<th>Open coding</th>
<th>Subcategory</th>
<th>Generic category</th>
<th>Main category</th>
</tr>
</thead>
<tbody>
<tr>
<td>They [physicians] talk with the family, they need to know, and accept, and then they can join the process, they will participate in the actions, and make them feel better</td>
<td>Family involvement</td>
<td>Join the process of dying</td>
<td>Empowering aspects</td>
<td>To promote family involvement</td>
</tr>
<tr>
<td>To give the patient’s life a quality of life, give comfort, make the patient not suffer from symptoms</td>
<td>Comfort</td>
<td>Caring actions</td>
<td>Enable quality of life</td>
<td>To care for a dignified death</td>
</tr>
</tbody>
</table>

*Chart 1: flowchart presenting two examples of the content analysis process in sequential order.*
Ethical considerations

There are ethical principles for consideration when conducting research involving human beings. Research can only be approved if human dignity, rights and freedom are being respected and preserved. The interest of human beings is always superior to interests of science and society. Every human being has rights to private life, kept integrity, information and free informed consent (CODEX 2015a). With these ethical research principles in mind, following actions were taken during the whole process of the study.

Present thesis started out with an ethical risk assessment, with conclusion that none of the participating nurses should be of greater risk than in their everyday life. According to Swedish law (SFS 2003:460), ethical approval was not needed. This was also the situation according to Brazilian law, since the author was a student from a foreign country. Each participant was given oral and written information about the aim of the study in Portuguese (appendix III), and informed consent was received from each participant (appendix IV). The informed consent contained information about confidentiality, participation being completely voluntary and that consent could be withdrawn at any time during the study without any explanation or questioning. No compensation of any kind was offered. Participants and participating ICUs were offered to take part of the final results. All parts of the research material that would have the possibility to establish identity of participants were anonymised, and each participant during the transcript and analyse process was coded into a letter and number combination. All research material was kept safe from others to gain access (CODEX 2015a; CODEX 2015b; Emanuel et al. 2004, pp. 930-936).

Pre-understanding

An important aspect during research is for the researcher to be aware of his or her pre-understanding, which can be described as existing preconceived beliefs and prejudices of the chosen subject. This can have a negative effect on research since this will affect researchers’ openness. However, pre-understanding can also be seen as important, because it enables our understanding (Dahlberg, Dahlberg & Nyström 2008, pp. 134-143). With the intention to recognize existing pre-understanding the author started out with determination to identify as many preconceived beliefs and prejudices of the chosen subject as possible. In order to try to bridle existing pre-understanding and to stay as objective as possible, a continuous reflection was kept to problematize and question existing pre-understanding throughout the whole process (Dahlberg, Dahlberg & Nyström 2008, pp. 134-143; Polit & Beck 2012, p. 495). The author has not intentionally excluded or distorted any research material. All research material has been included and analysed systematically according to content analysis, which has been accounted for earlier on (CODEX 2015c).
RESULTS

Three main categories were identified describing how nurses experience palliative care and family involvement in Brazilian ICUs: to care for a dignified death, to promote family involvement and areas for future improvement. Subcategories for each generic category are marked with italics (figure 1).

Figure 1: portrays the results consisting of main categories, generic categories and subcategories.

To care for a dignified death

This main category represents experiences on benefits and challenges regarding palliative care in ICUs from a nursing perspective. Palliative care is seen as important for both patients and family members at the EOL. It is also described as a complex situation not only for patients and family members to handle, but also for health professionals involved in EOL situations.

Enable quality of life

Today palliative care is only developed in few Brazilian hospitals, this according to several nurses. In the past, patients and family members usually were not informed about diagnosis and prognosis, or that palliative care even existed. At some hospitals, patients and family members are now being more involved regarding prognosis and options for medical treatments. When curing is no longer an option, awareness and knowledge about palliative care allows nurses to increase quality of life, for both patients and family members at the EOL. Several nurses described caring actions such as symptom relief as an important part of nursing, where pain was regarded as the most important to assess. Other important caring actions are to support and comfort patients...
during their dying process, and to understand that each patient have multidimensional needs:

“With the objective to elevate the symptoms of these, ehm, of this patient and making his life better quality. Not only physical, not only physically but more psycho... Psychosocially and spiritually too.” – Participant C

Palliative care can also ease the process of dying for family members. Several nurses highlighted the importance of supporting family members to understand the natural process of dying as a way to cope with the situation. Family members are usually in a lot of doubts and feel very insecure about EOLD. Caring actions during situations like these are to comfort and support family members, often by explaining what kind of nursing care that is being offered. Several nurses felt that it is important to ensure family members that they are doing everything they can to make their loved one feel as comfortable as possible, that the patient is being well taken care of:

