Beatrice Chesop & Christine Nabunya

PRIVACY OF PATIENTS ADMITTED IN THE ICU

Systematic Literature Review

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Thesis abstract

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Author(s): Chesop Beatrice & Nabunya Christine

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Supervisor(s): Salminen-Tuomaala Mari (Phd, Senior Lecturer) & Heino Johanna (MNSc, Senior Lecturer)

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Aim: The aim of this systematic literature review is to evaluate how nurses can uphold/ safeguard the privacy of patients admitted in the **ICU**. The objectives of this study are; to help nurses understand the need and effectiveness of patients' privacy in the **ICU** as well as to understand the concept of privacy and its benefits to patients admitted in the **ICUs**. This study research is part of the **EVICURES** people's project in anticipation of the building of a new **ICU** for the Seinäjoki Central Hospital.

Background: Privacy is not a concept deemed to be synonymous with the **ICU**, as the primary role of the **ICU** is to save lives. However, as the demand for **ICU** care increases, there has been documented cases of patients' privacy violation. This study sheds light on the concept of privacy in the **ICU** environment, family member involvement, end of life care/ decisions, nursing practices and other ethical issues.

Methods: A systematic literature review of 19 scientific articles obtained from Cinahl EBSCO*host (n=16),* PubMed (*n*=1) and text books (*n*=2). The data was analyzed using inductive content analysis.

Results: Two major themes were identified from the literature review: privacy (patients, family and end of life care) and nursing perspectives (practices, ethics and strategies) in the **ICU**. Similarities existed in the themes that were identified irrespective of the evidence in the study or the country of origin.

Conclusion: Privacy issues emerged on a broad spectrum and the difficulties of preserving and respecting patient's intimacy due to the **ICU** environment were clearly highlighted. Solutions and strategies to combat privacy issues came out quite clearly in this study. Decision making in the intensive care environment is also a complex phenomenon because the patient's clinical situation places time demands and ethical compromises on nurses.

Keywords: Intensive Care Unit, Privacy, Critical Care Nursing, Confidentiality, Personal space, Dignity, Patient Centered Care, Family Centered Care.

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Opinnäytetyön tiivistelmä

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Tavoite: Tämän systemaattisen kirjallisuuskatsauksen tavoite on arvioida, miten sairaanhoitajat voivat taata / turvata potilaiden yksityisyyden teho-osastolla. Tämän tutkimuksen tavoitteet ovat: auttaa sairaanhoitajia ymmärtämään potilaiden yksityisyyden tarvetta ja tehokkuutta teho-osastolla sekä ymmärtää yksityisyyden käsitettä ja sen edut potilaille teho-osastolla. Tämä tutkimus oli tuottaa tietoa **EVICURES** -hankkeelle ennakoiden rakennettaessa uutta teho-osasto Seinäjoen keskussairaalassa.

Tausta: Yksityisyys ei ole käsite, jolla on samamerkitys teho-osaston kanssa, koska teho-osaston ensisijaisena tehtävänä on hengen pelastaminen. Kuitenkin, samaan aikaan kun hoitovaatimus kasvaa teho-osastolla, on todistetusti ilmennyt teho-osastolla tapauksia, jossa potilaiden yksityisyyden on ollut loukattu. Tämä tutkimus valaisee yksityisyyden käsitettä teho-osasto-ympäristössä, perheenjäsenten osallistumista, elämän loppuvaiheen hoitoa, hoitokäytäntöjä ja muita eettisiä asioita.

Menetelmät: 19 tieteellisen artikkelin systemaattinen kirjallisuuskatsaus, joka on saatu Cinahl EBSCOhostilta (n=16) PubMedilta (n=1), ja kurssikirjoista (n=2). Aineisto analysoitiin käyttäen induktiivisen-sisällön analyysia.

Tulokset: Kaksi merkittävää teemaa tunnistettiin kirjallisuuskatsauksesta: yksityisyys (potilaat, perhe ja elämän loppuvaiheen hoito) ja sairaanhoidon näkökulmat teho-osastolla (käytännöt, etiikka ja strategiat). Samanlaisuudet havaittiin teemoissa, jotka tunnistettiin todisteista riippumatta tutkimuksissa tai alkuperämaassa

Johtopäätös: Yksityisyysasiat tulivat laajasti ilmi. Haasteita säilyttää ja kunnioittaa potilaan intiimiyden teho-osastolla korostetiin selvästi. Ratkaisut ja strategiat ennaltaehkäistä yksityisyysasioita tulivat esiin melko selvästi tässä tutkimuksessa. Päätöksenteko tehohoitoympäristössä on myös monimutkainen ilmiö, koska potilaan kliininen tilanne asettaa ajan vaatimuksia ja eettisiä kompromisseja sairaanhoitajille.

Avainsanat: Teho-osasto, yksityisyys, tehohoito, luottamuksellisuus, henkilökohtainen tila, arvokkuus, potilaskeskeinen hoito, perhekeskeinen hoito

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Abbreviations

AACN	American Association of Critical-Care Nurses
CCN	Critical Care Nursing
CCU	Critical Care Unit
CG	Control Group
CIT	Critical Incident Technique
EU	European Union
ICU	Intensive Care Unit
IV	Intravenous
OD	Organ donation
SFTA	Situational Form of Technological Atmosphere
SG	Study Group
WHO	World Health Organization

EVICURES:

EVI	Evidence-based
ICU	Intensive Care Unit
CURE	Heal
S	Seinäjoki

1 INTRODUCTION

Admission to an **ICU** may signal a threat to the life and well-being of the patient who is admitted. Critical care nurses perceive the unit as a place where fragile lives are vigilantly scrutinized, cared for, and preserved. However, patients and their families frequently perceive admission to critical care as a sign of impending death, based on their own past experiences or the experiences of others. Understanding what critical care means to patients may help nurses give improved care to their patients. (Gonce & Fontaine 2009.)

Patients admitted to the **ICU** are generally in a life-threatening condition, unaware of the severity of their condition or do not remember their stay in the **ICU**. Nevertheless, 30–100% of patients can recall part or all of their stay in the **ICU**. Owing to impaired ability to communicate and complete dependence on others, these patients have several specific problems and needs. Previous studies have focused on patients' unpleasant experiences during their **ICU** stay, including pain, lack of sleep, nightmares and feelings of isolation and loneliness. These experiences have a great influence on the patients' physical recovery, psychological well-being and quality of life after discharge. Meeting patients' needs is important for avoiding unpleasant experiences and providing patient-centered care. (Aro 2012.)

The concept of privacy is open to different interpretations with a range of clinical implications. For critical care nurses, and others involved in delivering care, a standard of excellence in practice is the concern for, and sensitivity towards, maintaining patient privacy. A qualitative study describing the views of intensive care nurses on patient privacy found three major themes: exposing the patient's body, intimacy or lack of intimacy and protection of the patient. (Latour & Albarran 2012.)

Exposure of the patients' body and intimacy were related to the nurses' attitude and application of routine interventions in daily care. Nurses and physicians maybe be unaware of a patient's preferences and or then forget them, resulting in

the violation of individuals' need for privacy, dignity and intimacy. The outcome is a dehumanizing experience for the patient. This is not a new issue and has been well documented. (Latour & Albarran 2012.)

Critical care providers are often privy to confidential information in the course of clinical practice. A dilemma can arise when confidential information is requested by family members or friends of the patient. Critical care nurses must be aware of the regulations regarding confidentiality, as well as situations where the use and disclosure of protected health information are permitted. (McGowan 2012.)

Dignity is another core concept in nursing care and maintaining patients' dignity is critical to their recovery. In Western countries, measures to maintain dignity in patients' care include maintaining privacy of the body, providing spatial privacy, giving sufficient time, treating patients as a whole person and allowing patients to have autonomy**.** Dignity, privacy and confidentiality are used synonymously but can have independent meanings.

Families are always at the center of the nurse-patient relationship in the **ICU** environment and play a vital role in decision making due to the fact that most **ICU** patients may lack the ability to communicate and make decisions. As such, family-centered care practices are also another way of respecting patient privacy in critical care units. The level of involvement and empowerment of a family in the care of the patient in the clinical reality varies in practice. (Latour & Albarran 2012.)

The aim of this study is to evaluate how nurses can uphold/ safeguard the privacy of patients admitted in the **ICU**. The objectives of this study are; to help nurses understand the need and effectiveness of patients' privacy in the **ICU** as well as to understand the concept of privacy and its benefits to patients admitted in the **ICUs**. This study research is part of the **EVICURES** people's project in anticipation of the building of a new **ICU** for the Seinäjoki Central Hospital.

2 NURSING IN THE INTENSIVE CARE UNIT - CENTRAL CONCEPTS

2.1 Intensive Care unit

The Intensive Care Unit (**ICU**) is a specialized section of a hospital that provides an all-inclusive and continuous care for persons who are in critical conditions and can benefit from this specialized treatment (Surgery encyclopedia 2014). **ICUs** are generally tasked with providing specialized holistic services to patients who have a variety of acute, chronic and life threatening conditions and diseases.

Critical care can be described as the direct delivery of medical care to a critically ill or injured patient (Perrin 2009). According to the American Association of Critical-Care Nurses (AACN) a critically ill patient can be defined as one who is at high risk for actual or potential life-threatening health conditions (Sole et al. 2009). This care in most cases, is delivered in specialized units in the hospital where there is advanced technological equipment that sustain life. The health care professionals working in the **ICUs,** are specially trained in advanced knowledge and skills in order to meet the various complex and broad spectrum of needs of the critically ill patients and their family members. The healthcare professionals work as a team and incorporate evidence based practices in their care to significantly improve the outcome of the patients' prognosis. (Perrin 2009.)

The origin of critical care as a specialty of medicine was in the 1950's when there was an outbreak of polio in the USA and thus these patients had to be taken care of in specialized departments. Progressively, in the 1960s, there was establishment of recovery rooms that took care of patients who had undergone surgery and simultaneously coronary care units (CCUs) were commissioned for the intended care of patients with cardiac problems. A consequence of patients being admitted in these specialized units was the unexpected improved outcome of their prognosis. In the 1970's, critical care nursing significantly evolved as a specialty of nursing being propagated by the development of general **ICUs**. Critical care nursing has continued to progress positively as evidenced by the broadening of its function and roles. Examples of common specialized critical care units are

cardiovascular, surgical, neurological, trauma, transplantation, burn, pediatric and neonatal units. (Sole *et al*. 2009.)

Typically, an ICU can be characterized by; blinking monitors, ventilators, intravenous (IV) pumps, noise from equipment and the many practitioners talking at the bedside, bright lights, a hurried pace in a crowded space, intra-aortic balloon pumps, extra-corporeal membrane oxygenation machines and other sophisticated technologies and terminologies. This could be a stressful and confusing environment for the patient, family and care giver. (Gonce & Fontaine 2009.)

The major concepts of **ICU** that will be encountered in this study are **ICU** nursing, palliative **ICU** and tele-**ICU**.

2.1.1 ICU Nursing

A critical care nurse is an approved professional nurse who is tasked with the responsibility of ensuring that the acutely and critically ill patients and their family members receive optimal care in intensive care set ups. According to the AACN, critical care nursing can thus be briefly described as that specialty that deals specifically with human responses to life threatening problems and conditions. (Perrin 2009.)

Critical care nurses practice in a magnitude of varied situations in managing and coordinating care to critically ill patients, who require in-depth assessment, high-intensity therapies and interventions, and continuous nursing monitoring. Critical care nursing is also concerned with how human beings respond to life-threatening problems, such as trauma, major surgery, or complications of illness. These reactions to life threatening situations can be defined as physical, emotional, spiritual and psychological phenomenon. The main focus of the critical care nurses includes both the patient’s and family’s responses to illness as well as prevention and curative care. (Sole *et al.* 2009.)

A critical care nurse is challenged to provide specialized care for patients who have multiple organ dysfunction or failure and complex medical needs. This trend is made even worse by the increasing aging population in the developed world, as people are living longer and longer. The elderly suffer from more chronic illnesses that contribute to the complexity of their care as compared to the younger patients. Geriatric patients are also prone to developing multisystem organ failure and opportunistic infections, which require longer hospital stays, increases cost of care, and generally increases the need for intensive nursing care. (Sole *et al.* 2009.)

Nurses are the primary care givers of the patients, as they spend most time by the bedside of the patients and as such are usually the first to hear about any perceived or unmet needs and dissatisfaction. Regular updates on the patient's state and condition, anticipated therapies or procedures, and goals of the critical care team are an easy and more effective way to dispel any anxiety while building a therapeutic relationship of mutual trust. Hence, critical care nurses assume the advocacy role in caring for the patients and their family members who have life-threatening illnesses and problems. (Sole *et al*. 2009.)

To be a critical care nurse, you should be competent in clinical judgement and clinical reasoning skills, have skills in advocacy and moral agency in identifying and resolving ethical issues, caring practices that are tailored to the uniqueness of the patient and family, collaborate with patients, family members, and health care team members, be familiar with systems thinking that promote holistic nursing care, have the ability to respond to diversity, use clinical inquiry and innovation to promote the best patient outcomes and acts as a patient/family educator to facilitate learning. (Sole *et al*. 2009.)

More so, the critical care nurse is considered to be the patient's advocate and their expected roles include supporting the right of the patient to autonomy and self-determination with informed decision making, intervene to support the best interests of the patient, help the patient to obtain necessary care, respect patient's values, beliefs and rights to privacy, confidentiality among others, represent the patient based on his/ her choices, intercede for patients who cannot speak for

themselves, monitor and safeguard the quality of care, and act as link between the patient, family and health care providers. (Sole *et al*. 2009.)

