Balinese nurses’ experiences of caring for patients in palliative care
An interview study with nurses in Bali, Indonesia

Balinesiska sjuksköterskors erfarenheter av att vårda patienter i palliativ vård
En intervjustudie med sjuksköterskor på Bali, Indonesien
Abstract

Background: Working as a nurse means close contact with dying patients and mourning relatives. To care for severely ill and dying patients is part of the nursing profession and this places great expectations on the nurse to meet the needs of all individual patients and their relatives. Therefore, it is essential that the healthcare professionals have a deeper understanding of all the various needs a human being can have at the end of time.

Aim: The aim of the study was to describe Balinese nurses' experiences of caring for patients in palliative care.

Method: An interview study with semi-structured interviews. The participants were nurses from Sanglah Hospital located in Bali, Indonesia.

Analysis: Qualitative content was organized in codes and categories according to Graneheim and Lundman.

Results: Five major categories emerged during the analysis: Being a nurse and experience personal challenges, Being a supporting nurse for the dying patients and their families’, Significances of support when a person is dying, Having ambitions and striving to meet them, Nursing approach and commitment and Communicating palliative care and dying.

Discussion: The results were discussed based on the selected theoretical framework; Katie Eriksson’s theory of caritas. Caring with love was/is fundamental. The Balinese nurses’ experiences of caring for patients in palliative care was discussed in relation to previous research and the concept of family-centered care.

Keywords: Indonesia, Nurses, Palliative care, Experiences, Nursing
Sammanfattning

**Bakgrund:** Att arbeta som sjuksköterska innebär nära kontakt med döende patienter och sörjande anhöriga. Att vårda svårt sjuka och döende patienter kan ses som en del av sjuksköterskeprofessionen och innebär ett stort krav på sjuksköterskan som ska tillgodose olika behov hos alla individuella patienter. Vi tror därför att det är betydelsefullt att sjuksköterskan får kunskap om hur det kan vara att arbeta med människor som är i slutet av livet.

**Syfte:** Syftet med studien var att undersöka balinesiska sjuksköterskorns erfarenheter av att vårda patienter i palliativ vård.

**Metod:** En intervjustudie med semistrukturerade intervjuer. Deltagarna var sjuksköterskor från Sanglah Hospital lokaliserat på Bali, Indonesien.

**Analys:** Kvalitativ innehållsanalys organiserades i koder och kategorier enligt Graneheim och Lundman.

**Resultat:** Från analysen framkom fem kategorier: Att vara sjuksköterska och uppleva personliga utmaningar, Att vara en stödjande sjuksköterska för de döende patienterna och deras familjer, Betydelsen av stöd när en person dör, Ambitioner och strävan efter att nå dem, Sjuksköterskans synsätt och engagemang samt Kommunikation inom palliativ vård och döende.

**Diskussion:** Resultaten diskuterades baserat på den valda teoretiska ramen; Katie Erikssons teori om caritas. Att vårda med omsorg och kärlek var/får grundläggande. De balinesiska sjuksköterskornas erfarenheter av att ta hand om patienter i palliativ vård diskuterades i förhållande till tidigare forskning, samt begreppet familjecentrerad vård.

**Nyckelord:** Indonesien, Sjuksköterskor, Palliativ vård, Erfarenheter, Vårdande
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Introduction

We both have personal and professional experience of being present at the end of a person's life. We learned that it is a very emotional and difficult moment, both for the dying person and the relatives. Our experience is that after our beloved ones passed away or when having cared for a dying patient, and time gave us distance to reflect, many thoughts occurred around what could have been done differently and had we helped the dying person to find peace at last? In the process of our grief, thoughts arose about the relevance that we as approaching healthcare professionals have a deeper understanding of all the various needs a patient can have at the end of their time, as we cannot rewind and create a better end. We are only given a limited time with our relatives and patients, and during the time of illness until death, is often an important period.

These experiences resonated on a personal level and opened questions about how it may feel to be a nurse, caring for a patient that soon will die. As nursing students, we would like to prepare ourselves with more knowledge within this area of caring for patients and we believe it is of importance that nursing students receive knowledge about how it can be to work with patients who are at the end of their life. Consequently, thoughts arose around how nurses in other countries with different cultures cares for patients who are suffering from incurable illnesses or injuries and what we can learn from their experiences? There is very limited information on the principles and practice of palliative care in many developing countries, as in Bali, Indonesia. For these reasons we intend to widen the understanding of what Balinese nurses learnt to be meaningful for the patient in palliative care.

Background

Indonesia and Bali, a basic overview

Indonesia is a multicultural country spread over approximately 17,500 islands and its 256 million citizens speak over 700 languages (Broderick, 2015). The population is extremely diverse and over hundred ethnic groups are believed to be represented in the country. Indonesia contains the world's largest population of Muslims, though the Hindu is the most common religion on the island Bali.

Indonesia became independent from the Netherlands in 1946 after being a Dutch colony for 450 years (Broderick, 2015). Indonesia was then governed by a communistic dictatorship and military regimes until the president was forced to resign 1998 because of 1990s economic crisis (Shields & Hartari, 2006). The country is today governed by the young elected
Democrat President Joko Widod and Indonesia has now one of Southeast Asia most stabilised economic and political platforms.

The main resource is mainly fisheries and agriculture and the greatest economic growth is due to tourism and natural resources but at the expenses of the environment. A tsunami in 2004 killed around 170 000 people in Indonesia and in 2002 and 2005, Bali was affected by two terrorist acts (www.ui.se). About 230 civilians and tourists died which resulted in a reduction in tourism which affected the financial situation of the Balinese (Swedenabroad, 2018)

**Hinduism, a part of the society**

The Hindus vision of health is well interpreted with their religious beliefs (Eiseman, 1990). Hinduism preaches rebirth of the soul in new forms depending of the individuals’ actions throughout life.

A Hindu religious perspective on health and illness, believe that people in some terms, can defend themselves from sickness and suffering if they practice their religion in their daily life (Wikan, 1989). To live nearby a temple, take part in ceremonies and make daily offerings will protect the family from becoming sick or injured.