“This includes that we always try to notice if the, ehm, the features of the patient, the face, if the face is showing pain. We try to make the atmosphere, ehm, the light in the morning and dark in the evening so... And this, all this procedure we tell, we tell to inform the family to make them feel better.” – Participant C

Palliative care – a winding road

There is a general lack of professional training, which is being described as a reason to why far from every hospital in Brazil offers palliative care. According to several nurses this approach has not yet reached acceptance as a medical treatment, and most health professionals do not fully grasp the importance of palliative care. Additionally, all nurses believed that there is not enough education offered where health professionals can practice core principles of palliative care. Some lectures are being offered at the private hospital but often also involving family members, the lectures are therefore being perceived as too general to meet needs of professional training. It is also being described as difficult to define patients who are in need of palliative care, to understand and recognize palliative needs. Most physicians are resistant to treatments that are not seen as an investments in order to save patients lives, which was also described as the case for several categories of health professionals:

“The aim is to give comfort in death but there are, ehm, other professionals involved, ehm, physiotherapists and people who do not understand very well, you know, I think they want to invest, ehm, to see investment and there is no investment. This is to give comfort to the patient, but people don’t see. They don’t grasp the whole understanding palliative care.” – Participant B

Another aspect of challenges is personal attitudes toward palliative patients. Palliative patients are usually admitted for long periods, and it is common that they start to get complications such as skin ulcers and infections. Complicated patients become even more complicated and consume a lot of resources. One nurse explained that this kind of patients will not benefit the hospital financially; they are more likely to be seen as a burden for the hospital rather than a human being in need of palliative care. She believed that health professionals often lack empathy for palliative patients, which is being described by several nurses:
“It’s not a patient that, ehm, gives the hospital money. There is a lack of humani... Ehm, humanisation, you know, ehm like love, understanding, the love in the, with this patient... Ehm, empathy. Yes, empathy, ehm, to be human.” – Participant C

There are also emotional challenges, this from a professional point of view. As a nurse it is likely to develop strong relationships with patients and their family members. One nurse described that it is sometimes difficult to stay objective in situations like these, to not give family members false expectations but at the same time infuse hope at an adequate level. Another aspect is that death and dying can be a challenge to cope with professionally, but when understanding core principles of palliative care it is being seen as a fundamental part of nursing to treat for a dignified death:

“At the beginning I was in shock, to associate the, ehm, moving from one treatment to another treatment involving death. Initially, you know, ehm, initially you are trained the, ehm, heal the patient and once you know that is not going to be possible, ehm, there is this treatment to give comfort to the patient I started to look at this treatment with other point of view because it's going to help the patient to die in a better way.” – Participant E

To promote family involvement

This main category represents experiences of benefits and challenges regarding family involvement during EOLC in ICUs. From a nursing perspective family involvement is being described as a fundamental part at the EOL and requires continuous communication. Family involvement can also be challenging when family members are not unanimous during the EOL decision-making process.

Empowering aspects

It is important to understand that family members usually comprehend gradually, that information may need to be repeated continuously. One nurse described that when family members get involved they can gain an understanding, then they can usually let go of their bad conscience of feeling like they abandon and give up on their loved one. They come to accept that their loved one is at the EOL and that everything possible is being done to ease suffering. One nurse said that in her experience palliative care is most difficult for family members to handle, to accept that their loved one is going to die and to prepare for that final goodbye. If family members are well informed they usually accept the situation and opt for palliative care, they can then join the process of dying:

“We had a case not long time ago, of a patient, that the family was very much in doubt of what to do. Sometimes they want, sometimes they didn’t want the procedures. So, they explained to them all the process how it worked, that the patient will not feel pain, she wouldn’t die of not breathing. And they were able to understand, and they opt for the palliative care and they participated until her end.” – Participant C

Supporting actions consist of evaluating the need of support and of which kind for each family member. Nurses in the public hospital explained that they call for a social worker
or a psychologist if needed. Nurses in the private hospital also described the need of spiritual support as an important aspect during EOL care:

“In some cases we call the hospital psychologist, and we offer prayers with family too. There is a pastor here and we, ehm, offer them you know we ask them if they want the pastor to intervene and to pray for them.” – Participant C

Other supporting actions are described as enabling proximity for family members by letting them stay past visiting hours when death is estimated to be near, they enable them to sit by their loved one’s bedside and to participate in the nursing care. Family members can give hand massage with a moisturiser, comb the hair, and moisturize the lips with balm. Sometimes even nurses can offer to pray with family members at the EOL, not only the pastor.