Clinical decision-making is an important element of critical care nursing practice as through this process, nurses make choices and decisions to meet the therapeutic goals of the specific patient care plan. Intensive care nurses' decision-making has received particular interest due to the complexity and urgency associated with these decisions. Categories of critical care nursing clinical decisions are related to: evaluation, diagnosis, prevention, intervention, communication with patients, clinical information seeking, setting of clinical priorities and communication with health care professionals. Clinical decision-making has been documented as being central to the science and practice of critical care nursing. (Hardy & Smith 2008.)

2.1.2 Palliative ICU

Palliation can be described as the provision of special care and interventions that are tailored to majorly alleviate symptoms of illness or injury that negatively affect the quality of life of the patient and/or family members. The most commonly documented symptoms that are associated with palliative care include: pain, anxiety, hunger/ thirst, dyspnea, diarrhea, nausea, confusion/ agitation, and sleep disturbance patterns. (Sole *et al*. 2009.)

Critical care medicine has a major role of saving lives but this may not be the case at all times as there are instances where this treatment can no longer sustain life or improve condition and as thus end-of-life care will be required. Hence the role of the critical care nurse changes from being the acute care provider to end-of-life care provider. (McCallum & McConigley 2013.)

In Sweden, it is estimated that at least 10–12% of patients admitted in the **ICU** die. The ICU environment is physically designed with the use of high-tech medical equipment and for the sole purpose of saving lives but when death is anticipated this may not be the ideal. Therefore, the **ICU** environment can be an impediment

yet the care of dying patients and their families is an important task for intensive care nurses. (Fridth et al. 2007.) The McCallum & McConigley (2013) study also suggests that over 45% of patient deaths in the **ICU** take place in shared rooms with other patients present, because of a lack of available single rooms. In this environment dying patients and their families have no privacy, which is not compatible with good end-of-life care and policies.

Palliative care has been highly recommended as an important element of an all-inclusive care package for critically ill patients, regardless of whether their diagnosis or prognosis is positive or negative. Documentation of the long- term impact of intensive care on those surviving acute critical illness is important, as it can be used to create palliative care plans that can help prepare and support patients and families members from expected challenges after **ICU** discharge. (Aslakson *et al*. 2014.)

There are two major controversial concepts that arise under palliative **ICU**; clinical trials and Organ Donation (OD). Under palliative **ICU**, consent is required for clinical trials and organ donations. According to one research "Protecting participants of clinical trials conducted in the **ICU**", critical care research conducted in the **ICU** poses a number of difficult scientific and ethical challenges, including

- Creating a thoroughly controlled trial that eventually gives useful scientific data and information whilst protecting participants from potential harms.
- Obtaining informed consent from some critically ill patients under conditions of legal and ethical ambiguity.
- Lowering the risk of conflict of interest with the increased interaction between industry and researchers and their institutions. (Flanagan *et al.* 2011.)

OD is a requirement for organ transplantation. Majority of the organs required for organ transplantation are harvested from deceased persons though some organs can be supplied by living donors for example kidney and liver. The OD process starts in the **ICU** with the identification of a potential donor, followed by a

discussion of the issue of OD with the family and concludes when the OD takes place, or at the withdrawal of the mechanical ventilation due to the absence of consent to OD. Nurses may be the first professionals to establish a relationship with family members and to initiate the discussion about donation and as such they strive to provide holistic care for potential ODs and their grieving families. (Flode´n et al. 2011.)

2.1.3 Tele-ICU

Tele-**ICU** refers to a set-up of networks of audiovisual communications and specialized computer systems that have a direct connection from critical care physicians (intensivists) and critical care nurses to **ICUs** in other remote hospitals. In general terms, tele–**ICU** provides an additional support to critically ill patients by the use of telecommunication technology.

Other definitions associated with tele-**ICU** are;

- **Telemedicine** - telemedicine is the use of medical information exchanged from one site to another through electronic communications to improve patients' health status.
- **Telenursing** – telenursing is the practice of nursing over distance with the use of telecommunications technology.
- **Tele-ICU Nursing** – tele-**ICU** nursing is critical care nursing practiced over distance using telecommunications technology. Tele-**ICU** nurses must have a high-level of competencies in communication, collaboration, decision making, systems thinking, and computer literacy, due to the nature of their practice. The tele-**ICU** nurse continuously monitors information on a large number of patients and acts as real-time clinical support to localized/bedside nurses on conditions that require urgent attention. (AACN 2013.)

Models of tele-**ICU** have been documented as early as the 1970s where on-site providers were linking with off-site consultants to discuss patients' conditions. Earlier on, the models were used by physicians only but with time the need to

incorporate critical care nurses in the tele-**ICU** models was established to improve patient safety and care. The current tele-**ICU** models incorporate nurses, physicians, and administrative support personnel. (AACN 2013.)

Generally, tele-**ICUs** are similar to other **ICUs** but the major distinguishing characteristics is that in the tele-**ICU** the assessment and communication is done hundreds of miles away from the patient, using high-resolution video cameras and speakers located in the patient's room. The camera zooms on the patient to allow the tele-**ICU** practitioner to assess such clinical status as pupil size, skin color, or mental status and to view settings on intravenous pumps, ventilators, or other supportive devices. There exists a two-way audio and video possibility to allow for communication with bedside staff, physicians, or the patient and family. Depending on the model, typically a tele-**ICU** nurse monitors up to 40 **ICU** patients, whereas a tele-**ICU** physician may care for 100 to 250 patients. It is important to note that the tele-**ICU** is not meant to replace bedside nurses but instead to act as a supportive tool. (AACN 2013.)

2.2 Privacy

The term privacy is derived from the Latin words *privatus* and *privo*, meaning to dispossess, to deny, to be lacking, and to lose something. In other words, it refers to privacy related to body areas which would otherwise not be seen, touched, or talked about by other people. It may also refer to anything specific to an individual or anything one does not want anyone else to know or have knowledge of. (Ozturk 2014.)

Privacy is also referred to as the state of being free from interference or commotion in one's private life or affairs (Hoidokki 2014). Privacy has a cultural dimension to it which defines the degree of one's personal responsibility to others in regulating specific behaviors that are viewed as intrusive. Privacy-regulating mechanisms may include physical barriers like closed doors or drawn curtains, say around a hospital bed and interpersonal types like lowered voices or cessation of smoking. (Mosby's Medical Dictionary 2009.)

Privacy means;

- Respecting autonomy
- Recognition of the right to privacy
- Respect for intimacy
- Respect for confidentiality
- Secrecy. (Fernandes & Moreira 2013.)

Privacy is one of the areas which continues to be of key concern for nurses in the care process because the architectural structure of the **ICUs** is a prohibiting factor when it comes to respecting patient's intimacy and the confidentiality of information leading to a confidentially breach though unintentionally. Difficulties may arise in regard to the incorporation of ethical and moral principles in daily clinical practice owing to the fact that the units are open spaces, sometimes overcrowded, where patients of different sexes, ages, and health conditions cohabit with family members as well as the professional team. (Fernandes & Moreira 2013.)

Nurses continue to recognize the universal right to privacy, and try to observe it mostly when caring for someone close to them. They feel particularly uncomfortable when they invade the other person's physical intimacy. Such situations are tough and difficult for nurses to share with the team. (Fernandes & Moreira 2013.)

2.3 Confidentiality

Confidentiality is the secrecy of information and its protection against unlawful disclosure (Hoidokki 2014). It is an individual right to have one's personal, recognizable medical information kept private. Such information should only be availed to health care and insurance personnel as needed. Protection of personal identifiable information is protected in the constitution of Finland (731/1999).

Critical care providers are often privy to confidential information in the course of carrying out their clinical practice duties. A predicament can arise when

confidential information is requested by family members or friends of the patient. Hence, the onus is on critical care nurses to know the regulations regarding confidentiality, as well as the circumstances where the use and disclosure of protected health information is permitted. (McGowan 2012.)

Furthermore, **ICU** nurses should strike a balance between the need of relatives to be in the know of specific information visa Vis the patient's right to confidentiality. Disclosure of confidential information has to be warranted at an individual level (Lisseman 2000.) The confidentiality rule safeguards all demographic information relating to the individual's past, present, or future physical, mental health or condition, payment and provision of health care and any other information that can be used to identify an individual; name, address, birth date, and Social Security number.

However, the confidentiality rule also gives nurses and other health professionals leeway to disclose protected health information without an individual's express approval. Use and disclosure of protected health information is permitted;

- To the individual who is the subject of the information
- For treatment, payment, and health care operations activities
- For notification and other purposes for example a family member with permission from the individual can be notified of the individual's health condition to enable them directly participate in the care giving process.
- For public health and benefit activities to prevent or control disease, injury, or disability; and to individuals who may have been exposed to a communicable disease.
- To appropriate government authorities regarding victims of abuse, neglect, or domestic violence. (McGowan 2012.)

2.4 Dignity

The word dignity is derived from two Latin words: 'dignitus', which means merit, suggesting that one has to achieve something to be dignified; and 'dignus', which

means worth, signifying a quality that renders something valuable or confers value for one's wealth (Lin *et al.* 2011).

Dignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a respectful way to their individual self. (RCN 2012). When dignity is present, people feel in control, appreciated, are assertive, contented and are able to make their own decisions. On the other hand, when dignity is absent people feel cheapened, humiliated, be self-conscious, lack control, unsatisfied with their state of being and might not be in a position to make their own decisions.

Dignity can be explained through two concepts 'human dignity' and 'social dignity'. Human dignity is the same as absolute dignity and it refers to one's self-worth and self-respect. Social dignity on the other hand means 'dignity-of-self' and 'dignity in-relation to'. This second concept of dignity looks at how much worth and respect is conveyed by others' behavior to an individual. (Rehnsfeldt *et al.* 2014.)

Enhancing patients' rights and upholding their dignity were declared as goals of the World Health Organization (WHO). Dignity is an essential concept of nursing care and thus maintaining dignified patient care is very important. Care deprived of dignity would affect patients' recovery. Respecting human rights and preserving dignity were also defined as ethical goals of nursing care cutting across regardless of a patient's race, age, religion, sickness, physical disability, gender, political affiliation, social or economic status. (Lin *et al.* 2011.)

This topic of dignity has been highlighted as one of the most central ethical concerns in nursing care. Some studies pointed out that people whose caring process was characterized by the respect for dignity received optimal care and were more satisfied with the care provided. Thus, dignity should not only be seen as an important part of nursing but also for the realistic outcomes of the care provided. Protection and respect of patient dignity are both described as an ethos in professional nursing care. (Gustafsson *et al*. 2014.)

2.5 Patient-Centered Care

Patient-centered care refers to providing care that is respectful of and responsive to individual patient choices, desires, and moral standards while ensuring that all clinical decisions are focusing on the patient (Institute of Medicine 2015).

The most important aspects to consider in the promotion of patient-centered care comprise of the;

- Humanization of care
- Right to the truth
- Right to information
- Right to self-determination
- Engaging the family in decision making. (Fernandes & Moreira 2012.)

Numerous on-going researches conducted into the experiences of critically ill patients and their families unanimously back up the hypothesis that care of the patients and the patient's families must be looked at holistically. Procedural life-sustaining practices and their treatments inevitably present complex ethical contemplations while caring for the most seriously ill and it is usually the family members who are tasked to make the tough decisions in regard to extending life versus the potential loss. (Sole *et al.* 2009.)

More often than not, the patients and their family members are cared for in the **ICU** surroundings without any prior preparation, a situation which usually causes a lot of stress and anxiety. The ensuing high stress levels are worsened by the uncontrollable inexorable sensory stimulation of light and noise coupled with the loss of privacy, limited nonclinical physical contact, and not forgetting the emotional and physical pain due to the medical and nursing procedures and the illness itself. Striving to maintain the safety, dignity, confidentiality and privacy of patients under such a state of affairs continues to pose a lot of challenges. (Sole *et al* 2009.)

Patients expect:

- To have their privacy, dignity and cultural beliefs put at the fore front
- Confidentiality
- The choice to have visitors as well as deciding their specificity; children and other loved ones
- Whether or not to include their relatives in the caring process
- A critical care team familiar with the benefits and worth of visitations. (Gibson *et al.* 2012.)

Undeniable benefits can be accredited to visiting critically ill patients; it gives them reassurance, prevents sensory deprivation and gives their hospital life a certain normalcy as they continue to share with their loved one's different things pertaining to the outside world. In addition, the presence of visitors in the **ICU** positively contributes to the patients' sense of well-being and healing process. (Tayebi 2014.)

It is important to involve the patient in the caring process regardless their state of consciousness. The (Fernandes & Moreira 2012) study, clearly highlights this importance especially in instances where the patient is in a clear state of mind to speak for themselves, as one of the participant in this study shared: *"...for ten minutes, they talked about everything, but they didn't talk to the patient. The patient was conscious, staring at them, hearing everything that they were saying; the patient couldn't speak because she was intubated, but she was able to communicate".*

Nurses and family members should make every effort to talk to patients, irrespective of their ability to interact because despite of the fact that they are sedated or unconscious, many may still have the ability to hear, understand and respond emotionally to what is being said. Conversation topics can be centered on reorienting the patients to time and place, giving them updates in regard to their progress, constant reminders that they are in safe hands and that their loved one's care about their well-being and are there for them. (Sole *et al.* 2009.)

2.6 Family-Centered Care

Family-centered care is simply a philosophical approach which emphasizes the provision of care to patients and their families. The basic principle of this philosophy is that patients are an integral part of the "holistic" picture and must not be forgotten in order to provide the best possible care. (Henneman & Cardin 2002.)

Family-centered care is the type of care which focuses on the collaboration of all members of the team to support and value this philosophy to ensure its success (Henneman & Cardin 2002).

Family-centered care refers to the notion of treating the patient and family as one entity, acknowledging that the illness or injury of one family member also affects all the other family members too. This all-inclusive approach to critical care nursing necessitates the involvement of the family in the care plan. (Sole *et al.* 2009.)

