

# Nurses Caring for Patients at the End of Life in Intensive Care Unit : A Literature Review

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**Abstract**—This article explored nurses caring for patients at the end of life in the Intensive Care Unit (ICU). A literature review was conducted by analyzing 56 scholar papers including research articles, thesis/dissertation, and books which met the inclusion criteria. Data were searched through PubMed, ProQuest, Wiley Online Library and Science Direct. Searches used combination of following keywords: 'ICU nurse', combined with 'caring', 'end of life', 'end of life care'. The result of the analysis presented the need of the patients and their families at the end of life, the nurses' goals of caring at the end of life, the nurses' role, problems and barriers in caring at the end of life in the ICU. Culture and religion have an influence in caring for patients at the end of life. The knowledge from this literature review can be guided the nurses to develop an effective caring model at the end of life in the ICU.

**Keywords**- *caring; end of life; intensive care unit*

## I. INTRODUCTION

The Intensive Care Unit (ICU) is a unit designed for saving the patient's life at the critical stage. However, the death rate of hospitalized patients in ICUs was higher than in other wards in the hospital [6]. ICU patients at the end of life (EOL) are usually suffering from illness and treatments and are commonly receiving invasive devices or technologies for human care, such as mechanical ventilator and hemodialysis machines as the way to sustain and prolong their lives [21]. Nurses role is vital in caring for EOL patients and demand for standard guidance for EOL care [27], formal training on EOL care [23, 27], and good communication between staff [23, 27]. Therefore, to enhance the quality of EOL care in ICU, it is necessary to review the existing knowledge regarding need of patients and families at the EOL, nurse goals, roles, problems and barriers in caring at the EOL.

## II. METHODS

Literature search was performed using PubMed, ProQuest, Wiley Online Library and Science direct for relevant articles published in between the year 2001 – 2016. Searches used combination of following keywords: 'ICU nurse', combined with 'caring', 'end of life', 'end of life care'. The search was limited to articles published in English. All clinical trials, randomized control trials, meta-analyses, and review articles were eligible for inclusion criteria. Data were extracted using the matrix table. The items in the table consisted of authors, year of publication, study design and length, sample characteristics, intervention, measurement, outcomes, results, and level of evidence by using grading of recommendation based on the Joanna Briggs Institute (JBI) for evidence-based nursing and midwifery [45].

## III. FINDINGS

### *Needs of Patients at the EOL in ICU.*

From the literature review, the needs of the patients in EOL can be categorized into three categories: 1) psychological and emotional need, 2) physical need, and 3) spiritual need. Regarding the first need, psychological and emotional need [35] should be fulfilled because the patients feel difficulty in decision making about providing care [52]. Furthermore, patients need their psychological distress to be controlled as the situation at the EOL is distressing and difficult [41]. Involvement of family members in providing bedside care helps the patient to feel much comfortable [31]. However, psychological need during the EOL is based upon the various human rights, human dignity, solidarity and the freedom of choice [53].

Likewise, physical need of EOL patients includes relieving from physical suffering, comfort measures and free of pain [31, 34, 52]. Physical suffering can be minimized and comfort measures can be provided by the administration of intravenous drugs, withdrawal of supporting measures [4].

Regarding spiritual need, patients at the EOL phase needed to satisfy their peace, therefore they have a willingness for a dignified and peaceful death [13]. Fulfillment of the spiritual needs of the patients at the EOL can improve the well-being of dying patients [3]. Spiritual need can be performed by calling a spiritual leader in the hospital to provide spiritual care at the EOL [31].

#### *Needs of Patients' Families at the EOL in ICU.*

The needs of family members of EOL patients admitted in ICU can be categorized into informational support, participation in decision making and psychological support. Lack of information is the most common complaint by the families of EOL patients. Hence, educational support regarding appropriate information is needed [27]. As the patients' families are not prepared regarding the patients prognosis, therefore the healthcare providers need to provide information gradually [31]. Information is needed to be shared timely, readily, straight, free of jargon and without any hurry [5]. For EOL decision making, patients' families need clear, direct, and consistent information [12]. Therefore, nurses play an important role in fostering communication, which will contribute in easing the environment of both families and patients.

The family participation in decision making is one of the important components at the EOL care and also the need of families of patients at the EOL [38]. In participation of making decisions, family members need to understand the conditions of the patient with an available option which include necessitates regarding receiving detail and truthful information [1, 36]. Participation in decision making held by a prompt family meeting is useful when the patient condition changes significantly [5]. Fulfilling the need of the family in decision making can help the patient to access appropriate services on time [55].