**Inhibiting factors**

*Visiting policy* at each ICU is being described as strict according to several nurses. Regular visiting hours are only one period a day, each consisting of one hour. Children under the age of 12 were excluded from ICU visits at both hospitals. Several nurses believed that the visiting policy of their unit should be more liberal because they believed that it is very important for both patients and family members to spend time together. Only in special cases family members can stay longer, visit at times past regular visiting hours or maybe even stay during the night. However, as one nurse explained, it is a medical decision:

“What is more common is that they let the family come maximum two hours in the morning, two hours in the afternoon or in the evening. It is very, very rare that family members can stay the night. It depends on the doctor if the doctor sees the need of that patient and then you know he will let and it’s his order. But it’s very rare that the families you know can stay all the time here no.” – Participant A

If family members are not informed about diagnosis and prognosis they are more likely to go against medical decisions, especially at times when transition from curative therapies to palliative care happens too quickly. These situations are described as difficult to handle for both family members and health professionals, when communicating bad news. If communication skills are poor among health professionals, family members will be in a lot of doubt and feel insecure about medical decisions. This can result in family members asking a lot of questions and lose confidence in health professionals. One nurse explained that if there is tension arising among family members and health professionals, they usually call for a social worker or a psychologist to try to solve conflicts and restore trustworthiness.

Another perspective of challenges can in some situations be *family members’ wishes*. One nurse described that when family members have different aspects and opinions of what they wish and think is best for the patient, this result in stressful dilemmas among nurses. Nurses may one day manage palliative care, and then the next day there can be a complete change in medical decisions because of *family members’ wishes*. As one nurse told, there can in some situations be different opinions among family members due to financial aspects, where decisions will be made whether they believe they can afford further treatment or not.
There are also excising paternalism and hierarchy at both participated units, where medical decisions are superior and physicians have the final say in discussions regarding patient care. Physicians are the ones who decide whether transition to palliative care is an option or not. Usually it is only nurses with a certain confidence who can give physicians suggestions on palliative care:

“It is a question of attitude, you need to have an attitude to talk to the doctor. But it is not everyone, every nurse that does that. They have to be more confident, because the correct procedure is the doctor telling the nurse – that’s a palliative treatment. But there are some nurses who feel confident in say I think he is a palliative, ehm, patient but the procedure is the doctor tells the nurse.” – Participant B

Additionally, nurses may not even be permitted to talk to family members about patient care:

“The nurses very little, they don’t talk about it. But they don’t talk so much here because the doctors ask them not to do that. They think that a lot of information can make family members sad, confused, can confuse them. If you are going to explain to the family why the, ehm, you have the feeding tube the doctors prefer them to talk to the family instead of the nurse.” – Participant C

Nurses discuss patient care with family members from a nursing perspective, such as pain control, maintenance of the skin, hygiene and vital signs. From one nurse’s point of view she felt that it is a safe decision that nurses do not talk to family members about more medical orientated patient care in order not to give misplaced information. She said that nurses have the ability to give another kind of comfort, more of a friendly and human kind since they spend more time with them to connect with them on a deeper level than physicians. However, other nurses felt that they were not trusted and that physicians did not listen enough to nurses’ opinions.

Areas for future improvement

This main category represents aspects of improvements regarding palliative care in ICUs from a nursing perspective. Most frequently there was an expressed need of education regarding core principles of palliative care, and that nurses should be seen as a corner stone to promote quality palliative care.

Professional training and teamwork

All nurses wished for palliative care knowledge among health professionals in order for palliative care to be a reality in all Brazilian hospitals. Health professionals need to know about the natural process of dying so that they in a proper way can explain to family members what is going to happen to their loved one throughout this process. One nurse said that this is an important aspect when e.g. a feeding tube no longer benefits dying patients and that removal of such tube is not going to starve patients to death. She believed that this is a common opinion among not only family members, but also health professionals. Several nurses expressed needs of having palliative patients well classified in order for health professionals to identify patients in need of palliative care.
With knowledge about this patient category, discussion among health professionals to identify palliative needs can become more common.

There was also a wish for teamwork with an empathic approach where all health professionals are united and familiar to core principles of palliative care. One nurse felt it was important for her unit to start communicating with each patient, even if all patients usually are sedated. For her it was of great importance to explain to each patient in advance what was going to happen during nursing and medical activities. All patients should be treated as a human being, not an object:

“We talk about a lot of, ehm, about humanising, make it more human the ICU but we haven’t done anything to make it more human, ehm, to bring the family in, to make it better for the family and, you know, the dying patients, but we haven’t done anything yet.” – Participant D

Several nurses felt that health professionals need to focus on each patient being an individual, that each patient and family is different from the other with different needs. One important aspect is that family members should be able to leave the hospital feeling satisfied of care offered, that everything possible was being done and that nurses provided successful symptom control – especially pain related.