A family focused entity looks at a patient's family as the unit to be given care and goes ahead to organize its delivery around the patient's family, as opposed to the more traditional patient-centered model.

Studies show that separating the family members and friends worsens patients' discomfort. It is therefore clear that **ICU** patients need support and reassurance that only family members can provide in addition to quality care. The positive effects of family members' contribution to the patients' recovery have been widely documented and many health care specialists continue to stress the significance of family-centered care. (Tayebi *et al.* 2014.)

Nurses are obliged to meet the 3 basic needs of the family:

- The need for information
- The need for reassurance/support
- The need to be near the patient.

Despite the abundant evidence to support the above basic needs, many critical care units are still faced with huge challenges to implement family-centered critical care. Family-centered care goes beyond the theoretical recognition of the significance of patients' family members in healthcare. It also requires us to extend our assistance to the family as the patient battles for their survival during the illness. (Henneman & Cardin 2002.)

Family-centered care is an old phenomenon. Many clinicians especially pediatricians have been practicing it for a long time with huge success but this does not mean that the **ICU** staff must relinquish all decision making to family members. Nurses should instead remain in control and initiate family member involvement in the care process hence the avoidance of perceiving families as a burden. The AU study indicated that nurses partnering with the families to provide care reduced their workload to a minimum. The nurses too are of the view that family members should be invited to be part of the patient’s care as a normal practice in **ICUs**. (Kean & Mitchell 2014.)

Family-centered care practices are another way of respecting patient privacy in critical care units (Latour & Albarran 2012).

3 PREVIOUS STUDIES ON ICU PATIENTS' PRIVACY

Numerous studies have been done to describe patients' experiences in relation to their stay in the **ICU**. In a systematic literature review of 26 studies, Stein-Parbury and McKinley documented that between 30% - 100% of patients studied could recall all or part of their stay in the **ICU**. The patients vividly remembered their experience in the **ICU** with positive, negative or neutral feelings. Negative experiences were generally attributed to fear, anxiety, sleep disturbances, cognitive impairment and pain or any form of discomfort. Positive experiences were generated by feelings of being safe and secure. The quality of care given by the nurses to the patients largely affected their experiences and the outcome of their feelings. In another related study the predominant themes were the need to feel safe and the need for information. Patients noted that the nurses' competences and effective interpersonal skills increased their sense of security, privacy and trust. (Gonce & Fontaine 2009.)

The **ICU** is a unique environment in the hospital that is said to be impersonal and technologically invasive. The general rules and designs of the **ICU** do not necessarily promote privacy. A phenomenological qualitative study was carried out in Son Dureta University Hospital in Palma de Mallorca whose objectives were to know the experience of patients admitted to the **ICU** in relation to their perception of privacy and its impact on their own experience. The participants of this study were patients admitted to the **ICU** who were older than 18 years and with a minimum stay of 48 hours. The patients had to have had a signed informed consent. The data was collected by exhaustive semi-structured interviews. The major results of this study were that patients admitted in the **ICU** perceived privacy in terms of the physical environmental space, family setting and privacy autonomy. The patients were able to evaluate the flexibility of rules, professionalism of the nursing staff and the need for family support when their health status had stabilized to less critical. The conclusion of this study was that the quality of nursing care should not only depend on the technological knowledge and ability but also on the humane side of caring. More so, it is of extreme importance to consider the various elements that mold the experience of being admitted to the

ICU and respect of the right of privacy of each patient as an individual. (Cerdá *et al*. 2008.)

A research study carried out in polyvalent **ICUs** in 4 Portuguese hospitals was aimed to identify the ethical issues perceived by intensive care nurses in their everyday practice. The second aim of this study was to understand why these situations were considered as ethical issues and what interventions/ strategies could be implemented in order to lessen these ethical challenges. The data was collected using a semi-structured interviews from 15 nurses working at the hospitals selected by the homogenization of multiple samples. The major findings that this study identified were end-of-life decisions, privacy, interaction, team work, and health-care access as the prevailing ethical issues. The reasons that led to the above ethical issues were attributed to personal, team, and institutional aspects. As a solution to the ethical issues, personal and team resources were deployed. The most significant strategies to combat these ethical issues were the moral development and training of the nursing staff. (Fernandes & Moreira 2012.)

A questionnaire survey study was carried out in 16 **ICUs** in 6 acute care hospitals in Estonia and whose aim was to find out the most important needs of adult patients admitted in the **ICU**. The data was collected over a period of 6 months in 2008 using the structured five-point scale questionnaire given to 166 adults patients who had been discharged from the **ICU**. The results showed that the patients had a variety of needs and these needs were sometimes unmet. According to the study, the most important needs were physical comfort and feeling safe. Privacy, involvement of family and friends and being involved in decision-making were less important as compared but still paramount to care. Based on this survey, it remains important to do more research on the aspects of privacy and the involvement of the family because of the increasing number of patients needing critical care. This research also further provides a basis for understanding the needs of critically ill adults in **ICUs** to provide them more patient-centered care and improve their psychological well-being and quality of life after discharge. This is a relevant topic in clinical practice because it identifies and acknowledges the personal needs of patients in **ICUs**. (Aro *et al*. 2012).

A quasi-experimental design study was conducted at a university hospital in Erzurum, Turkey The objective of this study was to examine the effect that the provision of information about the physical and technological environment of the **ICU** would have on the comfort of the patients during their **ICU** experience. The patients were selected through convenience sampling and there were 80 patients in the study; 40 in the study group (SG) and the other 40 in the control group (CG). The university hospital was the only hospital in Turkey where cardiac surgery was performed during the course of this study and as such the patients were given information prior to their heart surgery on what to expect on their stay in the **ICU**. The data was analyzed using the Situational Form of Technological Atmosphere in **ICU** (SFTA-ICU) which is a 24 item instrument designed to measure the level of discomfort felt by patients exposed to different environmental situations in an **ICU**. The findings of the study indicated the following disturbances were experienced; 2.9% of the SG and 45% of the CG about their inability to see their relatives; 14.3% of the SG and 40% of the CG about the closed environment of the **ICU**; 22.5 % of the SG and 40% of the CG about loneliness; 17.1% of the SG and 65% of the CG about nakedness; 11.4% of the SG and 37.5% of the CG about the instruments used on fellow patients; 20% of the SG and 50% of the CG about their inability to express their needs; and 14.3% of the SG and 42.5% of the CG about not being informed before procedures. The difference among the two groups was found to be of statistical importance. The study concluded that the provision of information well in advance or preoperatively to the patients about the **ICU** may reduce the rate of discomfort to patients postoperatively that may arise due to the **ICU** environment, procedures and treatments, and staff responses. (Özer & Akyil 2008.)

Maintenance of the dignity of patients admitted in the **ICU** can be a challenging issue and in particular minimizing the exposure of genitalia. This study was an action research methodology with the aim of developing usable strategies to maximize on the dignity of **ICU** patients. The first stage of this study was to assess the current practice through 62 hours of non-participant observation of patient care done by nurses. The findings of this first phase was that patient dignity was maintained in almost one-third of observed cases. However, more intimate areas such as bosom and genitalia were exposed in over 40% of the cases. Even though

screens were fully used in over a third of exposure incidents, full screening did not occur for all or part of the remaining incidents. Factors influencing exposure included gender and age as female and younger (< 60 years) patients were more likely to be exposed and older patients (> 70 years) were less likely to be screened when exposed. The second phase involved the identification of solutions and probable strategies to the problem of inappropriate patient exposure through the medium of a multi-disciplinary focus group. The following recommendations were given by the focus groups; raising staff awareness and documentation of situations that may compromise maintenance of dignity. The final stage of the study involved an audit of the effectiveness of these recommendations and the findings to this phase were more adequate clothing for patients together with a high standard of staff awareness of patients' dignity and needs. (Turnock & Kelleher 2001.)

Additionally, an observational study of 192 patients was conducted in 2 **ICUs** with 6 beds in an open bay area. The study reported 83·9% incidents where patients were observed not wearing any form of clothing and in 40% of these episodes either a patient’s bosom or genitalia were uncovered. Important to note also was the fact that screens were used in less than 40% of the observations. Further research in the emergency department settings revealed breaches in privacy relating to: inappropriate exposure of body parts to members of the public, overhearing conversations about other patients and clinical consultations being overheard. Of the whole sample group, 105 patients reported a privacy incident and a further 10% indicated that their expectations in this respect were unmet. The importance of addressing this issue can no longer be ignored as privacy is inextricably linked with providing dignified care. As a result, enhancing the privacy and dignity of the patient in the hospital remains a priority particularly in intensive care setting where patients are often unable to express their preferences. (Latour & Albarran 2012.)

A South American study entitled “Physical exposure of clients in care for basic needs at an **ICU**: critical incidences reported by nurses”, was conducted in Maringa-PR, Brazil. The aim of the study was to identify and analyze instances where there was physical exposure and invasion of clients' privacy and intimacy in the **ICU**. The targeted sample group consisted of 15 **ICU** nurses. The Critical

Incident Technique (CIT) was used in analyzing and documenting the results. The study came up with 30 reports, 15 of which were desirable and 15 undesirables. From these reports, 22 positive and 30 negative critical incidents were extracted and compressed in 6 themes. The results clearly documented that the nursing team was better prepared at handling problems related to basic care of **ICU** patients. Privacy protection, respect, confidentiality and guidance gave an assurance of the quality of care but the failure to protect clients' intimacy and privacy impacted greatly on the quality of care. (Pupulim & Sawada 2005.)

The perceptions that critical care nurses have concerning patient confidentiality may give us an insight as to what information they consider as protected health information. A PHD dissertation in the University of North Carolina was carried out with the purpose of exploring critical care nurses' perceptions and knowledge of patient confidentiality. In this qualitative study, semi-structured interviews and 2 structured scenarios were used to collect data from 12 respondents. The respondents were tasked with answering the following questions; (a) what knowledge of legislation and ethics critical care nurses have in relation to confidentiality (b) how critical care nurses define their roles with regards to patient confidentiality and how they apply this in their everyday practice and (c) how critical care nurses describe their roles concerning confidentiality in the ICU. The results documented that critical care nurses time and again used their knowledge and skills regarding confidentiality when interacting and communicating with their patients, family members and visitors. As thus nurses' applied ethical principles in their concern regarding the communication and on what information they should desirably provide to patient families and significant others. Nurses indicated that while the legislation was therapeutic, they recommended that more needed to be done to prevent breach of confidentiality. (Newman 2011.)

Privacy and confidentiality are critical when considering family presence during resuscitation. One of the presumed obstacles against family members’ presence is the infringement of patient confidentiality. However, research evidence is that while the resuscitation team may perform less effectively, confidentiality is not breached when family members are present. A case–control study surveyed 20

survivors of resuscitation and 41 patients admitted as emergency cases on whether they would want their families to be present and in particular whether they were concerned over breaches of confidentiality in this context. Both groups stated that they were unconcerned about confidential matters being discussed by healthcare staff with family members present during their resuscitation (91 and 75%, respectively). Patients recognized the practicalities of preventing infringements to confidentiality, however, they indicated and expected that staff should seek patient preferences, document these and ensure that members of the team were informed. (Latour & Albarran 2012.)

Previous studies have debated the experiences of relatives visiting an **ICU**, their needs in this environment, the interaction between the critical care nurses and the relatives, **ICU** visiting policies and the benefits attributed to the incorporation of relatives in patient care. However, the specific barriers that critical care nurses face in their quest to involve the relatives in the patient care process have received minimal exploration. So, this study aimed at identifying the barriers that prevent critical care nurses from involving relatives in **ICU** patient care. It comprised of two explanatory mixed study phases with phase 1 being quantitative and phase 2 qualitative. Data in phase 1 was collected through online questionnaires on 70 critical care nurses working in Australian **ICUs** while phase 2 used semi-structured interviews on 6 critical care nurses from a single Sydney **ICU**. Data was collected over 5 months in 2012-2013. Participants cited a number of obstructions to relative involvement in critically ill patient care. The hindering factors in allowing family members to participate in the caring process related to the **ICU** patients themselves, family members, critical care nurses and the ICU environment. This study pointed out that critical care nurses took on a paternalistic role when it came to deciding whether to include or exclude family members from patient care. Knowledge on the barriers to family involvement in critically ill patient care can offer a very good basis to find solutions which **ICUs** can use to revise the current visitation polices to open up more to patients' family members. (McConnell & Moroney 2015.)

Critical care visitation is viewed today as a very vital aspect of patient-centered care and its positive effects on patients and their relatives have been clearly

established. However, restricted visiting hours in the **ICUs** is often an approved norm. This study intended to find out the reasons behind the restricted visiting hours in adult **ICUs** in Iran. A qualitative design using a thematic analysis approach through semi-structured individual interviews was used to collect data. The participants in this study included 6 nurses, 3 head nurses, 2 patients and 4 visitors chosen through a purposive sampling method. Analysis of the data resulted in three themes: 'health protection', 'safety promotion' and 'privacy preservation'. According to the results, nurses try to protect the vulnerable **ICU** patients from physical, psychological and legal risk by restricting visiting hours. Although the **ICU** nurses' concerns are valid in various cases, it is still important to carry out an appraisal of the visiting policies to meet the needs of patients and their families. Health care professionals, especially nurses, must ensure that patients' family members are constantly updated about the patients' health status and permission must be granted to visit patients in suitable ward conditions. (Tayebi *et al*. 2014.)