Hinduism accounts for 83.5% of the religious population in Bali, unlike the rest of Indonesia, which consists 87% of Muslims (Thrane, 2010). Within Hinduism there is no beginning and no end of time (Singh & Freeman, 2011; Thrane, 2010). Time is cyclical, and all life is part of an everlasting cycle that will be reincarnated repeatedly, Samsara. The definitive goal of a Hindu is to be released from Samsara. The road to salvation is long and before reaching the final goal, the soul has undergone rebirth several times. To achieve eternal reconciliation also requires living a life filled with good deeds, Karma, that is related to our previous life.

**Health status for people in Bali, Indonesia**

Many of the Indonesians die an early death due to cardiovascular diseases, nutritional, diabetes, maternal, chronic respiratory diseases and various injuries (World Health Organisation, 2014)

According to the latest reports from World Health Organization (WHO) is the life expectancy at birth for men 67 years old and 71 years old for women (World Health Organization, 2017). Disadvantaged groups of people can be excluded from the health care due to gender, where they are located, their salary, level of education and other social and
cultural differences. Yet, Indonesia is determined to improve the accessibility to health services for the most underprivileged people and aim to ensure healthy lives for all people at all ages.

**The Indonesian health care system**

The first modernized hospital establishment was founded in 1626 during the colonial era when Indonesia still was a Dutch colony (Regional Office for South-East Asia & World Health Organization. 2017). It was primarily founded to care for soldiers from the army as well as servants. It was not until the late 18th century that the poorer population was offered healthcare. After the economic crisis in 1930, charity care disappeared, and healthcare was only given to those who had the opportunity to pay.

After Indonesia became independent in 1945, the healthcare system went from entirely being a private sector towards a private as well as public-based sector (Regional Office for South-East Asia & World Health Organization, 2017). The public hospitals are today primarily funded by the government while private hospitals and clinics are funded by private companies.

Over the last two decades, the healthcare system has made great progress and the government is making big efforts for a better healthcare system and a healthier population, but today there is still a large lack of resources such as health centres and healthcare professionals are still below WHO's recommendations (Regional Office for South-East Asia & World Health Organization, 2017). The ratio of nurses to population was the lowest among the countries in Asia with a number of 1 per 1000 people in 2014. According to a study by the World Bank (World Bank, 2014), there is a shortage of 87,874 nurses both at private and public clinics.

**Being a patient in Indonesia**

Patients in Indonesia are free to choose health care from either the public or private system (Regional Office for South-East Asia & World Health Organization. 2017). Although many people cannot afford access to the public hospitals as they charge patients for the nursing care, medicines, food and hospital bed (Hennessy, Hicks, Hilan & Kawonal, 2006). Admittance to the private sector is generally defined by the patients’ capacity to pay or local government insurance schemes (Regional Office for South-East Asia & World Health Organization. 2017). Private insurance is free of choice for everyone after their own need and ability to pay. Drug advertisements are common and widespread in all media and it is anticipated by the
Regional Office for South-East Asia & WHO (2017), that Indonesians rely on self-treatment privately purchased from pharmacies to avoid the cost of hospital care. According to Barber et al (2007), research, unemployed people and those on low income were less frequent in seeking medical care, in opposite to the wealthier population that more regularly seek health care. This leaves the indigent population strongly beside the health care system and so consequently the poor are extensively exposed to infectious diseases Indonesian health care strive to exterminate, tuberculosis, typhoid, dengue haemorrhagic fever, malaria and several other infections. According to Shields & Hartari (2006), many Indonesians are located far away from the colonized areas making it challenging to seek health care due to poor infrastructure and unsafe weather conditions like heavy rain.

**Palliative care and the nurses’ role**

The world health organisation (WHO, 2014) definition of palliative care:

> 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.

Palliative care intends to ease suffering for the whole human being and includes relieve for the physical body, the psychological mind as well as social and existential needs (International Council of Nursing 2012; Socialstyrelsen, 2013; WHO, 2014). The care aims to improve quality of life and to make sure the patient achieves a satisfying well-being until the end of time. In order to accomplish this and create best possible care for the patient it is important to maintain the patient's autonomy (Ternested, Henoch, Österlind & Andershed, 2017). When suffering from a life-threatening illness the patient may experience physical and mental disappearance that can challenge the patient’s identity.

An adequate palliative care is based on four foundations (Strang & Beck-Friis, 2012). The first one is symptom relief and focuses on relieving physical, mental and existential needs with respect for the patient's autonomy and integrity. The second foundation, Teamwork, involves the importance of coordinated work between various professions to achieve the best possible care for the patient. The third one focuses on good communication between healthcare professionals, patients and its relatives. A good communication and continuous relationships to the health staff is valuable for a good care and can help improve the patient’s
quality of life. The fourth foundation, support to relatives and family, focuses on providing practical and emotional support to relatives during the palliative phase until death and the time after the patient past away.

The International Council of Nursing, ICN, is a global guiding tool that is available for all nurses worldwide (ICN, 2012). The code works to ensure quality nursing care and brings nurses together to one common approach.

Being a dying patient
A dying person may need help with everything from fundamental hygiene, maintain comfort, support to express emotions, communicate desires, social inclusion, to greater relief of symptoms including physical and psychological suffering, care within these circumstances strives to facilitate satisfaction (Lindqvist et al., 2012) and ease suffering (Öhlén, Bengtsson, Skott & Segesten, 2002). According to Sand and Strang (2006) feelings of existential loneliness are common among patients and distressful thoughts about deaths inevitable approach instantaneously anguishes their everyday life. Patients suffer from feelings of loneliness related to unfamiliar thoughts about the meaning of life and the impending death, unimaginable for the surrounding to understand, consequently making them feel alone with their incurable disease and thoughts. Rousseau (2001) and Chapman and Gavrin (2010) means that dying patients instantaneously expands physical distress and decreased independence and so needlessly suffer psychologically when the needs of psychological comfort are not identified. Råholm and Lindholm (1999) means that suffering for a dying person involves tackling feelings of regret and isolation. The dying patient desirers to find meaning with the life situation, past the suffering.