**Quality improvement of palliative care**

There was an explicit wish for a separate unit where palliative patients could be transferred and treated by a well-trained multidisciplinary team. Health professionals at this kind of unit would be more comfortable with EOLC and more skilled to support both patients and family members, and to be able to explain to family members step by step as the process of dying progresses:

“We don’t have a team, a well trained team. Like a team of professional palliative care. We know a little bit of that, and that’s it. I want a strong team.” – Participant A

A palliative separate unit would enable patients to stay close to their family members with a more liberal visiting policy, an important aspect according to several nurses for palliative care to be of higher quality. One of the nurses explained that the privilege of allowing more liberal visiting hours is only for palliative patients at her unit, this made her feel unfair to other patients and their family members. All nurses felt that the visiting policy at their unit was too strict, that family members want to be able to stay longer by their loved one’s bedside. One of the head nurses pointed out the lack of visiting areas for family members to be received in, and separate areas for physicians to communicate with family members. She felt it would be of great value if her unit would be able to make space for a waiting room.

All nurses addressed a need for acknowledgement of the nursing profession during palliative care. Nurses need to be accepted as a part of patient care, to be able to have an opinion and to be a respected part of a multidisciplinary team:

“Because nurses are so present I believe that nurses are a fundamental piece in this, and that our voices could be heard and they are not. There is this historical culture
Several nurses believed that they are a fundamental part regarding patient care. They spend a lot of time with patients and their family members and get to know them on a deeper level than physicians. Nurses’ perspectives are seen as important and should be more respected, there was an explicit wish to empower involvement of nurses to improve quality palliative care.

DISCUSSION

Methodological considerations

The aim of present thesis was to explore nurses’ experiences of palliative care in Brazilian ICU settings, which is why a qualitative approach was chosen. A qualitative approach is seen as a suitable way to collect data when aiming to explore and describe multiple realities as a whole and does not aim to generalize to a population (Polit & Beck 2012, pp. 487-515). Qualitative interviews enable participants to share their experiences in their own words, and semi-structured interviews make sure to cover certain aspects of the subject still allowing probing for richer and more detailed information of the participants’ answers (Polit & Beck 2012, p. 537). The author of present thesis was not familiar with a qualitative design using semi-structured interviews, and had no experiences of an interviewing position. This could have influenced the results in a limiting way since interviewing can be seen as an art which one must practice in order to get skilled (Kvale & Brinkmann 2014, p. 33). Being a novice performing interviews, the author initially felt unsure identifying accurate probes with the aim to develop interesting aspects of the participants’ answers. However, as the interviews went by the author felt more comfortable, became more flexible towards the written topic guide and more responsive to the participants’ answers.

Other limiting aspects regarding the results were language and cultural barriers, which led the author to decide to use an interpreter with a master’s degree from the United States of America. To enhance credibility and trustworthiness of present study a pilot interview was conducted to evaluate the questions of the written topic guide before implementation and moving forward with the main interviews. When using an interpreter it was quite a challenge to gain total understanding of what had been said since the translation often was given as a summary of what the participants had shared in experiences and perspectives. Perhaps some interesting aspects went missing because of the fact that the author did not know Portuguese and the cultural meanings hidden in the Portuguese language, some words are simply not possible to translate into English. There is also a possibility that the interpreter could have had an impact on the results by using his or her own preconceptions related to the subject when translating the participants’ answers. In order to minimize this from happening the author and the interpreter had an open dialogue about the subject and when creating the written topic guide. They also wanted to make sure that the questions used in the written topic guide were to be understood by the participants and that the questions were correctly translated not losing its original meaning. This was the strategy used for both written and oral translation. The interpreter took no part in the data analysis process and was
bound to the same confidentiality requirements as the author. One single interpreter was used to keep translation consistent throughout the whole process of translation (Squires 2008, pp. 268-272). All written information about the study, including the informed consent, was translated into Portuguese in order for the participants to feel more comfortable to decide whether to participate or not (Emanuel et al. 2004, pp. 930-936).