Another study done in the USA on visitation practices in critical care units also established that 44% of critical care units still had restricted visitation policies. However, 45% of the units had open policies at all times and the restrictions were only imposed during rounds and change of shifts. Most acute care institutions forbid children to visit but there is not much research to support this policy. It was suggested in this study that decisions on whether or not to allow children in critical care units should be based on factors such as the developmental stage of the child and their adequate preparation to visit. One study even went ahead to demonstrate that allowing children to visit family members in the critical care unit reduced their negative behavioral and emotional outcomes. (Sole et al. 2009.)

This study on the "End-of-life care in **ICUs** – family routines and environmental factors" attempted to bring to light the significance of the physical environment and good caring practices for dying patients and their families in Swedish **ICUs**. The main research questions were: what are the physical environmental circumstances and facilities when caring for patients in end-of-life and are there any routines or guidelines when caring for dying patients and their families? Questionnaires sent out to 79 eligible Swedish **ICUs** in December 2003 and addressed to the unit

managers had a response rate of 94%. The findings illustrated that, despite recommendations stressing the importance of privacy for dying **ICU** patients and their families, only 11% of the respondents stated that patients died in single rooms in their **ICUs**. If a patient died in a shared room, nurses endeavored to ensure they got a dignified good-bye by moving the body to an empty room or to one specially designated for this purpose. The majority (76%) of the units had waiting rooms within the **ICU**. The guiding principles in end-of-life care were used by 25% of the **ICUs**. The study recommends **for** further research to obtain a deeper knowledge of the conditions under which patients die in **ICUs** and the impact of the **ICU** environment on bereaved families. (Fridh et al. 2007.)

In a related study by the same authors (Fridh et al. 2007) **ICU** privacy and proximity are reported to be important needs of dying patients and their family members. According to the research findings, good communication between the **ICU** team and families about end-of-life decisions avails more possibilities to meet families' needs, hence guaranteeing a dignified and peaceful death in accordance with end-of-life care guidelines. The aim of this study was to explore the circumstances under which patients die in Swedish **ICUs** by reporting on the family presence and whether patients died in private or shared rooms. Another additional aim was to investigate how often end-of-life decisions were made and whether nurses and family members were informed about those decisions. Data was collected on 192 deaths by completing a questionnaire based on the research questions when a patient died in the 10 **ICUs**. 40% of the patients died without a next of kin at the bedside and 46% of deaths occurred in a shared room. This number decreased to 37% if a family member was present. Patients without a family member at their bedside received less analgesics and sedatives. There was a significant relationship between family presence, expected death and end-of-life decisions. The results point out the necessity of improving the **ICU** environment to promote the need for proximity and privacy for dying patients and their families. The study also draws attention to the risk of underestimating the needs of patients without a next of kin at their bedside at the time of death.

A third study by the same authors (Fridh *et al*. 2009) aimed to explore close relatives' experiences of caring for their loved ones and the physical environment

when they died in an **ICU**. Interviews were then conducted with 17 close relatives of 15 patients who had died in 3 adult **ICUs** and were analyzed using a phenomenological-hermeneutic method. The analysis resulted in a number of themes; the need for privacy and togetherness, being confronted with the threat of loss, trusting the care given, adapting as well as trying to understand and facing death among others. The experience of a caring relationship was crucial and so the nurses helped the close relatives to cope in the strange environment characterized by its unfamiliar technology, distressing information and the long waits filled with uncertainty. Lack of a caring relationship on the other hand between the nurse and the close relatives was labeled in terms of not allowing relatives access to their dying loved ones in addition to not assisting them interpret various information. The participants exhibited forbearance with the **ICU**-environment. The serious conditions of their dying loved ones coupled with their dependence on the medical-technical equipment were more frightening than the equipment itself. The **ICU** can be a fairly humane place to lose a loved one and as such post death care was always arranged to enable family bid farewell in a dignified way.

The rapidly ageing populations and the soring increment in long-term illnesses around the globe gives support to the notion that more people will need palliative care in the future. Despite various attempts to increase end of life care in communities, many older adults still prefer, and will require, end of life care in hospitals. Providing a suitable physical environment for older adults in need of end of life care is very essential owing to the concerns already raised about hospital environments for this group. The above conclusions arose from an integrative review study to identify key elements of the physical hospital environment for end of life care of older adults and their families as reported by patients, relatives, staff and policy makers was carried out by (Brereton *et al.* 2011) Data was sourced from 13 databases from 1966 to 2010 including ASSIA, BNI, Cochrane Library, CINAHL, EMBASE, MEDLINE, PsycINFO, Social Science Citation Index, the Science Citation Index, HMIC and the National Research Register. This data was synthesized using a thematic analysis of the findings from the included literature. Only 10 articles were included and the major themes noted were: privacy as

needed; proximity (physically and emotionally) to loved ones, satisfaction with the physical environment; and deficiencies in physical environment.

Organ donation and transplantation have made it possible to save lives and to improve the quality of life for a large number of patients. The gap between the number of patients who need organs and organs available for transplantation has been drastically increasing in the past years leading to a worldwide focus on what strategies to take on to meet this organ shortage. This entire process gives rise to some ethical challenges. A hermeneutic phenomenological study to explore healthcare professionals' ethical experiences related to care and interaction with critically ill patients with severe brain injuries and their families was carried out in 2 **ICUs** in a Norwegian university hospital. 12 cases were observed and a total of 32 healthcare professionals were interviewed. The research findings revealed that the process of clarifying the patient's prognosis was characterized by vagueness, a lack of gradual clarification and a predictive way forward. The above had a significant impact on how the nurses interacted with the families and those same issues challenged their caring values in various ways. As a result, information was withheld, there was an obvious challenge of balancing between openness and withholding critical information, and a struggle to maintain patients' dignity under those difficult conditions. These components comprised to a big extent the participants' experiences of their ethical interaction with the patient's family which distinguished from caring for relatives of critically ill patients in general. (Oröy *et al.* 2015.)

It is envisaged that the existing shortages of critical care nurses and physicians will aggravate the problem of providing quality, affordable care to critically ill patients. The development of the tele-**ICU** model of care can be looked at as a possible solution in regard to the increased need for critical care and staff shortages. Research suggests that tele-**ICUs** are allied with decreased mortality rates, length of stay, and reduced health care costs. However, not much is known about patients' family members' knowledge and opinions of the tele-**ICU** care model. A study was conducted to assess how well informed patients' family members were about the tele-**ICU**, their preferred sources and types of information about the tele-**ICU**, and their perceptions of the impact of the tele-**ICU** on patient

care. In a survey conducted with a nonprobability accessible sample of patients' family members at 3 health systems, two-thirds of patients' family members stated that they had no information about the tele-**ICU** and chose staff as their preferred source for this information. The three most significant topical issues to be given information on were patients' physical privacy, impact on patient care, and the technology. This pilot study revealed major communication gaps about the tele-**ICU** between staff and patients' family members. These study findings will form a basis for defining goals, objectives, and methods in subsequent researches to improve communication with patients' family members about the tele-**ICU.** (Jahrsdoerfer & Goran 2013.)

4 AIM AND OBJECTIVES OF BACHELOR THESIS STUDY

4.1 AIMS

The aim of this study is to describe how nurses can uphold /safeguard the privacy of patients admitted in the **ICU.**

4.2 OBJECTIVES/ PURPOSE OF STUDY

The objective is to produce new information to help nurses understand the need and effectiveness of patients' privacy in the **ICU.**

The second objective of this study is to understand the concept of privacy and its benefits to patients admitted in the **ICUs**.

4.3 RESEARCH QUESTIONS/ TASKS

What is the privacy of **ICU** patients?

What nursing practices uphold patients' privacy in the **ICU**?

5 DATA COLLECTION PROCESS

5.1 Systematic Literature Review

A systematic literature review can be defined as a scientific research method used for classifying and gathering existing information in a particular topic of interest, evaluating the quality of the information and finally synthesizing the results on this topic in a broad and concise manner. It can also be defined as an all-inclusive study on the interpretation of specified literature that addresses a specific topic or an initial review before a larger study is undertaken. (Booth *et al*. 2012.)

A systematic literature review can be further defined as a summary of the study literature that is primarily focused on answering a single question. Such a study is conducted in a way that tries to classify, choose, evaluate and synthesize all the high quality research evidence available that is most relevant to that question. (Saltikov 2012.)

According to Booth (2012), if we intend to make our decisions based on evidence, it makes perfect sense to use the best available evidence. Additionally, the best available evidence for decision making is derived from a systematic review of all the evidence present. He further details that reviewing data in this way is a complete search for the entire truth, rather than just part of it, and is thus a 'fundamentally scientific activity'.

Literature review as a concept can be concisely defined as a 'systematic, explicit, and reproducible method for gathering, assessing and synthesizing the already existing, completed and recorded information produced by researchers, scholars, and practitioners' for evidence. The results of these studies must be further analyzed and summarized to give a more concise picture of the topic. Synthesizing available evidence helps us to find out what we know and don't know and about what works and what doesn't work. A good research synthesis should generally give us the most reliable and relevant estimate of the effectiveness of a specific intervention and identify specific gaps in our knowledge that require further research (Booth *et al*. 2012.)

5.2 Target Group and Perspective

The research focuses on adults both male and female admitted in the ICU, how their privacy, dignity and confidentiality could be compromised and what measures can be taken by nurses to ensure they are upheld. Data has been sourced from all over the world other than Africa because privacy in the ICU is a new and emerging concept and not a lot of research has been done on this subject. This could also be a controversial issue because privacy is not synonymous with the **ICU** as most care providers tend to prioritize the care giving process without keeping in mind the privacy of the critically ill patient.

5. 3 Key Words for Data Searching

Below are the key words and concepts which we used to search for literature material.

- Intensive Care Unit (ICU).
- Critical Care Nursing (CCN).
- Privacy.
- Confidentiality.
- Personal space.
- Dignity.
- Patient-centered care.
- Family-centered care.

5.4 Inclusion and Exclusion Criteria

The 37 articles were narrowed down using the following inclusion and exclusion criteria and we ended up with 30 relevant articles.

For this study we included articles written in English covering a wide range of geographical locations (Europe, USA; Asia, Australia and South America). We specifically focused on adult patients only admitted in the ICU of both sexes (male and female). The articles used were written between the years 2000 – 2015 and we included all types of material such as literature reviews, editorials published in nursing journals, research studies as well as class notes and textbooks. This is illustrated in table 1 below.

In this study, we chose to exclude all articles not written in English because of the language barrier involved. We did not focus on patients admitted in any other hospital department other than the ICU. Specifically, in the ICU environment, we excluded pediatrics and obstetrics to streamline our study. Any papers written before the year 2000 were excluded as well as any studies done in Africa. This is further illustrated in table 1 below.

Table 1 Inclusion and Exclusion Criteria

INCLUSION	**EXCLUSION**
Written in English language	Written in languages other than English
Papers focusing on patients in the ICU environment	Not focusing on patients in the ICU environment
Papers focusing on Adults both male and female	Papers on pediatrics, obstetrics
Papers written between 2000 - 2015	Papers older than 2000
Papers written in Europe, USA, Asia, Australia and South America	Papers written in Africa because there were no studies carried out that were relevant to our study
All types of studies, policy and expert opinions	
Textbooks	

5.5 Data Searching Process

Using systematic literature review and following the inductive reasoning, data was collected from the following nursing data bases;

- Cinahl EBSCO*host*
- PubMed
- Use of peer reviewed articles 10 years old or younger
- E- Journals
- Internet resources
- Text books

We searched the Cinahl data base using Cinahl headings for;

I. ICU and we got 17,608 articles
II. Privacy and confidentiality and we got 13,361 articles
III. After the two searches were combined we ended up with 41 articles
IV. We narrowed the search to articles from 2000 to 2015 and ended up with 37 articles.

We also searched PubMed using the mesh term and advanced search for;

I. Privacy and ICU combined in the search builder and got 36 articles
II. The articles were further filtered to focus on those published in the last 10 years and ended up with 31 articles
III. After reading through the 31 articles only 1 article was relevant to our study

Two relevant studies were sourced from textbooks.

5.5.1 Limitation of Material Based on the Titles

The searches were limited to titles with one or more of the research key concepts. We got a total of 77 relevant articles based on the tittles. 41 articles were obtained from Cinahl EBSCO*host* and 36 articles were got from PubMed.

5.5.2 Abstracts and Whole Texts

We read through the abstracts, introductions, aims, results and the conclusions of the 30 articles from Cinahl EBSCOhost and we settled for only 16 relevant studies. Thus together with the PubMed and textbook articles we settled on a total of 19 relevant articles for this literature review.