The body is often in intensive focus throughout the time of incurable illness towards the dying. Deterioration of physical capacity (Lawton, 2000; Price, 2000) and painful illness- or medical care-related expressions (Rasmussen, Tishelman, & Lindqvist, 2010) can be utterly worrisome for the patient and motivates palliative care. Consequently, being a dying patient, receiving physical support from health care professionals constrains nakedness to unknown people and makes it difficult for the patient to feel comfortable (Lawler, 2006). Misfortune of the integrity leads to vulnerability and feelings of being fragile (Conner, Allport, Dixon & Somerville, 2008; Lomborg, Bjorn, Dahl & Kirkevold, 2005).

Håkanson and Öhlén (2013) and Ek, Sahlberg-Blom, Andershed and Ternestedt (2011) emphasizes in their studies that the dying patients’ feelings drifted between experiencing relaxation at entrusting professionals with the accountability of caring for their needs and
yearning to stay adequate and self-sufficient in performing daily necessary procedures. Patients described, having to rely on staff for hygiene routines, as frustrating while others were more rational toward their dependency. Furthermore, the authors Boyd, Murray, Kendall, Worth, Benton and Clausen (2002) and Håkanson and Öhlén (2013) states many palliative patients experienced increased disability with an anxiety of losing independence. The patients later learned to conquer the impediments and increasingly felt more at peace and less exposed when receiving assistance from the professionals. One considerable important part of this process was managing to feel comfortable around staff and trusting them to care attentively (Håkanson & Öhlén, 2013). The stigma around disclosure of the naked body when being cared for was described as an adaptive procedure that felt easier with time.

**Palliative care and nurses’ education in Indonesia**

Palliative care was introduced in Indonesia in 1992 (Putranto, Mudjaddid, Shatri, Adil, & Martina, 2017). Since then it has been a slow and varying development around the country. Currently there is a limited availability and only in some major cities you can find a well-developed palliative care. The absence of palliative care can be related to government policy, lack of palliative care in health education, healthcare professionals' approach and general social surroundings in the country. According to a worldwide report in 2015 by The Economist Intelligence Unit, about the Quality of Death Index, Indonesia was ranked 53 out of 80 in palliative care. This is also something that is strengthened in Lynch, Connor and Clark (2013) study where palliative care development was categorized and Indonesia got a low ranking. The ranking is based on comprehensive national policies, comprehensive integration of palliative care in the National Health Service and community engagement.

Putranto, Mudjaddid, Shatri, Adil and Martina (2017) emphasize the importance of a well-educated nurse in palliative care and what a major role they can play in the end of a patient’s life. Although, most Indonesian nurses working with palliative care today are not specialist-educated (Putranto et al., 2017) and there is a severe shortage in trained nurses as the majority of nurses acquire only limited education and qualification for the title (Hennessy et al., 2006).

There are currently different levels of nursing education and the higher education institution system offers different levels of diploma, bachelor, master, specialist and doctor (Setyowati, 2015). Nonetheless there are many difficulties with the low level of basic nursing education.
• Sekolah Perawat Kesehatan (SPK, High School Certificate in Health Care) nurses graduate after completing nursing school which equals high school level. They represent the largest group of senior nurses with much practical training but lack theoretical expertise.
• Diploma III (D3) nurse study for three years on an academic level. Their education consists of a combination of both theoretical and practical knowledge.
• Bachelor nurses either precede from D3-level or after four years theory and one year of clinical practice. Student nurses on this level already hold plentiful both practical and theoretical experience.
• Master degree nurses are Bachelor nurses who achieved master degree in nursing. Nurses on this academic level mostly work as educators or managers at hospitals (Setyowati, 2015).

There is a deficiency of palliative care education in Indonesia (Witjaksono, 2014) and the palliative care concept and exercise are not fully implied by all health care professionals; nevertheless, the essential idea is implicated by most (Putranto et al., 2017). Yet, a considerable part of the palliative care is provided by health members who lack the expertise of palliative care. The government is now working towards a three-year specialist program to provide the nurses with an adequate palliative education (Putranto et al., 2017).

End of life in Indonesia
Indonesia acknowledge the need of palliative care at the end of a persons' life (Thrane, 2010). The family is closely involved in a Hindus death, and the eldest of the family makes the decisions for the dying person. The family will often perform rituals, ceremonies, sing songs and stay closely to the dying person's bed. Death is seen as a transition rather than an ending, rituals are crucial to ease the transition of the living soul to afterlife and it is the families' duty to perform these rituals (Singh & Freeman 2011). Interfering with these can possible bring bad karma to the family. According to Thrane (2010) the nurses’ try to help to the extent that it is possible to create private space for the family to perform their ceremonies and it is vital that the nurse consult with the family in every step of the care that is being provided for the patient. Contrary to the western world where it usually is essential for the patient to be involved in their own care and the different alternatives.

Problem statement
Caring for dying patients is part of the nursing profession and working as a nurse in palliative care means you are in close relation with dying patients. Studies show that a nurse plays a
vital part and whom can facilitate a difficult situation with the correct knowledge and skills. Previous research also shows a major lack of palliative care education within the nursing profession in Indonesia, which results that nurses are not sufficiently prepared for what is required when working with such a vulnerable group of patients. Research also shows that patients who admitted to palliative care often experience exposure and vulnerability due to loss of integrity and autonomy. The authors hope that this study will widen the understanding of the nurses' experience of working within the palliative care area and that the result can support and prepare other nursing students and even certified nurses. To further understand nurses’ situation and the various aspects that may affect her, it is therefore necessary to explore nurses’ own experiences.

**Aim**

The aim of the study was to describe Balinese nurses' experiences of caring for patients in palliative care.

**Theoretical framework**

Katie Eriksson’s theory of caritas caring means that faith, hope and love is the foundation and attitude a nurse should have in all care, as well as caring as a communion where human beings’ dignity establishes the fundamental worth (Eriksson, 2007). Eriksson (2002) further emphasises that human being implicates internal freedom and authority to decide over our own lives. When discussing the results of the study the theory can be used as a theoretical framework to generate a greater understanding of the nurses’ experiences of caring for dying patients.