Another aspect to keep in mind when performing interviews is that the relationship between the interviewer and the participants often is asymmetric. The interviewer can be seen as the one who controls the interview and is well-known to the subject, this leading to participants not feeling comfortable enough to open up and speak freely about the subject (Kvale & Brinkmann 2015, p. 52). The author and interpreter both tried to maintain the reality of them being guests at each participants’ hospital and appreciative for the opportunity to visit and conduct the interviews. The interviews started out by introducing the author and the purpose of the interview, and continuously during the interviews the author tried to encourage each participant to share whatever came to their mind reassuring that there were no right or wrong answers (Polit & Beck 2012, p. 537).

Collecting data was limited due to time limit and financial aspects related to translation costs. However, the time limit could have had a positive impact regarding dependability of present study since time limit will prevent data from changing over time (Graneheim & Lundman 2004, p. 110). Only five interviews were included for data analysis, at only two hospitals in the city of Rio de Janeiro. However, the author was able to interview nurses in both private and public ICU settings, which can be seen as an enhancing factor of present study gaining both perspectives. Nurses offered to participate although they had difficulties taking time off their regular working hours to be interviewed. Due to this fact, there could be limitation towards the results if nurses felt they were under time constraint during the interviews. Another limitation is that the sampling resulted in only female nurses, where male nurses would have been required in order to reflect the reality of the composition of each ICUs’ nursing staff (Polit & Beck 2012, pp. 516-528).

There was only one single author performing present study, which limited the amount of interviews performed. The interviews were analysed using content analysis according to Elo and Kyngäs (2008), followed systematically. Throughout the content analysis process the author went back and forth continuously to original text data in order neither to exclude nor to distort any data. The author also used documented pre-understanding as a constant reminder of preconceptions with determination to identify any influences regarding the results. A chart of the content analysis process, as well as quotations derived from original text data are used throughout the presentation of the results to enhance transferability and trustworthiness (Graneheim & Lundman 2004, pp. 109-110). The author had continuous contact with the Swedish supervisor for feedback and support, and also kept frequent discussion with the Brazilian supervisor in field who had a doctoral degree within the medical field.

The author did not have any personal relationship to Brazil and had never visited any countries in South America and therefore had no specific existing pre-understanding regarding palliative care in Brazil. Identified pre-understanding consisted of working experiences, both positive and challenging ones from a Swedish perspective. There was
an interest to explore palliative care in a context other than Sweden, with the intention of an equal exchange of possibilities and challenges regarding palliative care in ICUs. When the author started out with a review of previous literature regarding chosen subject and context, there were only a limited amount of articles that highlighted Brazil in the context of palliative care. However, the author did not know Portuguese so there was a struggle evaluating existing research about palliative care in Brazil since the author only had access to research written in English. The articles and reports that were found became the basis of the authors pre-understanding regarding palliative care internationally and most importantly in Brazil. Notes on pre-understanding were kept continuously throughout the whole process of present thesis to enhance trustworthiness (Malterud 2001, p. 484).

Discussion of the findings
The aim of present thesis was to explore nurses’ experiences of palliative care focusing on family involvement in Brazilian ICUs, which is considered being achieved. The results reveal that even though there may be several challenges in achieving family-centered palliative care in Brazilian ICUs, such as hierarchy and personal attitudes among colleagues regarding the subject, nurses find palliative care at the EOL highly important. Patients at the EOL and their family members have a great impact on nurses who put a lot of effort in performing and improving palliative care at their ICUs. The author has chosen to discuss head findings, which is why the results will not be discussed as a whole.

Lack of professional training
One head finding is that there is a lack of professional training regarding palliative care in the ICUs in general. According to Swedish standards of critical care nursing (Riksföreningen för Anestesi och Intensivvård & Svensk Sjuksköterskeförening 2012, p. 6) critical care nurses must be able to respect the individuals of patients and family members, and promote patient and family involvement throughout the care. Furthermore, critical care nurses shall support and give accurate information to both patients and their family members at the EOL. In order to meet these needs nurses requires education and training, and according to WHO and WPCA (2014, pp. 27-28) most health professionals worldwide are lacking knowledge of palliative core principles. However, there is a growing interest of this subject and curricula do exist but unfortunately most existing programmes are in English. Lack of professional training is not a unique challenge in a Brazilian context, thus it is known as a global concern. Nurses have reported that they often feel unprepared to provide EOLC due to lack of education and previous experiences (Espinosa, Young, Symes, Haile & Walsh 2010, p. 276; Espinosa, Young & Walsh 2008, p. 91).