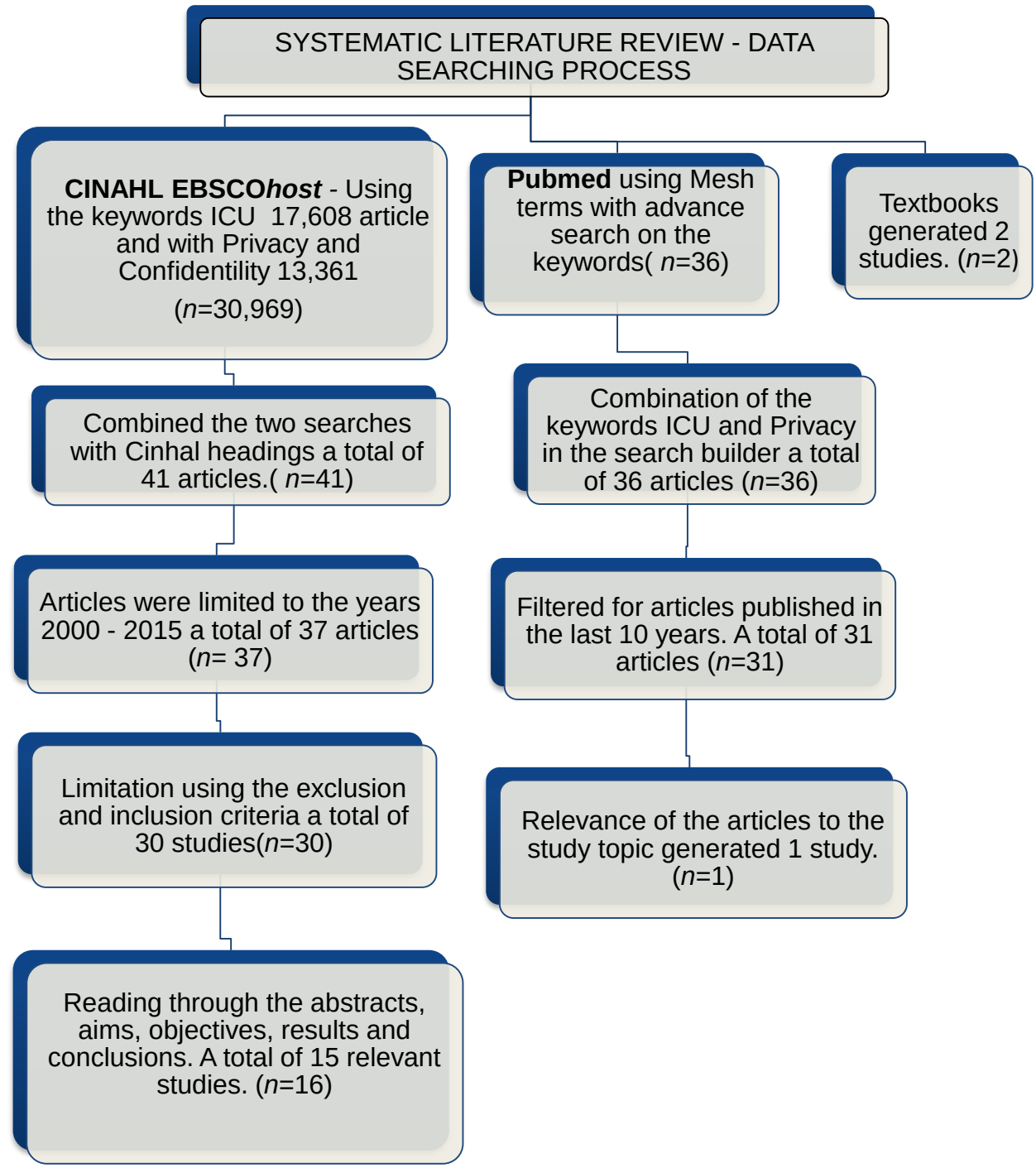

Figure 1 Data Searching Process

6. DATA ANALYSIS PROCESS

Content analysis is a method of analyzing written, verbal or visual communication messages and it is used in many nursing studies. It was first used in the 19th century to analyze hymns, newspaper and magazine articles, advertisements and political speeches. Today, content analysis is mostly used in psychiatry, gerontology and public health studies. (Elo & Kyngäs 2007.)

Content analysis as a research technique is a systematic and impartial means of describing and measuring phenomena (Krippendorff 1980). It involves cataloging the phenomena into the identical categories, words and phrases that share the same meaning. This gives the researcher an opportunity to test hypothetical issues to make it easy to interpret the data. The content analysis process also enables the researcher to break down the words into fewer content-related categories. ((Elo & Kyngäs 2007.)

Content analysis is also a research method for making replicable and valid implications from collected data putting them into context, with the purpose of providing in depth knowledge, new insights, a thorough representation of facts and a hands-on guide to action (Krippendorff 1980). The goal of the analysis is to achieve a summarized but broad explanation of the phenomenon which results in concepts or categories describing the phenomenon. Those concepts or categories are usually used to build up a conceptual map or category. (Elo & Kyngäs 2007.)

Content analysis as a research process can either be carried out in a qualitative or quantitative way and it can also be used in an inductive or deductive way. The purpose of the study determines which category it will fall under as explained above. This study used inductive content analysis to analyze data obtained from the 19 studies of the literature review.

Inductive content analysis

A research methodology based on inductive analysis moves from the precise to the general, so that particular instances are observed and then combined into a

general statement. This process consists of open coding, creating categories and abstraction. Open coding refers to making notes and headings in a text while reading it. The written material is read through again, and as many headings as necessary are written down in the sidelines to describe all the different facets of the content. The headings are then collected from the sidelines on to coding sheets and categories are freely created at this stage. (Elo & Kyngäs 2007.)

After this open coding, the lists of categories are grouped under superior sorted headings. The sole purpose of grouping data is to condense the category numbers by putting all the similar and dissimilar categories into broader superior sorted categories. The idea behind creating such categories is to offer an easy way of describing the phenomenon, to enhance understanding and to generate knowledge. During the process of formulating categories by inductive content analysis, the researcher using interpretation decides which things to put in the same category. (Elo & Kyngäs 2007.).

Abstraction refers to creating a general description of the research topic by coming up with categories. Each category is labeled using content-characteristic words. Subcategories having similar events and incidents are grouped together as categories and then grouped as main categories. The abstraction process continues as far as is necessary. (Elo & Kyngäs 2007.)

After the data collection process, we read through the 19 articles several times while coding and creating categories. Using the categories, we were able to come up with an abstraction process. Below (*table 2*) is an illustration of the abstraction process, from the original sentence to the reduced sentence and further more to the sub category, generic category and main category.

Table 2. Example of abstraction process

Original sentences	The physical structure of the ICUs is characterized by being open units without privacy, without individual curtains, in which the beds are extremely close together ‘‘(. . .) a unit in which we have eight beds in the same open space . . . sometimes we even forget that the patient at our side is awake.’’ (Fernandes & Moreira, 2012).	Nurses participating in the study believed that visitation disturbs their practice. They mentioned that visitors break their concentration and subsequently increase the incidence of nursing errors and endanger patients’ safety. *‘ICU is a highly sensitive environment [because] patients are on complex medications and interventions. When visitors are in the unit, the nurses’concentration is broken and consequently, the risk of nursing errors increases.’* *(*Tayebi, et al, 2014).
Reduced sentences	The environment of the ICU physically does not allow for patient privacy as the beds are close together just divided by curtains.	Nurses believe that visitation of patients has to be restricted to specific times when nurses are not administering medications to avoid errors due to divided attention.
Sub categories	Intimacy and dignity preservation	Family involvement and visitation policies.
Generic categories	Patients’ privacy	Ethics
Main categories	Privacy	Nursing perspectives

7. RESULTS

Articles for this study originated from the USA (*n* = 4), Sweden (*n* = 3), UK (*n* = 2), Netherlands (*n* = 2), Estonia, Portugal, Spain, Turkey, Brazil, Australia, Norway and Iran each (*n* = 1), dated between the years 2000 and 2015. Out of the 19 studies, two were research studies retrieved from editorial articles, two were systematic literature reviews and the rest were research studies (one quantitative, one mixed study and the rest were qualitative studies).

Two major themes were identified from the literature review: privacy (patients, family and end of life care) and nursing perspectives (practices, ethics and strategies) in the ICU. Similarities existed in the themes that were identified irrespective of the evidence in the study or the country of origin.

7.1 Privacy

This theme was further simplified into three sub – themes; patients' privacy, family involvement and privacy, end of life care and privacy. These sub themes are further illustrated in *figure 2* below.

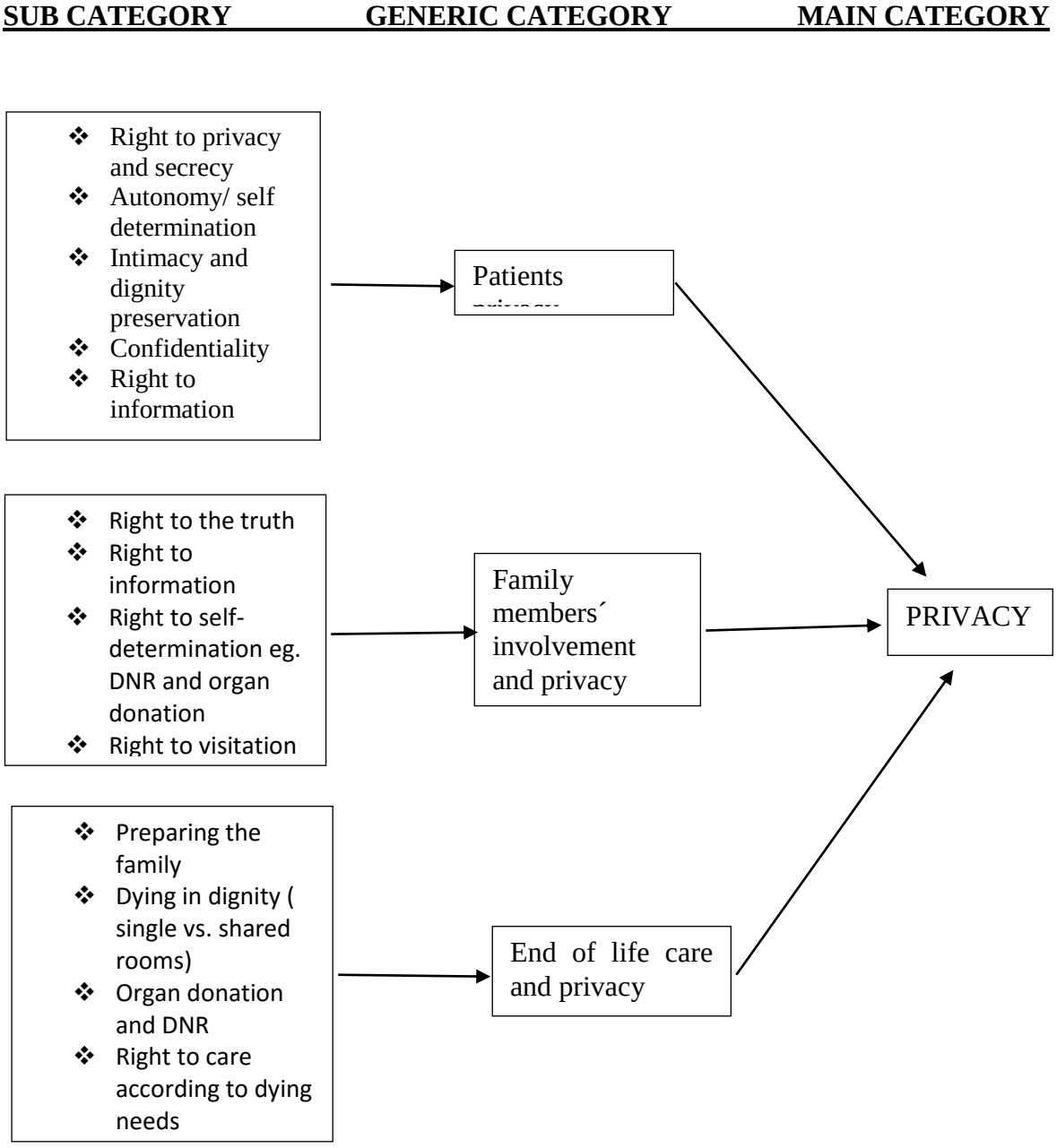

Figure 2 Privacy Concept

7.1.1 Patients' Privacy

Perception of privacy in patients admitted to the ICU was described in relation to surrounding physical space, family setting and privacy autonomy (Cerdä 2008).

Privacy was identified as an important characteristic of the hospital environment by patients, relatives and nurses (Brereton et al. 2011, Fridh et al. 2007, 2009, Pupulim & Sawada 2005). Privacy was also seen as an ethical issue as nurses recognized the patients' universal right to privacy (Fernandes & Moriera 2012).

30% -100% of the patients recalled all or part of their stay in the ICU. Among the positive experiences were feeling safe and secure (Gonce & Fontaine 2009), and Aro *et al* (2012) documented the above experiences as the most important needs of the **ICU** patients. The need for physical comfort was important to more than 97% of the patients. Most patients (>94%) agreed that physical comfort was ensured to them during their **ICU** stay and more than 95% felt that the staff was always present, responded sensitively to their signals and responded adequately to changes in their condition.

The recognition of the right to privacy, which is universal, is perceived by nurses particularly when caring for patients in the **ICU**. Nurses feel especially uncomfortable when they invade the other person's physical intimacy. This situation is very difficult, and nurses have difficulties in sharing it with the team. In addition, is the respect for the patient's autonomy, especially because most of them are sedated and unable to communicate and leads to a situation in which their will is not questioned (Fernandes & Moriera 2012.) According to Aro *et al* (2012), the need to be respected by the staff as a unique individual was important as 64% agreed that the staff always took their presence into consideration when discussing issues concerning them at their bedside, and about three quarters agreed that the staff respected their personal values and habits.

Patients recognized the practicalities of preventing infringements to confidentiality (Latour & Albarran, 2012) as more than two-thirds (69%) were informed about all circumstances concerning them confidentially in the Estonia study Aro *et al* (2012). Privacy protection, respect, confidentiality and guidance guaranteed the quality of care. (Pupulim & Sawada 2005).

The humanization of care, patient and family's right to the truth and to information, as well as the family's engagement in decision making are significant aspects in the promotion of the right to self-determination. This is particularly significant when

there is no sharing of information with the conscious patient, engaging him/her in the decision, as a participant mentions (Fernandes & Moriera 2012).

The necessity of improving the **ICU** environment to promote the need for proximity and privacy for dying patients and their families was another important aspect of privacy. Fridh et al. (2007) identified the need for greater privacy in **ICU**, a finding supported in their later study where some patients died in a shared room with screens erected between beds (Fridh et al. 2009). However, Fridh et al. (2009) also found that, although relatives noticed other patients and their family in the **ICU** environment, they were considered to be part of the background and 'unimportant. They also highlighted the need to balance privacy and being left alone with company that meets the social needs of patients, some of whom reported that a shared room reduced their sense of loneliness.