Eriksson (2007) means that the body, soul and spirit are the entity of the human being. The body carries on the life we lived, the soul processes and memorizes all we experienced while the spirit is elevated above the earth and seek deeper meaning with life. Health is a changing state that we can estimate differently depending on where in life we are, and the human being can experience health and suffering simultaneously. Eriksson (2000) emphasize that the human goal is to find balance within the entity and the nurses’ purpose is to support, alleviate and share the suffering with the patient when the burden is too heavy to handle for the patient alone, so the human being can feel whole despite illness.

Eriksson (2007), view the human being as a creation in symbiosis with the body, soul and spirit, in which health and suffering can exist at the same time. Nonetheless, Eriksson means
that the nurse should try different approaches by playing and learning in her professional performance and states that the foundation of all nursing is to relieve suffering for the patient as well as creating a comforting balance within the entity of the human being (Eriksson, 2015). This ethic may illustrate nurse’s working approach towards the dying patients.

Moreover, Eriksson (2015) idea of caritas means love, compassion and generosity in relation to caring for other human beings and suggests that love in the sense of compassion, constitutes caring for suffering patients. These principles could illuminate nurse’s personal thoughts around the exposure of losing love in caring for dying patients.

**Method**

**Preparations**
According to Schatzman and Strauss (1973) and Bengtsson (2016), it is essential to get knowledge about the country’s culture, environment and population to be able to get the authenticity of the interviews. Therefore, before leaving Sweden the authors got prepared through reading previous studies and relevant literature to be enlightened in the subjects relevant to the topic and to have better understanding of how the nursing education is structured and what the nursing profession encompasses. The authors also increase their expertise in how the palliative care is structured, both in Bali and in general, and how the nurses work with the palliative care approach in Indonesia. This according to Bengtsson (2016) is crucial to be able to step in to a professional manner.

**Design**
The study has been conducted with a qualitative descriptive study design with data collection during semi-structured interviews. The technique was chosen as it has the advantage of following a specific pattern of interview questions, while providing space for flexibility through open questions (Danielson, 2012). It also allows participants to further develop issues that they consider to be important (Kvale & Brinkmann, 2009; Olssen & Sörensen, 2011; Polit & Beck, 2010). A qualitative method is also appropriate when focus is to deepen understandings of experiences (Polit & Beck, 2010).
Participants
Four participants were recruited from the local hospital Sanglah Hospital in Denpasar, the only hospital in Bali that provides palliative care. The nurses were all handpicked by the research manager. How the selection was made is unknown to the authors as well as if more than four were asked to participate and whether they chose to decline. They were all women between the ages of 22 and 37 and originally from different parts of Bali. All participants were qualified nurses but with an education and experience of different amount of years. N1 was a bachelor nurse with ten years’ experience of caring for patients in palliative care and the only one with a proper palliative training. N2 and N3 were D3 nurses and had obtained four-five years palliative experience and N4 were a SPK nurse with seven years palliative working experience. All nurses worked with patients in need of palliative care distributed at different departments in the hospital.

Data collection
To get in contact with nurses willing to participate in the study, an introduction letter was sent by email to various hospitals in Bali. The letter contained information about the study, an information letter (Appendix 1) and an interview guide (Appendix 2) to the participants, this according to what Bengtsson (2016) determines to be important preparations before a study's performance. The authors got in contact through Whatss-app with Bali’s largest local hospital, Sanglah Hospital located in Denpasar and received an invitation to a meeting with the hospital director, head nurse and research manager to inform more about the studies aim and design. The authors received an approval letter from the research manager to conduct research at the hospital.

All four interviews were conducted face to face in an office at the hospital where the interviews could be performed without distraction. According to Lantz (2007), the physical environment is a significant factor that may affect the communication in positive or negative manner. Lantz describes that to achieve a more lucrative interview the premises should be free from disturbing elements.

All interviews were recorded after approval and lasted for approximately 20-40 minutes.

Data analysis
Qualitative content analysis is frequently used in nursing to analyse different experiences (Elo & Kyngäs, 2007; Erlingsson & Brysiewicz, 2017). The method is effective, when using semi-structured interviews, to analyse data and to condense and organize meaning units in themes
and subthemes (Bengtsson, 2016; Danielson, 2012; Elo & Kyngäs, 2007; Graneheim & Lundman, 2004). The interviews were recorded and listened to several times by both authors. The material was transcribed verbatim and compared by both authors. This to ensure the quality of the transcribed data (Bengtsson, 2016; Burnard, 1991; Kvale & Brinkmann, 2009; Graneheim & Lundman, 2004). In accordance with Dahlberg (1997), transcripts were made on the same day or day after the interviews were conducted, to ensure validity.

In the analysing process, focus has been directed towards the manifest content of the interviews, which means the visible and obvious content of the text (Kondraoki, Wellman & Amundson, 2002). Meaningful units that respond to the aim were assorted and discussed together by the authors. The meaningful units were carefully condensed and thereafter encoded. This process was repeatedly made to ensure that no important data was missing from the transcriptions. Thereafter multiple codes with similar content was organized and constituted into themes that are represented in the result. This according to Graneheim and Lundmans (2004), qualitative content analysis method.

According to Patton (2002), the categories should be internally homogeneous and externally heterogeneous, no code should be omitted from any category and no code should be suitable into several categories. However, according to Lundman and Häggren-Graneheim (2008), this can be difficult as the text is about experiences.

**Ethical considerations**

The authors intention was to meet the ethical aspects of conducting research and anticipated to not harm the participants in any context. This is important both for the sake of the participants, and for scientific field work in general (Caplan, 1991; Kjellström, 2012; Rothman, 1991). Therefore, participants received an introductory letter (Appendix 1) containing all information that explained the extent and purpose about the study. The nurses’ was reassured that it is voluntary to participate and that they could end the interview at any time without having to explaining the cause or reason. The nurses’ perspective was not questioned, this to avoid the risk of harming the participants. The importance of this has been established internationally by, for example, Caplan (1991) and Rothman (1991).