Regardless of the amount of professional training all participants reached consensus that palliative care is important for both patients and family members. Even though the interviews focused on family involvement all participants answered with both patients and family members in mind. The most frequent caring action mentioned regarding symptom control was assessing pain. Even though lack of professional training, the nurses seem to be very passionate about doing everything possible in order to make
patients and family members as comfortable as possible. According to the Danish philosopher and theologian Knud Ejler Løgstrup (2009, pp. 41-60) an ethical demand occurs in meetings between human beings, trusting each other to care for the other’s wellbeing. The ethical demand is silent and unspoken. It is absolute and when it has occurred it cannot be ignored nor either fulfilled. It is also unconditional, meaning one ask nothing in return when responding to the demand. Løgstrup describes the meeting as to hold the other person’s life in one’s hand and that you respond only for the other’s best interests in mind. When applying this philosophy nurses may feel a moral and ethical calling to act on patients and family members needs when caring for a dignified death in ICU settings. It seems to be important for the participants to do their utmost in order for the EOL to be as positive as possible for both patients and family members, helping them find coping strategies and at peace with the situation. When facing critical illness patients may lose their Sense of Coherence (SOC) feeling disconnected from their personal relationships in their everyday life, this resulting in patients becoming vulnerable (Dahlberg & Segesten 2010, p. 108). This has been described in a metasynthesis by Baumgarten and Poulsen (2015, pp. 209-210) where patients treated with mechanically ventilation often feel as though they lose control over their situation and their body, this leading to feelings of abandonment and vulnerability. When being left alone in the ICU it creates feelings of anxiety, fear and loneliness – and even fear of dying. Presence of family members is experienced as great support and comfort, especially since they are often more competent to interpret attempts to communication.

With the study by Baumgarten and Poulsen (2015, pp. 209-210) in mind, it is important for nurses to identify strategies to reach patient involvement and restore SOC. Patients come to hospitals to get high quality healthcare, i.e. an ethical demand occurs for health professionals to respond to. Patients always know best how their illness is experienced and how it affects them, therefore it is important for health professionals to gain this knowledge in order to meet ethical demands successfully. This can be a struggle for health professionals, balancing between patient involvement and paternalism being the medical experts. Health professionals need to seek understanding of each patient’s lifeworld and at the same time deliver evidence-based healthcare to treat patients’ illnesses. There must be collaboration between health professionals and patients since patients are the experts on how illness affects them, and health professionals are the experts on delivering healthcare. In situations where critical illness is threatening patients’ lives and their lifeworld are unable to reach, health professionals must turn to others in order to gain access. Usually it is family members who must try to identify the patient’s needs and wishes, they contribute with an interpretation of the patient’s lifeworld (Dahlberg & Segesten 2010, pp. 108-131). This can be related to a study by Fridh, Forsberg and Bergbom (2009, p. 236) where critical care nurses who treat patients without any family members present feel that those patients will remain anonymous. Patients with family members present however become personified since family members can establish a link between patients and health professionals in order for health professionals to get to know the person behind every patient.

**Visiting policy**

Visiting policy within hospitals and ICUs are most commonly restrictive (Alvarez and Kirby 2006, pp. 616-617), which was also the situation in the ICUs who participated in
present thesis. Family members could usually only visit one hour at one period a day, and children under the age of twelve were denied access. Today it is known that liberal visiting policy will benefit both patients and family member, strict visiting hours will only leave family members feeling dissatisfied. This is also the situation regarding children who are often excluded due to the idea that experiencing critical illness and hospital environments will result in children developing psychological trauma. However, supporting and comforting children and motivating them to visit will actually help them find coping strategies. Additionally, children become less willing to blame themselves for what has happened and reduces feelings of abandonment (Alvarez & Kirby 2006, p. 617).

Furthermore, proximity is by family members their most important need during EOLC (Al-Mutair et al. 2013, p. 1808). This could be a challenge at the ICUs who participated in present thesis to meet this need due to strict visiting policy, and also due to the fact that it may be a medical decision dependent on the physician in charge if he or she believes that the patient will benefit from having his or her loved ones close by. Family members become even more important during EOLC (Dahlberg & Segesten 2010, p. 119) and with core principles of palliative care in mind family members as well as patients are recognized as natural parts of the team (WHO 2015). Human beings are dependant on interaction with others. Family members often take responsibility of some of the caring actions regarding patient care, and they can have a central role in patients’ ability to feel safe. To feel safe is an important human need that can be met when feeling close to others and is strongly connected to SOC (Dahlberg & Segesten 2010, pp. 83-121). In a grounded theory by Vandall-Walker and Clark (2011 pp. 154-169) the analysis showed that family members have high sense of perceived responsibilities regarding their loved one being critically ill. They feel committed and obliged to stay bedside, not only for their loved one but for themselves as well. Nurses play an important role in enabling family members to gain physical access. Nurses work close by every patient’s bedside, it is therefore natural that they become the ones family members turn to for proximity. Nurses then have the power to decide whether to support the need of proximity, or prevent the need of being fulfilled. Regardless of the intimidating situation of having a loved one admitted to an ICU, hope is the one thing that keeps family members feeling enough courage to keep pulling through. When family members later have to give up on hope of recovery, hope is then connected to be able to say goodbye and to be strong enough to handle the passing of their loved one. As several nurses expressed in present thesis, it is important for them that family members leave the hospital feeling at peace that everything possible had been done for their loved one to feel as comfortable as possible when passing away.