Patients' physical privacy, impact on patient care and the technology were the three most important topics of information on the study of Tele-**ICU**: The three most frequently selected topics of information that patients' family members considered important to know about the tele-**ICU** were; strategies to protect patients' physical privacy, impact of remote monitoring on patient care, and how the remote technology works. When asked to indicate their understanding of the purpose of the tele-**ICU**, 64.8% of the family members indicated that the system was intended to help **ICU** staff care for their loved one and 60.2% noted that the tele-**ICU** helped keep an eye on the patient when no one was in the room (Jahrsdoerfer & Goran, 2013). These findings collaborated with the rest of the findings of the other studies as much as the rest of the studies were done in normal **ICU**s as opposed to Tele- **ICU**s concerning the concept of patients' privacy.

Despite these findings, lack of privacy was a source of dissatisfaction in the **ICU** that resulted in negative experiences such as fear, anxiety, sleep disturbances, cognitive impairment and pain or discomfort (Gonce & Fontaine 2009, Aro *et al* 2012). Lack of physical privacy was characterized by nakedness (genitalia and bosom exposure), being in open rooms with mixed sexes and no partitioning systems (screens) (Özer & Akyli 2005, Tayebi *et al*. 2014, Latour & Albarran 2012, Turnock & Kelleher 2001 Pupulim & Sawada 2005).

Patient dignity was not maintained as 65% of the patients were disturbed by nakedness (Özer & Akyli 2005) and intimate areas such as bosom and genetalia were exposed in 40% of the cases in Turnock & Kelleher (2001). More so, there were 83.9% incidents where patients were observed not wearing any form of clothing as they were only covered with a sheet. Female and younger (<60 years) patients were more likely to be exposed than older patients. (Latour & Albarran 2012). Nurses mentioned that **ICU** patients are usually unconscious and unable to preserve their own privacy when exposed. As a result, they felt a strong responsibility for maintaining their unconscious patients' privacy during visiting A neurology **ICU** nurse said, *'During some procedures, the presence of visitors is absolutely forbidden. When the patient is exposed, even his/her immediate family members should leave the unit'* (Tayebi *et al. 2014.)*

The physical structure of the **ICUs** is characterized by being open units without privacy, without individual curtains, in which the beds are extremely close together. Consequently, beds, when needed, are separated only by the use of simple movable curtains ('Fernandes & Moriera*,* Tayebi,*et al, 2014).* Latour & Albarran reported that screens were used in less than 40% of the observations and 37.5% of the Control group were disturbed about the instruments used on fellow patients lying nearby during certain procedures due to improper use of screens. (Özer & Akyli 2005). In Aro *et al* (2012) 17% of the patients reported that agreed their privacy was not ensured by not being curtained from other patients.

As a result of economic restraints resulting in lower staffing, private rooms were often not utilized even if available. The results also show that recently built units did not have more private rooms than older units. According to the respondents about 30% of the patients often or almost always die in a shared room. (Fridh *et al*. 2009.)

Despite recommendations highlighting the importance of privacy for dying ICU patients and their families, only 11% of the respondents stated that patients never died in shared rooms in their ICU (Fridh *et al*. 2007.)

Other issues that signified lack of privacy were; treatment of the patients as if they were machines, not speaking with patient, not calling patient by their names and the use of medical terms by the nursing staff but with no significant statistics (Özer & Akyli, 2005)

7.1.2 Family Members' Involvement and Privacy

Family members ranked privacy statistically higher than patients did in a survey of quality of end of life care suggesting that privacy was needed for confidential discussions and the comfort of relatives (Brereton et al. 2006).The need to involve family and friends was important to the patients as more than 70% agreed that their family and friends were allowed to stay with them whenever they wanted, and half said that information and explanations were given to them in the presence of their family member. At the same time, the staff do not always ask the patients 'opinion when involving the patients' family members. (Aro *et al* 2012.) According to Özer & Akyli (2005), 2.9% of the Study Group(SG) and 45% of the Control Group(CG) felt disturbed by their inability to see their relatives as well as 22.5 % of the SG and 40% of the CG experienced loneliness when admitted in the **ICU.**

Factors related to the **ICU** patient, family members, critical care nurse and the **ICU** environment contributed to difficulties encompassing family member involvement in care (McConnell & Moroney 2015). Communication with the patient/family and team work are among the problems experienced in the daily interaction with the patient. This is a particularly sensitive area because of the patient's critical condition, which required health professionals to remember the relational dimension during health-care provision, since information is a right both of the patient and the family (Fernandes & Moriera 2012). Latour & Albarran (2012) reported that both groups stated that they were unconcerned about confidential matters being discussed by healthcare staff with family members present during resuscitation (91% and 75% respectively).

When considering family involvement in patient care, critical care nurses take on a paternalistic role on whether to include or exclude family members from patient

care (McConnell & Moroney 2015). Through restricted visiting hours, nurses try to protect vulnerable ICU patients from physical, psychological and legal risk. Health care professionals, especially nurses, are required to create the conditions in which patients' family members are informed about the patients' health status and patients can be visited in suitable ward conditions (Tayebi*,et al* 2014*).* Sole, *et al*(2009) reports that in America 44% of critical care units still have restricted visitation policies and 45% of units had policies that were open at all times, or restricted only during rounds and change of shift. Also most acute care institutions prohibit visitation by children.

In line with the concern of nurses about visitation, there were cases where the patients admitted in the **ICU** felt like family members disturbed or aggravated them and opted for less visitors instead. This is illustrated by a 45-year old kidney-pancreas transplant recipient pointed out that the presence of other patients' visitors disturbed him. He said: *'Family members must be considerate of us; they must not crowd into the ICU; visitors must manage the condition in such a way that all the patients'* family *members would be able to visit their loved ones' (Tayebi et al 2014).*

There was a significant relationship between family presence, expected death and end-of-life decisions (Fridh *et al*. 2007). Most relatives in reported difficulty in seeing so many dying patients together and half were disturbed by knowing that they were being nursed in the same room as less ill patients. However, most relatives in the same study thought that mixed gender wards were unimportant as patients were not conscious of others in the room (Brereton et al. 2011). Patients without a family member at their bedside received less analgesics and sedatives. Risk of underestimating the needs of patients without a next of kin at their bedside at the time of death was highlighted (Fridh et al. 2007).

Family members and nurses in 2 studies identified proximity as important (Brereton et al. 2011 and Fridh et al. 2007), with a 1/3 making reference to proximity immediately after a patient's death (Fridh et al. 2009). Proximity was so important that relatives were willing to stay in a chair overnight to be near their loved one (Brereton et al. 2011). Despite this, Fridh et al. (2007) found that the **ICU** environment did not always enable relative's proximity needs to be met as

39% of the 192 patients studied died without a family being present at the bedside although 19.7% of these had relatives somewhere in **ICU**. Patients who died during resuscitation were significantly more likely to have relatives waiting elsewhere in **ICU** than other patients. Fridh et al. (2009) indicated that after a patient's death, the room should be arranged so that family can bid farewell to the patient in a dignified manner.

Two thirds of the patients' family members reported that they were uninformed about the tele-**ICU** and identified staff as the preferred source for this information. When asked about contact with the remotely located tele-**ICU** staff, 66.8% of the family members indicated that they had contact with both the nurse and physician, whereas 33.2% reported that they had interacted only with nursing staff. The most frequent reason for interacting with the tele-ICU staff was contact initiated by the remote staff during a patient visit, which was reported by 51 family members, whereas 34 family members indicated that they had contact with the remote staff when they pressed the call button for assistance (Jahrsdoerfer & Goran 2013.)

7.2.3 Privacy in End of Life Care

ICU can be a 'fairly humane' place to lose a loved one (Fridh et al. 2007). The acknowledgement of the right to health care according to one's needs and the right to die with dignity are issues expressed by these participants and by professionals from different hospitals. In a ward in which it is possible to prolong life using artificial means and in irreversible situations one is only inflicting suffering. This is an issue for many participants, as expressed; "apparently that situation will not be reversible, we are investing, but sooner or later instead of preparing a dignified death, why don't we provide palliative care in **ICUs**." (Fernandes & Moriera 2012.)

In the category of ''end-of-life decisions,'' nurses consider that the therapeutic obstinacy, the DNR decision and the organ donation decisions as ethical issues of paramount importance both to the **ICU** nurses, patients and their family members

(Fernandes & Moriera 2012, Oröy *et al*, 2015). These special situations of end of life care, may create ethically difficult situations regarding the interaction with the patient's and their families. Findings revealed that the process of clarifying the patient's prognosis through prognostic ambiguity, gradual clarification, and prognostic certainty had a significant impact on how the healthcare providers (HPs) interacted with the family and challenged their caring values in various ways (Oröy *et al*. 2015.)

Despite recommendations highlighting the importance of privacy for dying **ICU** patients and their families, only 11% of the respondents stated that patients never died in shared rooms in their **ICU**. 46% of the deaths occurred in a shared room but that number decreased to 37% if a family member was present if a patient died in a shared room, nurses strived to ensure a dignified good-bye by moving the body to an empty room or to one specifically designated for this purpose. Nurses moved patients to a single room or kept beds empty when death was imminent, although statistically more patients died in a shared room when relatives were absent (Fridh et al. 2007, 2009).

According to the respondents, almost half of the families of patients who die in Swedish **ICUs** are seldom offered a follow-up visit. If the family returns to the hospital for a meeting, they usually meet a physician. Such meetings most often occur after unusual death for example when young patients are involved in unexpected death or in organ donation cases (Fridh et al. 2007, Oröy *et al* 2015). The majority (76%) of the units had waiting rooms within the ICU and guidelines in the area of end-of-life care were used by 25% of the ICUs (Fridh et al. 2007).

7.2 Nursing Perspectives

This theme has three sub – generic categories; nursing practices, ethics and strategies and solutions. These sub themes are illustrated further in the *figure 3* below.

SUB CATEGORY **GENERIC CATEGORY** **MAIN CATEGORY**

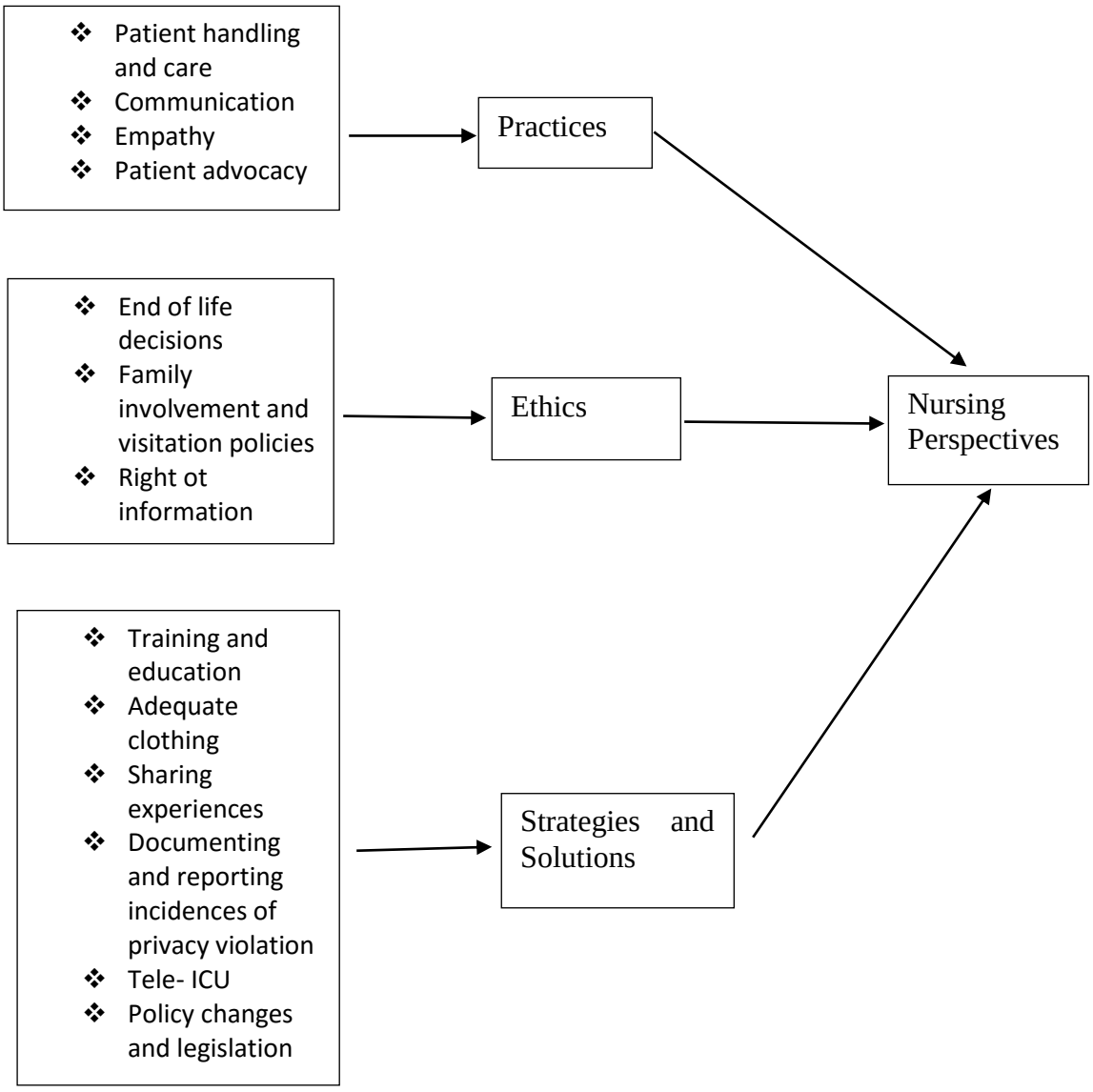

Figure 3 Nursing perspectives to privacy

7.2.1 Nursing Practices

In the Gonce & Fontaine (2009) study, often, care given by the nurses was attributed to positive feeling. From the Fernandes & Moreira (2012) study, a perspective associated with the nurses' information emerged in which intimacy and sensitivity focusing on the patients' needs indicated a compromise in ethics of care. Özer & Akyil (2005) identified other practices in regard to patient handling such as the treatment of patients as if they were machines, not speaking with them, not calling them by their names and the use of medical terms by the nursing staff but with no significant statistics.