The questions are designed in such a manner they cannot be angled to any direction. The participants were informed that the collected data are completely confidential and information that risk revealing the identity of the participants are being converted, this is according to Kjellström (2012), important to guarantee the anonymity of the nurses.
The letter also contains contact details for the participants to use if they come up with additional questions or wish to get in touch in case the interviews stirred up memories or emotions. The importance of the non-harm principle has been acknowledged and the nurses’ must not end up in a worse position than before participation in this study (Sandman & Kjellström 2015).

The ethical committee at Ersta Sköndal Bräcke University College approved of this study in January 25th, 2018 (diary number 1706/A).

**Results**

Data analysis revealed five categories: *Being a nurse and experience personal challenges; Being a supporting nurse for the dying patients and their families; Having ambitions and striving to meet them; Imprecise communication and perceptions of palliative care and dying and Nursing approach and commitment.* The categories will be presented individually, and the Nurses’ experiences will be clarified with quotes.

**Being a nurse and experience personal challenges**

This category illustrates how the nurses experienced various personal challenges in the work with palliative patients. The nurses announced that palliative care implies several challenges on both a professional and personal level. They described that it is sometimes difficult to keep the relationship with the patient and the relatives at a professional and well-balanced distance. When the nurses have cared for a patient for a period they got close and became attached and when the patient dies they described it is difficult to stay focused on being a nurse and not get too emotional by the situation. This was exemplified as:

*So when I have been in touch with that patient and the family for a long time and when the patient is about to go to the end of life I feel a deep loss. Sometimes I can’t help crying.*

The nurses described that learning to handle situations like this is an ongoing process they hope to learn over time.

They also described that it is stressful and draining going back and forth between being professional and emotional. Although they experienced grief or sadness when a patient passed away, the nurses described the need to keep up appearances and not show too much feelings
since they were all aware they are still responsible for other sick patients who need their help and they must stay professional and give their attention to them in the way they were obligated to.

Some nurses described that it is sometimes hard to leave the emotional thoughts when they finished their shift. This affected them since it made it difficult to relax which contributed to increased stress.

Despite the emotional stresses the work implies, the nurses experienced the work as interesting and enriching. Nurses described that the relationship between patients and their relatives were approached in a different way than when caring for curative patients. One of the biggest satisfactions along the palliative work was when the nurse managed to help a patient reach acceptance and died as peaceful as possible. This made them proud and cheerful and were the main reason they were able to find the strength to continue when challenges and tough periods appeared.

Several nurses mentioned their own impression of morality. It seemed to be a way for the nurses to cope with all the death and life. The nurses said they believed in faith and that death is part of the path and out of their control. They expressed that these thoughts made it easier to accept the dying.

**Being a supporting nurse for dying patients and their families**

This category defines how the nurses try to sense and provide suitable support for the patient and their families. The nurses described that patients often suffered from severe pain that required urgent and effective treatment, often using several drugs in combination. Nevertheless, this was the doctors’ area of expertise, whereas the nurses focused on non-medical treatment and comfort. The nurses emphasised that many patients are in comprehensive need of emotional support during the transition from being treated as curative to becoming a dying patient. Support was for the most part described as providing comfort in shape of their own company, conversing, inviting the family to come and be with their loved one, including comforting them so they in turn have the strength to be supportive to the patient and meeting the needs of the patients. According to the nurses´ doctors decision was sometimes made too late, leaving the nurses with little time to provide the support and care the patients’ need. Nurses defined the patients transition as a phase of fear, as they do not understand why treatments are not continued, adding that every patient reacts differently. Nurses met a broad variation of reactions, while some patients cry when being moved to palliative care, there are others who become angry or want to be left alone in silence and
listen to songs, pray, practice mantra or mindfulness. The nurse explained that she, in situations like this, will help to provide the support the patients need to calm their minds. Having time to converse and stay close by, were described as important. Furthermore, meditation, breathing exercises, arrange for a meeting with a religious person or inviting the family were described as parts of care. One nurse meant that the patients have a need to talk more and deeply about the purpose of life and the lives they have lived. Another nurse said that most patients want to talk or have a chat about anything from what makes them happy to deeper thoughts:

*We talk about everything including fear, anything they think they have done or problems... feelings of guilt related to the illness. Talking will make them feel relived and happier.*

The nurse described that conversations like this seemed to have a healing effect on the patients, who consequently wanted to encourage other dying patients to share their thoughts with them. One nurse said that the support patients receive from the hospitals community group for palliative patients, appears to be relieving in a way that they give the impression of being happier once they can share their thoughts with someone going through the same thing.

Nurses spoke of comforting the patient and being there for them as supportive company as significant for the patients. It was expressed that they wanted the patients to know that they could rely on them as nurses, to be there beside and allow them to share their thoughts and pain. Suffering could be eased by time and talk, both for the patient and the relatives. One nurse said:

*Morphine will reduce the body pain, but they still have pain in their mind. I know the pain will ease if I talk to them.*

The nurses described that the support from the patients' family helped to make the dying process easier, although one significant part of this process was comforting the family before they could be of good support to the patient. The families' immediate reaction was often described as being angry, upset or very sad and anyone could be blamed both the nurses and the doctors. Some nurses said that it seemed the families anger could cause worrisome for the patient. Therefore, were the support given to the families described as urgent for the sake of the patients’ inner peace.
Meeting the needs, was for the most part described as assisting the patient and family with religious traditions and rituals. Many Hindus often request a holy bath and a priest when death is approaching, and Muslims tend to fast. Nurses tried their best to fulfil the patients' religious wishes and emphasised that they treat every patient according to their religious beliefs as this is considered important in Bali.