**Acknowledgement of the nursing profession**

Similar to several studies (Espinosa et al. 2010, p. 275; Espinosa et al. 2008, pp. 84-90; Fridh et al. 2009, p. 238) participants of present thesis felt excluded from EOL decisions (EOLD) regarding patient care. Several participants highlighted that since nurses spend most of the time at every patient’s bedside they should be invited and accepted as a team member. Hierarchy, where physicians and medical decisions are superior, is also accounted for in a Brazilian study by Paganini and Bousso (2015 pp. 807-810). Nurses establish a strong connection to patients and their family members, and often suffer if
they are not able to care for patients and family members properly. By being part of a multidisciplinary team nurses feel more comfortable conducting advanced care planning. When not being accepted and included for EOLD nurses feel as though their profession and competence are not being trusted. This results in feeling insecure and therefore only doing what the physicians tell them to do, and then nurses’ autonomy is lost. However, the medical field is starting to recognize that EOLD need to be combined with knowledge and skills from a nursing perspective. All nurses interviewed for present thesis felt as though their voices as nurses should be respected and accounted for.

**Sustainable development**

The World Commission on Environment and Development (1987) states that “sustainable development is development that meets the needs of the present without compromising the ability of future generations to meet their own needs [...].” Identification of palliative patients and good communication skills in order to reach consensus within the team consisting of patients, family members and health professionals may reduce unnecessary medical interventions and suffering. From an economical perspective strategies as such may save unnecessary costs and direct resources to patients in need of interventions in order to save lives. Medical interventions where the outcome is not compatible with life should actively be discussed whether to withhold or withdraw. Caring for family members meeting their needs and supporting them the best evidence-based way possible could hopefully prevent family members to develop serious psychical illness, saving healthcare costs and resources in the long run. Preventing psychical illness may also help family members get back to and continue work and keep contributing to the social and economical welfare. It is known that depression, posttraumatic stress disorder and complicated grief are common to persist during a long period of time after the ICU stay among family members of critically ill patients. Successful implementation of a palliative approach within the ICU settings may have positive impact on family members being more equipped to handle psychological challenges in the future connected to their ICU experiences (Aslakson, Randall Curtis & Nelson 2014, pp. 2419-2420). The author therefore believes that patient and family-centered critical care with a palliative holistic approach may have positive impact regarding sustainable development.

**CONCLUSION**

There are several challenges regarding palliative care globally, where Brazil is no exception. There are dedicated nurses working in Brazilian ICUs putting lot of effort in providing palliative care for patients at the EOL and their family members. There are several struggles to family-centered palliative care in Brazilian ICUs, e.g. strict visiting policy, lack of professional training and paternalism. Nurses may feel inhibited in caring for a dignified death since the nursing profession is perceived inferior compared to the medical profession. There is a unified wish and need for acknowledgement of the nursing profession regarding patient care at the EOL in Brazilian ICUs. The results may draw attention to and initiate discussions among health professionals on how the
nursing profession can contribute and be empowered during palliative care in ICU settings, aiming to improve quality of life for patients at the EOL as well as for their family members.

**CLINICAL IMPLICATIONS**

- Identification of health professionals in ICUs dedicated to palliative care with a team approach, developing educational programmes of palliative core principles.
- Develop strategies in how to empower nurses becoming more independent planning for palliative patients’ EOLC in ICUs.
- Recognition of benefits including the nursing profession during the process of EOLD in ICUs.

Suggestions for further research: 1. To conduct an interventional study investigating family satisfaction after liberalization of visiting policies in Brazilian ICUs. 2. To conduct a study investigating nurses’ work satisfaction and opportunities for influence regarding patient care at the EOL when being involved in EOL decision-making discussions in Brazilian ICUs.