The nursing team was better prepared to handle problems related to care for basic needs (Pupulim & Sawada, 2005). Newman (2011), reported that critical care nurses employed their knowledge and values regarding confidentiality in the interaction and communication with their patients, family members and visitors.

Health protection, safety and promotion were the rationales given by the participating nurses in the Tayebi (2014) study for enforcing restricted visiting policies. The nurse participants considered protecting the patient's health as one of the main rationale for implementing restricted visiting policy in Iranian ICUs. This theme consisted of two sub-themes, including mental health protection and physical health protection. The participants considered the protection of the patients' mental health as an important justification for restricted visiting policy. The participating nurses believed that unrestricted presence of visitors in ICUs disturbs the patients who need a peaceful environment;

'I think that the ICU patients' need for peace and calm is far beyond their need for visitors; however, visitors only think of themselves. I believe that patients are more important [than visitors]. They need silence during their hospitalization in ICU.'(P. 6, A Gynecology ICU Nurse).

The other rationale for restricted visiting policy, as expressed by the participants, was to protect the ICU patients' physical health. The main aspect of physical health protection was minimizing the risk of infection transmission. This concept

was acknowledged by the participating nurses, patients and visitors. A nurse having 10 years work experience said,

'Not all the visitors should be permitted to visit the patient. [Suppose that] a recently-extubated patient is experiencing severe respiratory distress as well as high fever. His visitors insist on visiting and talking to him from the nearest possible distance. They are unaware of the risk of infection transmission'.

However, a few participating nurses believed that visitors must be able to visit their patients, provided that they obeyed the protective measures like handwashing. Besides the risk of infection transmission, the participating nurses were worried about the aggravation of the patients' clinical condition secondary to their own and their visitors' intense excitement during visitation,

***ICU** is different from other units; sometimes visitors show strong feelings and cry; consequently, their patients experience agitation, tachycardia and respiratory distress.'* (An **ICU** nurse).

Sometimes, visitors unintentionally aggravate their patients' clinical condition. An **ICU** nurse having 6 years of work experience mentioned,

'We were caring for an addicted patient recovering [from a disease] and regaining consciousness; we extubated him; but his visitor came and gave him opium furtively. He lost consciousness again. We re-intubated him and forbade visitation totally.'

Head-nurses, based on their responsibility for maintaining patients' safety, were worried about the risk of malice towards patients during visiting hours. They agreed with restricted visiting policies and arranged restricted visiting hours in the morning shift when they were on duty themselves. Another aspect mentioned in the Tayebi (2014) study was Legal abuse. Sometimes head-nurses imposed more visiting restrictions to protect unconscious patients from familial challenges and subsequent risk of legal abuse.

'Most of our patients are unconscious. We do not know their familial background and their probable familial challenges. In case of familial challenges, the family visitors may want to illegally take the unconscious patient's fingerprints. In my

*opinion, nurses are patients' advocates and should protect their rights.' (A Head Nurse of the Neurosurgery **ICU**)*

Nurses participating in the study believed that visitations disturb their practice. They mentioned that visitors break their concentration and subsequently increase the incidences of nursing errors hence endangering patients' safety.

*'**ICU** is a highly sensitive environment [because] patients are on complex medications and interventions. When visitors are in the unit, the nurses' concentration is broken and consequently, the risk of nursing errors increases.'*(Nurse of the Gynecology **ICU**)

Besides breaking nurses' concentration, visitations also endanger patient safety through distancing nurses from their patients. Nurses tend not to provide nursing care straightforwardly; so during visiting hours, they limited their practice to the essentials. A medical **ICU** nurse – who disagreed with open visiting policy – mentioned,

'When visitors are present, nurses are reluctant to provide care; because they are worried about visitors' interference or may feel that the presence of visitors interferes with their practice.'

Fridh et al (2009) stated that 'warm and professional' care was more important than deficiencies in ICU's physical environment

7.2.2 Nursing Ethics

The perceived ethical issues in the everyday work life of **ICU** nurses were related to situations resulting from their educational backgrounds and the physical and relational settings in which they exercised their practice. They identified the following as areas in which ethical issues exist: end-of-life decisions, privacy, interaction with the patient/family including visitation policies and flow of information from the nurses to family members (Fernandes & Moreira 2012.)

The minimization of the ethical issues experienced by nurses in their daily work is, from their perspective, dependent on personal and professional aspects (Fernandes & Moreira 2012). According to McConnell & Moroney (2015), when considering family involvement in patient care, critical care nurses take on a paternalistic role on whether to include or exclude family members from patient care. In their study, Tayebi et al (2014) added that through restricted visiting hours, nurses try to protect vulnerable **ICU** patients from physical, psychological and legal risk.

Nurses play an important role both in identifying potential donors and in caring for the donor patients and their families. The time between identification of a potential donor and the request is experienced as difficult and ethically challenging. Discussing brain death and OD with the family is described as a specialized component of end-of-life decision making and care that requires extensive experience and competence of those involved. The question about OD will almost always arise as a possible outcome of the situation when caring for critically ill or injured patients with severe brain injuries. Even in cases where the HPs are struggling to save the patient's life, they cannot avoid these thoughts. Moreover, these thoughts are not always explicitly expressed but still may create ethically difficult situations regarding the interaction with the patients and their families (Oröy et al. 2015.)

The same study continues to explain that the process of clarifying the patient's prognosis was characterized by ambiguity, which resulted in withholding information, balancing between openness and withholding, and striving for dignity under difficult conditions. Ambiguity resulted in withholding information. In situations with prognostic ambiguity, the main focus for the HPs was saving the patient's life and giving the best available treatment while waiting for clarification of the patient's prognosis. During this phase, the healthcare team both treated the patient and prepared the family for an ambiguous outcome. The information to the family was generally perceived as open and honest, and the severity of the patient's situation was communicated.

The Oröy (2015) study also pointed out the aspect of balancing between openness and withholding. During gradual clarification of the prognosis, the HPs' focus of

treatment and care was blurred. This confusion was difficult to explain to the family, and different ethical challenges arose. Although the intention with the treatment was to save the patient's life, the focus was experienced as confusing. Moreover, the physician appeared to be confused as to why he did not manage to present to the family that OD was an option if the patient did not survive. To the family, he said that the ''prognosis was extremely bad but that there probably was a prognosis.''

Striving for dignity under difficult conditions was the third aspect mentioned in the same study. Even in situations when the outcome was clarified, the provision of care was often challenging because the HPs could not care for the dying patient and his family as they generally do. In these situations, they must continue to optimize medication, conduct follow-up observations, and care for the dying as if they are still alive. Although this nurse was aware of the significance of OD and also honored those who consented to donation, she experienced the treatment of the dying as unethical because it seemed to be in conflict with her caring values about how to arrange for a peaceful death. Others described this as a dilemma, because they generally did not treat dying patients. This issue involved respect for the dying or dead and the family. The knowledge about how this was occurring was sometimes experienced as burdensome vis-a-vis the family, and some stated that it was easier to care for the patient when the family was not present. This part of the process appeared to be a type of silent knowledge the nurses withheld from the family. The nurses expressed empathy and respect by being with the family without words or in silence. This situation also made the last farewell difficult for the family and probably because it involves a ''living body". (Oröy 2015.)

7.2.3 Nursing Strategies and Solutions

Fernandes & Moreira (2012) highlighted three aspects in the personal domain that are related, contribute to and should be used in problem solving; personal and moral development, training and questioning and reflecting on what was experienced. They also suggested that nurses sharing these

experiences/distresses related to daily work problems and decision making in problematic situations with relatives and friends may lead to the promotion of nurses' moral development.

Further education for critical care nurses about specific state legislation as well as organizational policy and training is needed since nurses' application of ethical principles exemplifies their concern regarding the communication and information they should provide to patient families and significant others. The same nurses in Newman's study (2011) indicated that while the legislation is therapeutic, there is still work needed to prevent breach of confidentiality. Understanding the critical care nurse's perception and knowledge may lead to adjustments in decision making regarding the protection of health information.

Latour & Albarran (2012) were of the view that staff should seek patient preferences, document these and ensure that members of the team were informed. Tayebi (2014) emphasized the need by health care professionals, especially nurses to create the conditions in which patients' family members are informed about the patients' health status and that patients should be visited in suitable ward conditions.

2/3 of patients' family members reported that they were uninformed about the tele-ICU and identified staff as the preferred source for this information (Jahrsdoeefer & Goran 2013).

8. DISCUSSION OF RESULTS

8. 1 Discussion

This systematic literature review was to evaluate how nurses can uphold/ safeguard the privacy of patients admitted in the **ICU**. The major themes that arose from the study were privacy in the **ICU** and the nurses' perspectives in **ICU** nursing. These two themes are inter-twined together as nurses are the primary care givers of patients admitted in the **ICU** and thus they are tasked with the responsibility of upholding and maintaining patients' privacy in the course of providing curative and general care.

8.1.1 Patients' Privacy

Patients' privacy was determined from our study as the right to privacy and secrecy, right to self-determination and autonomy, intimacy and dignity preservation, confidentiality and right to information. The architectural structure of **ICUs** is a conditioning factor in terms of patients' privacy as these units are open spaces, sometimes cramped, where patients of different sexes, ages, and health conditions cohabit with family members and the professional teams. Difficulties may arise as well as breach of privacy though not intentionally regarding the integration of ethical and moral principles in daily clinical practice.

Family members' involvement and privacy entails right to the truth, right to information, right to self-determination (organ donation and DNR) and right to visitation. Nurses should promote, facilitate and invite the integration of families in care in the **ICU** and this is obligatory as families are the caring resource for these patients during an often prolonged recovery trajectory. Families should not be perceived as a burden because they speak and make decisions on behalf of these unconscious **ICU** patients.

End of life care and privacy from our study involves preparing the family, dying in dignity (single vs shared rooms), organ donation and DNR as well as the right to care according to dying needs. In the **ICU**, ethical challenges concerning life and death are common as nurses have to shift their nursing interventions and care from lifesaving policies to promoting a dignified death as per the circumstances.

Privacy in the **ICU** is a very broad and ambiguous concept that is paramount in the care of the patient. Privacy cuts across all the spheres of care be it physical, emotional and it is enshrined in the Finnish constitution. Incorporation of family in the care and decision making for patients admitted in the **ICU** is a vital component of respecting and maintaining their autonomy as individuals regardless of their consciousness. The studies have clearly illustrated that patients, regardless of their state could remarkably remember instances where their privacy was violated. Family members also highlighted occasions where they felt that more can be done to uphold the privacy of patients like in the case of a dying loved one in a shared room.

8.1.2 Nurses' Perspectives in ICU Nursing

Nurses are responsible for most of the privacy violation occurrences, either intentionally or unintentionally in their day to-day implementation of care. According to the study, these violations are portrayed in the way nurses handle patients, how they communicate to each other and the patients in the course of giving care, their show of empathy and how they advocate for the patients whenever need arises. The nurses' competencies in critical care nursing are constantly tested by the limitless boundaries exhibited by the unfavorable environmental structure of the **ICUs** in their pursuit of providing dignified care. As such more needs to be done to ensure that there is a reduction in these privacy violation incidences.

This study reveals the ambiguity surrounding ethical values when it comes to caring for patients and their families especially in end of life decisions like potential

organ donors. Contention arises when nurses have to decide on when, how and what information to give to the family regarding the status of their loved ones as much they are entitled to the whole truth. Additionally, family involvement and visitation policies are ethical concerns that nurses have to make decisions on routinely. Courtesy of the above ethical issues, nurses in **ICUs** continuously work on a narrow line in order to strike a balance in providing care without going against the nursing ethics and ethos.

Nurses need to remain in control over their work environment. Specific strategies and solutions to support the progressive role of critical care nurses is crucial. These could be focused to regularly upgrading their training and education, provision and usage of adequate clothing and curtains, creating forums for sharing experiences from which fellow nurses can learn, documenting and reporting incidences of privacy violation and incorporating technology like Tele-**ICU**. Nurses can assist in promoting, advocating for and implementing policy changes through evidence based nursing to ensure quality nursing practices.

8.2 Emerging/ Controversial Issues

In the course of this study, we came across three outstanding controversial issues; tele-**ICU** nursing, organ donation and DNR.

Tele-**ICU** nursing has come into existence as a viable option for improving care delivery and safety for the sickest patients but this care model is still in its infancy and no solid research evidence has been done so far. This ever changing and broad nursing model necessitates nurses to be flexible and team work to create an enabling environment for it to thrive. Tele- medicine growth rates are guaranteed to multiply because of the increasing number of the aging and high acute patients there by increasing the need for critical care services. However, integration of the tele-**ICU** into the **ICU** as we know it today will compel the formation of new partnerships requiring role appreciation, mutual respect, and a common desire to improve patient outcomes. The **ICU** as an individual tele-**ICU** system will

eventually also vary in culture, types of patients served, size, resource availability, and other variables that can make acceptance and integration a challenge. Identifying various strategies to boost the growth of a healthy **ICU**/tele-**ICU** partnership by the providers is very important to achieve optimal patient outcomes.