**Having ambitions and striving to meet them**

This category discloses the nurses ambition of palliative care and was often described as a desire to help the patients reach acceptance, find peace, retain quality of life and live to the end. The denial phase was described as a stage when the patients are scared and suffer both on a mental, physical and spiritual level. One significant part of the denial phase was helping younger patients to accept that they are dying. Nurses described that younger patients, who do not feel or physically look like they are dying, sometimes denied the doctors diagnose and became distressed and anxious, whereas older patients easier accept that they were at the end of life. Most nurses also described finding it hard to reach out to the patients when they become angry, afraid and close themselves off, this was experienced as a challenging part of their work. When describing situations like this, nurses expressed that their ambition was to help the patient die happy and feel calm. Talking about the patients' fear was described as way to help the patient reach acceptance and satisfaction could be experienced for the nurses if they managed to help. Observing the change in the patient was described by one of the nurses as:

*The hardest part is to be with the patient when they found out that they suffer from an incurable disease, when they are in the denial phase... The best part is when you have helped them reach acceptance. And they can die in peace.*

To maintain quality of life for the patients, was also described as the nurses' main focus and was according to all nurses something that was achievable first once the patient has come to peace with the dying. Nurses repeatedly emphasised that the way to happiness is by accepting their destiny. The shared experience was also that fellowship with other dying patients helped to retain quality of life, to share their feelings and get together and practice yoga, meditate, eat or pay a visit to another hospitalised patient, was described as meaningful activities for the patients. One of the nurses said that she tried to inspire the patient to be happy by showing them that she was happy. Another nurse said:
At the end the patient is happy, and we can accept and be happy with them. They know that they are very sick and for me to see them able to accept that they are sick and still be able to be happy makes me happy.

One of the nurses' mutual experience of caring for dying patients was that they want to live life to the end once they have come through the transition and found peace. To live life to the end was described as making the most of the situation, being able to continue their life despite the illness and not worry too much about what happens tomorrow. All nurses said that they try to provide the patients with whatever makes it more comfortable for them to enjoy the time left, including spending time with them, inviting the family and helping them to get in contact with the hospital's palliative community, along with reducing body pain using medication as well as complimentary care.

**Imprecise communication and perceptions of palliative care and dying**

The category revealed that communication about palliative care and dying was experienced as time consuming and important. Most of the immediate fear the patient experiences when being moved to palliative care, was described by the nurses as related to shortfall of information given to the patients when going from curative care. To communicate knowledge about the progress of the illness was therefore described as the elementary action within palliative care. For these reasons, do the nurses spend a large amount of time educating both the patient and the family about the condition and the expected progress of the illness. It was expressed by all nurses that the patient and family need comprehensible information to be able to understand and accept that the patient is dying. One of the nurses said:

*It is difficult for me, they do not understand that they are at the end of life. For instance, they know that they suffer from cancer but have not understood that they are no longer curative. They have high expectancy that they are going to live long and that the pain or illness will be cured. They want to be healthy. That is when a problem for me as a nurse will arise.*

The nurses also expressed that they often felt they have limited time to help the patient and family to grasp the importance of the situation and this could be less stressful. They argue several times that it is better for the patient when palliative care is provided earlier as it allows
the patients more time to accept the dying and generates a greater opportunity for the palliative nurses to assist the patients and their families. Awareness and readiness was described as important to be able to face what is coming. One of the nurses said:

"It is so sad when, nor the patient nor the family, are aware that the illness is incurable. And I must communicate to them that there is no hope for a cure of the illness. Especially at the stage when they are almost already at the end of their life."

The nurses described the patients as anxious to learn more about the progress of the illness when they have overcome that there are no more curative treatments to put hope into. Nurses spoke about the importance of informing the patients about the course of the illness and plan their care together. This was experienced by the nurses to help the patients cope better, knowing in advance what they must go through. Nurses described patients who understood the progress of the illness to be happier at their end of life. To have knowledge was associated with acceptance.

**Nursing approach and commitment**

This category illuminates the importance of the nurses’ commitment to their work. One of the things the nurses repeatedly returned to during the interviews was the importance of the right approach when caring for palliative patients. Nurses describe that more is required on a personal level comparing with other areas within the nursing profession. They described that when caring for dying patients one of the most important things is to care your patients by heart and perform it with love. They also explained the value of passion and engagement for the profession and that willingness is of great importance for care. One of the nurses said that when you have the right approach towards the patient and they feel it's authentic that will help them feel safe and secure. Caring was described as "have to be performed with heart". One nurse said:

"You must be passionate about the patient and do it by heart, that is the most important thing. Do it by heart and have time"

Time was another prominent aspect that was consistently featured. When the authors asked the participants about what's important when caring for palliative patients all nurses answered, "Time to spend". When the nurses showed they genuinely had time, the patient was given
space to open for communications that could help develop the relationship between nurse and patient. It also made it easier for the nurse to get a better perception of the patient's wishes and needs of support. They expressed time and engagement as fundamental factors that is required to be able to maintain person-centred and high-quality care.

Although time was one of the fundamental cornerstones of palliative care, there is no abundance of time available. Even if the nurses felt the need to spend more time with a patient it was not always possible due to high workload. Exemplified as:

*We work as a team, but work is hard, is not much staff in our ward and it is always a lack of time. Sometimes I must spend the time on other things even if I rather spend it with the dying patient*

The lack of resources resulted in reprioritisations and caused conscience stress among the nurses.

**Discussion**

In this section the authors will consider the chosen method and the results of the interviews in relation to the theoretical framework.

**Methodological considerations**

The chosen design was appropriate while the focus in our study was to interpret and understand the nurse's own experiences (Polit & Beck, 2010). The semi-structured technique provides the participants to further develop issues that they consider to be important (Kvale & Brinkmann, 2009; Olssen & Sörensen, 2011; Polit & Beck, 2010).

Erlingsson and Brysiewicz (2017), determines the difficulty for a novice to analyse qualitative data and Kvale and Brinkman (2009), says it is a skill that requires a lot of training to successfully obtain high quality in the study. The authors' novice may have influenced the result as it is easy to miss out on the nuances that could have benefitted the result and could have been developed through follow up questions in the participants stories.

The study has some disadvantages, mostly due to the small size of the study. To increase the reliability of the study, an increased number of participants would have been beneficial. Considering the selection of participants was made by the research manager the authors do not know if this might have impacts on the result. Even some cultural barriers such as the fact
the study has been conducted in English, which is neither the authors nor the participants first language. When authors and participants speak different languages, a part of the trustworthiness in the collected data may be lost. This may have affected the content of the data and could have been altered by using an interpreter meanwhile the interviews were conducted. Squires (2008), determinate that to obtain the understanding of the research topic it is suitable to conduct the interviews in the participants first language. This especially when conducting health care studies.