In addition, the family also needs psychological support because of the high level of stress. This stress can be reduced by communication with respect, sensitivity and compassion of the patient and family [11, 20, 53]. The family members also need psychological support from the nurses regarding their loss and grief's reactions [33]. A Family member of the patient at EOL may find difficulty to accept the situation and may feel comfort with being emotional and crying [29]. The family of the patient at EOL is needed to feel secure that the patient is receiving the best possible care [5]. Family members are very sensitive and seek for caring, kindness, and respect for the patient's and themselves. Understanding the family's needs during the EOL can improve patients family's

experiences and also improving a quality of care of the patient [44].

#### *Goal of Caring at the EOL in ICU.*

Several studies have defined the goal of the EOL care in ICUs. According to [16] described that the goal of EOL care is to achieve a peaceful death by reducing symptom distress and by using comfort care. A study by [16] defined the goal of the EOL care as to provide palliative care for anyone who is nearing death. In addition, another study by [19] reported that the goal of EOL care in the ICU is strongly associated with the quality of care provided by nurses. Quality care at the EOL will support the patient to survive and minimize suffering, as well as compassionately support the dying process [7].

#### *Nurses' Roles in Caring at the EOL in ICU.*

Based on the literature review, the roles of nurses in caring for patients at the EOL in ICU are an educator, advocator, collaborator, care-provider and supporter.

##### *Educator*

The nurse, as an educator, is commonly associated with the educational process at the EOL care to patients and their families. Education during end-of-life care is a requirement. This educator role focuses on giving information to the patients families about the patient's conditions [18]. According to [35] stated that nurses are responsible for educating patients families about options available at the EOL, as well as about specific care needs for their conditions. In addition, based on [4] reported that nurses educate patients families about symptom management, medication regimens and how to seek help out of hours.

##### *Advocator*

This is an essential aspect of a nursing professional. Advocator is considered to have fundamental value for the professional nurse [22]. According to [35] said that nurses can empower patients families to advocate for themselves by encouraging them to express their wishes to the healthcare team. A study by [24] reported that nurse as an advocator has an important role to communicate the information and feelings of patients families to the doctors.

##### *Collaborator*

The role of nurse as a collaborator is how nurses work in a team. Based on [43], collaboration is the condition of the nurses and physicians working together with cooperation and making decisions to fulfill plans for patient care. In addition, According to [33] wrote that collaboration among health professionals and families will be essential to critically ill

patients in guiding them when choosing health treatment. Based on [42] has explored current understanding about inter-professional collaborative client-centered practice, found that nurses were one of the professionals in a hospital who should collaborate in patient-centered care.

#### Care-provider

Nurse plays a vital component in providing comfort care. Lack of procedure to care can contribute to poor quality EOL care in ICU [23]. The continuity of care in which nurses take an interest in holistic care rather than treating the family and the condition as another routine task [15]. Valuing a proper time to care in which nurses consider the best fit of EOL care and prepare the patient's family member according to patients' dying and death [33]. Providing basic care at the EOL in the ICU can begin with comfort and frequent communication when possible with patients and families [54]. In providing care for patients at the EOL, nurses can do the basic nursing care such as bathing, hair care, mouth care, pressure area care, spiritual care, and the administration of analgesics, sedatives and mucolytic drugs [35]. Care for the body wherein the nurses still care for and are responsible for the patient until they leave [15].

#### Supporter

The nurses support is focused on the family. The family is the center of decision making on the condition of patients in end of life. Based on [7] stated that building relationships of trust and mutual respect with the family are an important part of the key success of care for patients in the EOL phase. Nurses are expected to have a meeting with the patient's family members since the beginning of the patient's admission into the ICU. The nurse's role in supportive family care is expected to create comfortable feelings for the patient's family members. Nurses help the patient's family members to understand the critical condition of the patient, and are able to provide information about the patient's progress. Nurses are expected to understand the expectations of the patient's family [53].

#### *Problems and Barriers in Caring at the EOL in ICU.*

Problems and barriers in caring at the EOL include communication, nurses knowledge and experience, environment, religious beliefs, cultural beliefs, and hospital/organizational policy.