Organ donation is the second ethical consideration encountered in this study. The health practitioners have to decide between moral obligations and utility ethics, in that, is the action morally right as opposed to its benefits and usefulness to the patient. This was particularly challenging to the nurses as once the health practitioners noticed that the patient's prognosis was negative they initiated tests to confirm whether the patient was a suitable candidate for OD and contacted the OD coordinator without notifying the family. The nurses felt in such cases that they had to holdback information from the family members as much as it was in accordance with the protocol of OD. Even once the family had consented to the OD, care now shifted to sustaining the organs to be harvested as opposed to giving a dignified end-of-life care to the patient. This made the process of the last send off by the family members difficult as they were informed that their kin were dead yet they seemed to be alive as the ventilators kept the organs viable for donation.

On the other hand, it is also true that despite the successes in transplantation, there is a severe shortage of organs to meet the growing demand. The issues emerging from the organ donation process present situation risks of using patients simply as a means to an end for other patients.

Lastly, family members have to make the decision to remove the patient from the ventilator or for the patient not to be resuscitated. This may be controversial in that the primary role of the ICU is to save life but in this case, the nurses have to abide by the wishes of the family members however much they are in a position to prolong life.

8. 3 Relevance of the study to Critical Care Nursing

This research is relevant because it highlights the importance of privacy, dignity and confidentiality of **ICU** patients who in that state are not in a position to advocate for themselves. The outcome of this study can be used to empower nurses on better ways of promoting the privacy of **ICU** patients. It can also be used to determine the benefits of improved privacy to patients

This study highlights the critical role that nurses play in the **ICU** as not only care givers but also a center point of coordination between family members, patients and other health care professionals to ensure holistic care is provided.

This study may be used to forecast in the future on how to cater for the expected increase in the need for critical care. This increase in the need for critical care corresponds with an increased need of more critical care nurses. Despite the above increments, the study may be used to emphasize how to improve critical care nursing without compromising on the quality of care.

This study was part of the **Evicures** peoples project whose main focus was to collect evidenced based data and information for the building of a new **ICU** unit for the Seinäjoki Central Hospital. As such this study may offer guidance on the current and expected privacy violations in the **ICU** and how to counter them.

8.4 Strengths and Limitations

The strength of this study is that the topic is relevant, interesting, engaging and very current. ICU nursing is an evolving branch of nursing and thus the study was timely in ascertaining the right to privacy in the **ICU** but was the same time controversial.

This study increased our theoretical knowledge on the **ICU** working environment, **ICU** terminologies and other complex issues associated with critical care nursing.

This study was limited by the lack of sufficient previous studies carried out that were directly linked to this topic. It was demanding having to deal with a limited number of studies to come up with a quality study devoid of bias. At the beginning of the study, we had expected to be overwhelmed by the number of studies but unfortunately this was not the case. Regardless, this challenge worked as the driving force and not a hindrance to our progress.

8.5 Recommendations for further Research

This research can be used as a bench mark for further researches to evaluate the following aspects of the **ICU**;

- Due to its importance, ethics in intensive care necessitates a thorough research in terms of context and culture so as to deepen knowledge in this area for health practitioners.
- Clear policies on visiting practices based on evidence to negate arbitrary decisions by nurses regarding who can visit, and to lessen confusion and dispel myths which can only bring benefits.
- Benefits of single rooms as opposed to shared rooms in the **ICU** and how this can improve patients' privacy.
- How tele-**ICU** can be incorporated in the current **ICU** models and structures in order to alleviate the increasing demands for critical care services, the anticipated challenges and possible solutions.
- Legislation to govern and guide organ donation supply to counter the rapidly increasing demand.

8.6 Ethics and Reliability

The data collected in this study was from already established scientific sources and thus their authenticity, reliability and ethical considerations were of the highest standard possible. Plagiarism was avoided at each stage of the thesis writing process by maintaining and acknowledging the sources used, citing them in the text and further illustrating them in the bibliography. Since the thesis doesn't include any original research, third party participants or questionnaires; there was no need to seek approval from relevant ethics committee.

This study was done according to the approved thesis guidelines for bachelor's degree programmes at the Seinäjoki University of Applied Sciences.

8.7 Conclusion

Privacy issues emerged on a broad spectrum and the difficulties of preserving and respecting patient's intimacy due to the **ICU** environment were clearly highlighted. Solutions and strategies to combat privacy issues came out quite clearly in this study. Decision making in the intensive care environment is also a complex phenomenon because the patient's clinical situation places time demands and ethical compromises on nurses.

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APPENDICES

APPENDIX 1. Results of the previous studies and Evicures seminar poster

	NAMES/ AUTHORS	YEAR	TYPE OF STUDY & SAMPLE	MAIN RESULTS
1	Gonce & Fontaine	2009	Qualitative -26 studies	• 30% -100% of the patients recalled all or part of their stay in the ICU. • Negative experiences were fear, anxiety, sleep disturbances, cognitive impairment and pain or discomfort. • Positive experiences were feeling safe and secure. • Often, care given by the nurses was attributed to positive feeling.
2	Cerdä	2008	Qualitative -Adult patients admitted in the ICU for a minimum of 48 hours	• Perception of privacy in patients admitted to the ICU is described in relation to surrounding physical space, family setting and privacy autonomy • Patients evaluated the flexibility of rules, professionalism of nursing staff and need for family support
3	Fernandes & Moreira	2012	Qualitative 15 nurses working at polyvalent ICU in 4 hospitals	• The emerging ethical issues were; end of life decisions, privacy, interaction and health care access • Personal and team resources were used to solve those ethical issues • Moral development and training were the most significant strategies
4	Aro	2012	Qualitative 16 ICUs in 6 acute care hospitals on 166 adult patients	• The most important needs of the ICU patients were physical comfort and feeling safe. • Privacy, family and friends and patient

				involvement in decision making were less important
5	Özer & Akyil,	2008	Quantitative quasi experimental design 80 patients; 40 in the study group (SG) and 40 in the control group (CG)	• 2.9% of the SG and 45% of the CG about their inability to see their relatives; • 14.3% of the SG and 40% of the CG about the closed environment of the ICU; • 22.5 % of the SG and 40% of the CG about loneliness; • 17.1% of the SG and 65% of the CG about nakedness; • 11.4% of the SG and 37.5% of the CG about the instruments used on fellow patients; • 20% of the SG and 50% of the CG about their inability to express their needs • 14.3% of the SG and 42.5% of the CG about not being informed before procedures. • The difference among the groups was found to be statistically significant.
6	Turnock & Kelleher	2001	Qualitative 62 hours of non-participant observation of patient care in the ICU	• Patient dignity was maintained in 1/3 of observed cases • Intimate areas such as bosom and genetalia were exposed in 40% of the cases • Female and younger (<60 years) patients were more likely to be exposed and older patients (>70 years) were less likely to be screened when exposed. • Raising staff awareness and documentation of situations that may compromise maintenance of dignity • Adequate clothing of patients

7	Latour & Albarran	2012	Qualitative 192 patients, care episodes conducted in 2 ICUs with 6 beds in an open bay area	• There were 83.9% incidents where patients were observed not wearing any form of clothing • In 40% of these episodes either a patient's breast or genitalia were uncovered • Screens were used in less than 40% of the observations • In their sample of 105 patients who reported a privacy incident, 10% indicated that their expectations in this respect were unmet
8	Pupulim & Sawada	2005	Qualitative 15 adult ICU nurses	• The nursing team was better prepared to handle problems related to care for basic needs • Privacy protection, respect, confidentiality and guidance guaranteed the quality of care but the failure to protect clients' intimacy impaired greatly on the quality of care
9	Newman	2011	Qualitative 12 respondents	• Critical care nurses employed their knowledge and values regarding confidentiality in the interaction and communication with their patients, family members and visitors
10	Latour & Albarran	2012	Qualitative 20 survivors of resuscitation and 41 patients admitted as emergency cases	• Both groups stated that they were unconcerned about confidential matters being discussed by healthcare staff with family members present during resuscitation (91% and 75% respectively) • Patients recognized the practicalities of preventing infringements to confidentiality • Staff should seek patient preferences, document these and ensure that members of the team

				were informed
11	McConnell & Moroney	2015	Mixed study; phase 1 quantitative and phase 2 qualitative Phase 1 = 70 critical care nurses working in Australian ICUs Phase 2 = 6 critical care nurses from a single Sydney ICU	• Factors related to the ICU patient, family members, critical care nurse and the ICU environment contributed to difficulties encompassing family member involvement • When considering family involvement in patient care, critical care nurses take on a paternalistic role on whether to include or exclude family members from patient care
12	Tayebi, et al	2014	Qualitative 6 nurses, 3 head nurses, 2 patients and 4 visitors	• Three themes emerged; health protection, safety promotion and privacy preservation • Through restricted visiting hours, nurses try to protect vulnerable ICU patients from physical, psychological and legal risk • Health care professionals, especially nurses, are required to create the conditions in which patients' family members are informed about the patients' health status and patients can be visited in suitable ward conditions
13	Sole, et al	2009	Qualitative Critical care units in America	• 44% of critical care units still have restricted visitation policies • 45% of units had policies that were open at all times, or restricted only during rounds and change of shift • Most acute care institutions prohibit visitation by children
14	Fridh, et al	2007	Qualitative 79 eligible Swedish ICUs	• Despite recommendations highlighting the importance of privacy for

				dying ICU patients and their families, only 11% of the respondents stated that patients never died in shared rooms in their ICU. • If a patient died in a shared room, nurses strived to ensure a dignified good-bye by moving the body to an empty room or to one specifically designated for this purpose • The majority (76%) of the units had waiting rooms within the ICU • Guidelines in the area of end-of-life care were used by 25% of the ICUs
15	Fridh, et al	2007	Qualitative 10 ICUs and data collected on 192 deaths	• 40% of the patients died without a next of kin at the bedside • 46% of the deaths occurred in a shared room but that number decreased to 37% if a family member was present. • Patients without a family member at their bedside received less analgesics and sedatives • There was a significant relationship between family presence, expected death and end-of-life decisions • The necessity of improving the ICU environment to promote the need for proximity and privacy for dying patients and their families • Risk of underestimating the needs of patients without a next of kin at their bedside at the time of death was highlighted
16	Fridh, et al	2009	Qualitative Phenomenological –hermeneutic	• Need balance between being left alone and having staff support

			study on 17 close relatives of 15 patients who died in 3 adult ICUs	• 'Warm and professional' care is more important than deficiencies in ICU's physical environment • ICU can be a 'fairly humane' place to lose a loved one • Post death, the care environment was arranged to enable family to bid farewell in a beautiful and dignified way
17	Brereton, *et al*	2011	Qualitative An integrative review on 13 databases from 1966 to 2010	• Major themes identified were: privacy as needed • Proximity (being physically and emotionally close to the loved ones) • Satisfaction with physical environment • Deficiencies in the physical environment
18	Oröy, et al	2015	Qualitative 2 ICUs, 12 cases were observed and 32 healthcare professionals were interviewed	• The process of clarifying the patient's prognosis was characterized by ambiguity, which resulted in withholding information, balancing between openness and withholding, and striving for dignity under difficult conditions.
19	Jahrsdoerfer & Goran	2013	Qualitative Patients and family members at 3 health systems	• 2/3 of patients' family members reported that they were uninformed about the tele-ICU and identified staff as the preferred source for this information • Patients' physical privacy, impact on patient care and the technology were the three most important topics of information

PRIVACY OF PATIENTS ADMITTED IN THE ICU

Systematic Literature Review

By Chesop Beatrice & Nabunya Christine

AIM

The aim of this study is to describe how nurses can uphold /safeguard the privacy of patients admitted in the **ICU.** This study research is part of the **EVICURES** people's project in anticipation of the building of a new ICU for the Seinäjoki Central Hospital.

OBJECTIVES

To produce new information to help nurses understand the need and effectiveness of patients' privacy in the **ICU.**

To understand the concept of privacy and its benefits to patients admitted in the **ICUs**.

RESEARCH QUESTIONS

What is the privacy of **ICU** patients?

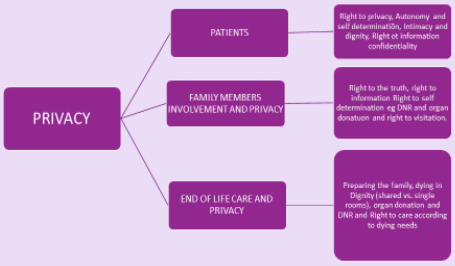
What nursing practices uphold patients' privacy in the **ICU**?

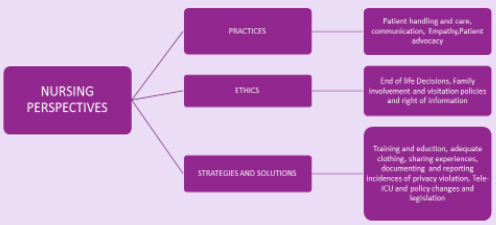
INCLUSION AND EXCLUSION CRITERIA

INCLUSION	EXCLUSION
Written in English language	Written in languages other than English
Papers focusing on patients in the ICU environment	Not focusing on patients in the ICU environment
Papers focusing on Adults both male and female	Papers on pediatrics, obstetrics
Papers written between 2000 - 2015	Papers older than 2000
Papers written in Europe, USA, Asia, Australia and South America	Papers written in Africa because there were no studies carried out that were relevant to our study
All types of studies, policy and expert opinions	
Textbooks and class notes	

DATA SEARCHING PROCESS

RESULTS





CONCLUSION: Privacy issues emerged on a broad spectrum and the difficulties of preserving and respecting patient's intimacy due to the **ICU** environment were clearly highlighted. Solutions and strategies to combat privacy issues came out quite clearly in this study. Decision making in the intensive care environment is also a complex phenomenon because the patient's clinical situation places time demands and ethical compromises on nurses.