One strength in the study is that we were two authors, multiple authors is described as a strength by Burnard (1991) and Graneheim and Lundman (2004.) The material could therefore be compared and discussed several times, this is according to Bengtsson (2016) helpful to maintain as high degree of quality as possible throughout the whole process.

The interviews were conducted in a calm and familiar environment for the participants, which according to Lantz (2007), is to be recommended. The participants may have experienced time pressure as they needed to return to their work immediately after the interviews were conducted. This may have affected the depths of their answers. But even so, the nurses were eager to tell their stories and the material became comprehensive.

**Results discussion**

With the purpose of exploring nurses’ experiences of caring for patients in palliative care, it appeared in several interviews how the nurses experienced caring for patients in palliative care as challenging and enriching in various ways. When the nurses were attached to the dying patients, it could contribute to emotional stress. This carried mixed reactions for the nurses and are conditions that can affect her working environment, the quality of care for the patient as well as her working situation and even her personal life. This is resembling to the founding’s in Cheung et al., 2001, Chiang et al., 2013, Johansson & Lindahl, 2011 study where the nurses in similar ways describe palliative work as energy-consuming and sometimes grief-fully. The nurses in these studies described how they distanced themselves from the patient in try to deal with the reactions and how they struggled to not show too much emotions in front of the patient and its relatives. In Blomberg & Sahlberg-Bloms (2005) study the nurses describe how they instead of providing psychological support focused on their practical routines in a way to cope with the emotional challenges. This differs from the results in our study, where the nurses are more focused and prioritise spiritual and psychological support in front of practical routines even when this entails emotional stresses.
The emotional challenges were associated with nurses’ being attached to the patient and although it was expected that the patient would eventually die, this caused personal stresses for the nurse. All four nurses in this study highlighted the importance of caring with love. This is in line with what Katie Eriksson (1994) says is fundamental in caregiving. If the nurses had not been personally engaged and genuinely cared with heart and love, the emotional reaction after a patient passing away would not have been so prominent. This thus reinforces both Katie Eriksson's theory about caritas, love, and the nurses' words about how palliative care should be practiced.

Although the nurses described the work as emotionally stressful, it emerged from the studies result that they at the same time experienced the work as interesting and enriching. This in parable to what the nurses described in Abbaszadeh m.fl. 2014, Glackin m.fl. 2013, Holms m.fl. 2014 studies. Although their studies were conducted in various settings within the palliative area, all their results demonstrate, just like ours, the enriching part of the work as a common factor.

The result also revealed the importance of the right resources for adequate palliative care. Nurses described that time is of great importance but an obvious shortcoming. The same results were found in Abdulla Karim m.fl. 2015, Andersson m.fl. 2016, Cheung m.fl. 2001, Chiang m.fl. 2013, Johansson & Lindahl 2011 studies where nurses describe that resource shortages made them frustrated and stressed and led to emotional tension and in the end exhaustion. Friedrichen (2012), results support these findings and mean that time and continuity is fundamental to build a good relationship and to be able to perform an adequate palliative care. In a study made by Mohan et al. (2005) all participants considered that the work situation did not allow enough time to support the severely ill patients. Eriksson (1994) highlight, like the nurses in our study, the importance of giving time to the patient. Eriksson believes that this is a way to confirm the patient's suffering. Eriksson also raises the importance of protecting patient dignity and integrity to alleviate suffering. To be able to perform a good and person-centred care, it is important to find out what the patient want and needs, and this is done by offering time and engagement.

The results also illustrate that dying patients are intensely exposed and have a combination of various needs and how nurses strive to meet those. Nurses described caring for patients with severe pain and the importance of pain management to optimise comfort and how this was done with regular treatment, controls and communication. Nonetheless, this was not defined as their focus as they followed doctor’s recommendation, whereas the nurses emphasised that the answer to pain is not always more medication. Symptom relief for
physical, psychosocial and spiritual pain was by all nurses well described and identified. Among the examples of needs were the significance of receiving recognizable information about the progress of the illness and what to expect. Nurses emphasised that patients and their family often felt excluded from information and care planning when decisions to withdraw treatments were made by the doctors, and so immediately the nurses acknowledged the need of further information. Situations were described that relate both to acceptance and better quality of life until the end, as well as for the patient and the family. For instance, nurses positive experience of being able to communicate knowledge about the course of the illness and witness the patient go from anxious to acceptance and inner peace. Similar experiences of sufficient communication have been illuminated in several previous studies (Barbosa da Silva m.fl. 2010; Glackin m.fl. 2013; Holms m.fl. 2014).

The dying patient have many thoughts about their situation and the impending death and according to the Swedish National Board of Health and Welfare (SOU 2001:6) is one of the foundations of palliative care communication. However, it is also common that the patient struggle to have these conversations with their families (McDonnell, Johnston, Gallagher & McGlade, 2002). Therefore, the communication with the nurse is often valuable for the patient and can lead to increased well-being. This agrees with the result of the nurses' experiences, that most patients distance themselves at first, although they have an extensive need to talk and express their inner thoughts. Nurses emphasised that even though most patients suffer from severe body pain, the psychological and existential suffering is agonizingly and much of the suffering could be reduced when they shared their thoughts with the nurses.

Communication also included listening, and patients who allowed themselves to talk about their fear, guilt, anger and frustration appeared to be happier and calmer. All nurses experienced their company being of great support and with a meaningful impact on the dying patient and therefore their families too. This equivalent to Eriksson (2000) vision of Caritas, that health is a unit consisting of the body, soul and spirit, in which all three dimensions strive to maintain balance and awareness. Eriksson (2015) further means that to be a nurse and care for a patient implicates "being" alongside, allowing the patient to share their suffering, to carry the heavy weight so the patient find the energy to regain health, and do this by heart. Nonetheless, this was closely described by the nurses participating in this study.
Conclusion

With the aim to explore the significance of being a nurse meeting patients in palliative care, the conclusions from our study determines that working within the palliative care area places high demands on the nurse. Nurses often come close to both patient and relatives, which requires emotional commitment and might be stressful for the nurse. Simultaneously they experience diverse satisfying aspects. To provide nurses and nursing students with the ability to cope with challenges coincided with palliative care it would be advantageously to introduce more discussion about palliative care both in education and in clinic. In this way, nurses can prepare themselves and learn how to cope and handle the challenges the work involves.