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APPENDIX I
To whom it may concern; information addressed to head managers

A quem possa interessar

Meu nome é Maria Tillquist e trabalho atualmente como enfermeira graduada em Gothenburg na Suécia. Estou matriculada na University of Borås cursando pós-graduação em Enfermagem Especializada. Atualmente, estou em curso de minha a dissertação de mestrado (60 hrs creditos) em tratamento em cuidados intensivos, com foco em cuidados paliativos no fim de vida. A fim de realizar um "objetivo secundário de estudo", eu recebi uma bolsa de estudos, administrada pelo Conselho Sueco para o ensino superior e financiado pela Agência Internacional de cooperação de desenvolvimento sueco. O objetivo da bolsa é promover a compreensão internacional e conhecimento global.

O objetivo do tratamento paliativo é melhorar a qualidade de vida dos pacientes terminais e de seus familiares, baseado em suas necessidades físicas, psico sociais e espirituais. Quando um paciente é internado num centro de terapia intensiva (CTI), onde os fatores ambientais são complexos com equipamento técnico avançado, os membros da família sofrem grande angústia física e emocional. As necessidades importantes para esses familiares são proximidade, manter a integridade de seu ente e obter informações sobre o prognóstico do mesmo. Para algumas famílias, também é importante tomar parte das decisões de fim de vida e dos desejos expressos do paciente para o tratamento de manutenção da vida.

O objetivo dessa dissertação é identificar políticas de visitação e as experiências dos profissionais de saúde no tratamento paliativo e do envolvimento familiar durante o fim de vida nos CTIs brasileiros. Para tanto, serão realizadas entrevistas semiestruturadas com um intérprete. Dados da pesquisa serão analisados por estatística descritiva e análise de conteúdo. A participação é voluntária e os participantes podem recusar a assinar seu consentimento ou retirá-lo a qualquer momento. A confidencialidade e o anonimato dos participantes serão mantidas através do estudo e os dados da pesquisa serão mantidos em segredo e seguros.

Com esse termo de consentimento livre e esclarecido peço sua autorização para realizar o estudo sobre As políticas de visitação e as experiências dos profissionais da saúde sobre cuidados paliativos e o envolvimento da família durante o cuidado de fim de vida nos CTIs brasileiros, com a coleta de dados a partir de setembro de 2015. Favor entrar em contato com Maria Tillquist, caso haja dúvidas.

Atenciosamente

Maria Tillquist
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Phone: 997680552

Orientadora:
Isabell Fridh RN, CCN, PhD
Palestrante Senior
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APPENDIX II
The written topic guide

1. Questions on palliative care:

When did you first hear about palliative care?
• What were your thoughts about it?

What are your feelings about palliative care today?
• What are the challenges of today in your unit according to you?

In your unit, what does palliative care mean to you?
• What are the benefits?
• What are the difficulties/challenges/struggles

2. Questions on family involvement during EOL care:

Tell me about your experiences about family involvement in the ICU environment

What are you opinion about discussing EOLC with family members?
• What are the positive aspects in your opinion?
• Are there any negative/challenging aspects in your opinion?

How do you feel when the family members don’t understand the prognosis and have unreasonable expectations about the outcome?
• How do you cope with that?

3. Questions on future aspects:

What would you like EOL palliative care to be at your unit in the future?

4. Questions for closure:

Is there anything you would like to add about palliative care, some aspects you would like to tell me about?

Is there anything you would like to add about family involvement during EOLC, some aspects you would like to tell me about?
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Formulário de Consentimento Livre e Esclarecido

Título da Pesquisa: Políticas de visitação e as experiências dos profissionais de saúde sobre os cuidados paliativos e o envolvimento da família durante os cuidados de fim de vida em CTIs brasileiros

Pesquisadora: Maria Tillquist

Eu recebi e li a informação da pesquisadora, Maria Tillquist sobre as Políticas de visitação e as experiências dos profissionais de saúde sobre os cuidados paliativos e o envolvimento da família durante os cuidados de fim de vida em CTIs brasileiros, referente a sua pesquisa de mestrado pela University of Borås na Suécia.

Eu compreendo que minha participação é totalmente voluntária e que posso interromper ou retirar meu consentimento a qualquer momento durante essa entrevista. Caso eu tenha quaisquer perguntas sobre o estudo, poderei entrar em contato, a qualquer momento, com Maria Tillquist (maria.tillquist@hotmail.com) ou com sua orientadora, Isabell Fridh (isabell.fridh@hb.se).

Assinando abaixo, eu dou meu consentimento para a participação neste projeto de pesquisa. Eu entendo que a coleta de dados da minha participação será usada para uma dissertação de mestrado e eu dou meu consentimento livre e esclarecido para tal uso.

Data:

_________________________

Assinatura:

______________________________________________________________________________

Nome (favor usar letra de imprensa):

______________________________________________________________________________