#### Communication

Communication is a major problem in caring at the EOL. Lack of effective communication skills can become miscommunication among nurses, doctors, patients and patients' families. Good communication was vital in teamwork [27]. According to [25], communication skills are the basis to support the EOL experience. The style of

communication where accurate communication from nurses and doctors is valued to give the right decision [18]. Effective communication is a strong factor of the quality of care at the EOL, and that patient's value non-verbal communication such as sensitivity, presence, and warmth [10]. Good communication by nurses can help to promote coordination between health care teams and help to coordinate the treatment plan [35]. A lack of communication skills means missing the chance to facilitate interaction with patients and family [16].

A study by [2] on nurse-perceived barriers to effective communication regarding prognosis and optimal EOL care in the surgical ICU identified 34 barriers to optimal communication regarding prognosis. These 34 barriers can be summarized into four domains: logistics, clinician discomfort with discussing prognosis, inadequate skills and training, and fear of conflict. Good communication skills enable nurses to establish comfortable communication with the patient and his/her family, thus enhancing the quality of life for the patient in the hospital setting [40]. Communicating caring through touch is non-therapeutic communication that is able to provide comfort to the patient and build trust among nurses, patients and their family [33].

#### Nurses' Knowledge and Experience

Knowledge is the basis for the advancement in professionalism. According to [27] found that ICU nurses do not feel adequately prepared to give proficient EOL care. Based on [16] revealed that critical care nurses have an essential role in providing effective EOL care. It is noted that educational opportunities need to be provided for critical care nurses to increase their knowledge of planning and delivering EOL care [16]. The education and training wherein EOL care skills principally learnt through good and bad experiences and watching other members of staff [27]. Having no experience in dealing with patients at the EOL will influence nurses' lack of emotional control [17]. A lack of experience would be a barrier, so nurses who do not have adequate training would not feel confident in dealing with patients at the EOL [45].

#### Environment

The intensive care environment can affect the EOL care [23]. The busy environment of the ICU has been described as "not the ideal place" for dying patients and their families [27]. The function of the ICU is unsuitable for end-of-life care wherein the ICU environment is inappropriate for dying and gives priority to lifesaving [30]. Based on [18] mentioned that there is a lack of private rooms for providing EOL care because the ICU environment has not been designed for family-oriented care. This type of environment causes dying patients to be apart from their families thus creating further anxiety [16]. The ICU environment in which the family needs a private room separated from other patients [15] would be a barrier in caring for patients at the EOL.

### Religious belief

The nurses lacking religious belief will affect the perspective in caring for the EOL patients. Every religion has a belief in deciding the treatment in the end-of-life decision [49]. A lack of religious belief can cause people difficulty in understanding about the process of the end of life, and in some it may cause them to be in denial. Religious belief affects the experiences and creates peace in which patient's perceive and experience illness, including the end of life [26].

### Cultural beliefs

The differences of race and ethnicity would be cultural barriers in EOL care [9, 12]. The cultural beliefs of family members have an important role in influencing a peaceful death for the dying patient [33]. Cultural beliefs can significantly influence patient's reactions to their illnesses and the decisions they make [37]. Lack of cultural beliefs brings misunderstanding and make patient not feelings comfortable with end-of life care due to the contrast of culture belief between patient and care provides [2].

### Hospital/ organizational policy

Lack of understanding the hospital/ organizational policy can become a potential barrier in providing care for patients at the end of life [14]. Understanding of the hospital/ organizational policy will influence nurses in taking action and making the right decisions [51].

## IV. CONCLUSION

A patient at the EOL in ICU is the state of a patient in the last phase of the patient life or terminal disease and is supported by technology as provided in the ICU. In caring for patients at the EOL, nurses have to know the needs of the patients and their families especially in regards to physiological and emotional support. The goal of caring for patients at the EOL is to achieve a peaceful death with enhanced quality of care. Nurses have many important roles, such as: educator, advocator, collaborator, care-provider and supporter. Nurses can facilitate families in making good decisions and avoid miscommunication. The problems or barriers in EOL care in ICU included lack of knowledge and experience; environment; religious beliefs, cultural beliefs, and hospital/ organizational policy.

This literature review revealed the existing knowledge of nurses caring for patients at the EOL in ICU. The findings can be used to inform the nurses to understand and emphasize the significances and problems of caring at the EOL. The nurses can use the knowledge in this literature review to guide the quality of EOL care in ICU

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