The purpose with this study is to increase awareness of nurses’ experiences of caring for patients in palliative care. The study contributes with analysis of interviews with nurses, who throughout the interviews were devoted and gave thoughtful answers about their experiences. What the result determine as key in the work of palliative care is how essential it is to have a comprehensive view of all the various needs that may exist within a multidimensional human being. Conditions that creates a good beneficial palliative care is communication, to give them time, meet their needs, providing different forms of support for both patients and their close relatives and that the care needs to be performed with tenderness, love and heart, in alignment with Katie Eriksson's theory of Caritas.

Clinical implications

To care for a dying patient and sense their signals and needs with an approach that is suitable comes with knowledge. The results can provide an insight and offer a better understanding of the complex care and expertise that is desirable for nurses who work in palliative care or the potential role, including nursing students. Additionally, the result gives an understanding of how the palliative care is interpreted in Bali, Indonesia. The result can also be beneficial when forming guidelines in palliative care, or as subject for discussion when supervising nurses or during nursing education. Nonetheless the results may contribute to an increased awareness for doctors and head of department who are responsible for the decisions involving the patients’ treatment, considering it was argued that nurses thought the decision sometime was made too late. Hopefully this also pursue that palliative care settings will recognize the nurses valuable work for the patient.
Further research

The results of the study show that communication in palliative care is essential to establish a person-centred care to help the patient and family through serious illnesses. However, communication is something that can be difficult for nurses without experiences. It is therefore suggested that further research include development of conversation tools targeting inexperienced nurses.

The study has limitations as all nurses who participated work at the same hospital. To accomplish a more comprehensive survey of Balinese nurses experience of palliative care should further research be carried out in other Balinese cities or on the countryside and include nurses from different hospitals, to establish if the working conditions affects nurses' experiences. It is also of importance to include what other challenges nurses address when caring for a dying patient, especially nurses with less experience and newly graduated. Furthermore, it would also be of interest to include the patients' perspective of palliative care.
References


Appendix 1

Participant letter

To the participants in the study “Nurses’ experience of caring for palliative patients”

This study is addressed to health care professionals and intend to explore the nurses’ experiences of providing palliative care to adult patients. The aim of the study is to describe experiences of palliative care from the nurses’ perspective to generate knowledge about care of a vulnerable category of patients.

With this letter you are asked if you would like to participate in the survey. If you wish to partake in this study, you will be individually interviewed about your experiences considering the subject. The interview is like an ordinary conversation and will last about 30-60 minutes. Emma Gustavsson and Annelie Persson will be conducting the interviews. If you allow it, we will record the interview, in order to ease the process. No names or other personal information will be kept that could reveal who has been interviewed; to guarantee the participants full anonymity. The recording will be saved on a USB and all gathered material will be kept sealed. The result of the study will be available in paper format and online through Ersta Sköndal Bräcke University College library.

Your participation in this study is voluntary, and this means that you at any time can choose to interrupt the interview and withdraw what you have shared without any need for explanation.

The Research Ethic Committee of the Institution of Health Care Science at Ersta Sköndal Bräcke University College, Stockholm, Sweden has approved of this study: 18-01-25

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Appendix 2

Interview guide

We have some questions but want this to be more like a conversation and there is no right or wrong answers we are just interested to take part of your thoughts and experience…

- How do you experience working with palliative care?
- How do you experience the difference in caring for patients in palliative care comparing to curative patients?
- How do you experience the transition of caring for a patient who goes from curative to palliative?
- How do you experience the change in the patient’s needs?
- What do you think is important when treating patients in palliative care?
- What do you think is important for the patient in palliative care?
- What do you experience makes a difference for the patient?
  - How do you relieve the symptoms the patient suffers from?
- What advice would you give to a new colleague about palliative care?
- What else would you like to add besides what we talked about?

Follow up questions

- Can you explain a little bit further?
- Can you give an example of what you mean?
- When you say…can you explain more about that?
- How did you feel about that?
- What else?

What to say…

That is interesting, can you tell me more about that?
How do you mean when you say…?
### Appendix 3

**Chart of meaningful units, codes and categories**

<table>
<thead>
<tr>
<th>Meaningful units</th>
<th>Condensed units</th>
<th>Codes</th>
<th>Categories</th>
</tr>
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<tbody>
<tr>
<td>It is an interesting job but I feel that it is a bit easy to be carried away.</td>
<td>Interesting job, easy to be carried away</td>
<td>Emotional Attached</td>
<td>Being a nurse and experience personal challenges</td>
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<td>Touched</td>
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<td>It’s important that the patient know we are there for them. And have time to</td>
<td>Patient know we are there and have time to talk, feel they are not alone</td>
<td>Comfort</td>
<td>Being a supporting nurse for the dying patients and their families</td>
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<td>talk to them, so they feel they are not alone.</td>
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<td>Company</td>
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<td>Deep talk</td>
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<td>If acceptance, they will be happy because they will understand that they are</td>
<td>Acceptance will make them happy</td>
<td>Acceptance</td>
<td>Having ambitions and striving to meet them</td>
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<td>going to die, die with happy. Maintain the quality of life for the patients.</td>
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<td>Quality of life</td>
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<td>They want to live the days left.</td>
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<td>Live to the end</td>
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<td>By talking to them you know the pain is still there or has been gone you</td>
<td>Talking to them make it easier</td>
<td>Information</td>
<td>Imprecise communicating and perceptions of palliative care and dying</td>
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<td>know but it will make it easier by talking with them.</td>
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<td>Education</td>
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<td>You must be passionate about the patient and do it by heart, that is the most</td>
<td>Passionate and do it by heart is important.</td>
<td>Engagement</td>
<td>Nursing approach and commitment</td>
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<td>important thing. Do it by heart.</td>
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<td>Care with love</td>
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<td>Being with the patient</td>
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