

# INTENSIVE CARE UNIT NURSES EXPERIENCES OF PROVIDING END OF LIFE CARE

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## Abstract

**Introduction:** Critically ill patients and death are common in the intensive care unit. Evidence indicates problems that affect the quality of end of life care. Non-beneficial or palliative care is not explicitly supported by critical care policy. Many patients do not feel comfortable in the ICU. This situation can distress ICU nurses when providing end of life care.

**Aim:** The aim of this thesis was to describe ICU nurses' experiences of end of life care.

**Method:** A literature review was used and 16 recent scientific articles were included in this study. Findings were organized in Word files and data analysis was inspired by qualitative content analysis.

**Result:** The result emerged that many of ICU nurses' challenges may affect the quality of end of life care. This included incompatible ICU environment, different behaviours and cultures, feeling of unnecessary care and lack of the following; emotional support, involvement, procedures, standards and knowledge. On the other hand, it found that an effective teamwork might improve nurses' feelings in providing end of life care. Further, ICU nurses have significant roles in supporting dying patients and their families to be at peace, comfort and meet their needs. Yet, modifying dying patient's environment and allowing family presence in the ICU are important, as well as, single rooms are considered as an ideal place for dying patients and their families.

**Conclusion:** Many challenges of providing end of life care were presented. These challenges may affect the quality of end of life care, frustrate ICU nurses and may struggle with nursing care and the personality of nurses. On the other hand, ICU singles rooms were recommended in end of life care and there are some significant roles that may support dying patients and their families.

**Key words:** ICU, End of life care, Nurse's experiences

## Introduction

Critically ill patients and death are common in the ICU [1]. A large epidemiological study estimates that one in every five ICU patients dies [2]. Further study shows that two and a half million people die every year in the United States, 60 percent of them die in hospitals, half of this 60 percent die in ICU. These figures illustrate a situation that may be similar to other countries. The number of individuals dying in intensive care units has increased significantly [1]. The intensive care unit does not clearly increase the survivor rate, but futile medical interventions may prolong the dying process for patients who have a fatal condition [3].

Critically ill patients in an ICU commonly need life-saving treatments in order to prevent premature death [4]. It is considered that the ICU is a place for aggressive treatments to cure critically ill patients and death is a treatment failure. Furthermore, the appropriateness of the location of death may be affected by some factors such as gender, illness, age and socioeconomic status [5].

The number of patients in the ICU can increase rapidly; an ICU environment does not necessarily improve quality of life and patients' satisfaction. Thus, demands for appropriate ICU care for patients with terminal illnesses increases [6]. Moreover, most end of life care research generally is focused on improving quality of care in hospitals [7].

Many patients die in critical care settings with ongoing technological interventions rather than making use of palliative care or hospice facilities [5]. End of life care is an essential part of ICU care. However, evidence indicates that there are problematic issues with the quality of end of life care within ICU facilities. For instance, patients die with mild or acute pain and physicians often do not perceive patients' preferences. Families of ICU patients have symptoms of depression, anxiety and stress disorder [8]. Critically ill or dying patients experience feelings of loneliness, pain, anxiety and fear. Unconscious patients cannot communicate their wishes and needs [4, 9, 10].

Currently, non-beneficial or palliative care is not explicitly supported by critical care policy. This leaves critical care nurses without obvious guidelines to deal with dying patients [11, 12]. In this study the author focuses on describing ICU nurses' experiences about end of life care in two perspectives' ICU nurses' challenges and supporting dying patients and their families.

## Aim

The aim of this study was to describe ICU nurses' experiences of end of life care.

## Method

In order to have a thorough overview of ICU nurses' experiences of end of life care, a literature review was used. The search process was performed through both PubMed and CINAHL databases. Author performed MeSH terms and key words in accordance to the study's aim. Then, the chosen key words were linked by (AND) and searched between 2004 to 2014 publications in both PubMed and CINAHL; search process in databases was described (Tables 2, 3 and 4). The inclusion criteria for this study is academic database resources such as MEDLINE and CINAHL, nursing discipline, articles up to date or limited to last ten years and qualitative and quantitative original primary scientific articles.

## Data analysis

The selected articles were read several times and analyzed manually by the author. Then, findings that were relevant to the study's aim were digitally highlighted in word file. In the findings, two are as were focused on in accordance with the study aim. ICU nurses challenges of providing end of life care was highlighted in green colour and supporting dying patients and their families was highlighted in yellow colour. The findings were read again, then the coloured sections were divided and each colour copied into separate Word files. The coloured sections of text were organized in themes inspired by qualitative content analysis. Manifest content analyses were conducted. Manifest maintains the original thought and text without any change [13]. The author used the coloured sections of text, as meaning unit, then condensed the text and made an interpretation. The interpretation was done in close of the condensed meaning unit. The interpreted data were sorted into sub themes. The common sub themes were posted beside each other. Then the sub themes were sorted into the two themes, ICU nurses challenges of providing end of life care and supporting dying patient and their families (Table I). Copies of condensed meaning units were posted in the matrix. All these processes were conducted in Word files.

## Validity of this study

When the validity is complex Lincoln and Guba (1985) suggest that validity criteria is based on the credibility and authenticity as a mark for quality. To enhance credibility and authenticity of the study, the academic database resources MEDLINE and CINAHL were used. The quality of selected articles was assessed and classified based on the classification guidelines of Berg, Dencker [14] and Willman, Stoltz [15].

The data analysis was inspired by qualitative content analysis methodology and it was used for handling the text systematically. The author checked that the interpreted data, condensed meaning units, sub themes and themes were consistent in accordance with the meaning unit. Then, every part that was checked was underlined to assure that every part was done. The author conducted this procedure to assure that interpretations and understanding of the results were rigorous and reliable.

## Result

Of 59 recent articles, 12 articles were included in this study. Further, a reference list of the included articles was examined, for references that were relevant to the study aim, and four articles were added and a total of 16 articles that met the study criteria were included in this study. The majority of the selected articles were qualitative study (81%) and survey (19%).

The results of the study are organized into two main themes. The first theme is ICU nurses' challenges of providing end of life care while the second theme is supporting dying patients and their families in the ICU. The challenges are revealed in the following:

### **Intensive care unit environment incompatible with end of life care**

The ICU environment may affect nurses' provisions of end of life care due to many tasks and crowded situations [16]. Moreover, patient privacy may not be considered in the ICU structure, as evidenced by lack of individual curtains and beds that are very close to each other. When the patients are naked in the ICU and only wear a gown sheet, this may affect nurses' feeling toward patients such as a disrespect of patients' privacy and confidentiality of their information [17]. Further, the complexity of end of life care is not valued or understandable because the intensive curative culture may affect end of life care [18].

### **Conflict regarding goals of care**

The physicians order aggressive medical managements that can lead to exhaustion of the dying patients [19]. In addition, aggressive medical management without benefit may frustrate nurses [20]. Besides, many issues may lead to continued aggressive medical management such as waiting for family to come or poor prognosis [21].

Instead, physicians may not be quite sure of the prognosis and effectiveness of care [22]. Therefore, patient prognosis may cause conflicts or disagreements among different specialized physicians that may affect the provision of end of life care. Disagreement in prognosis is a big issue; it confuses family members due to ambiguity and fearfulness [23]. However, it was considered that the big challenges of providing end of life care are dying patients who suffering from a painful intervention and family members who refuse the poor prognosis [24]. As well as, the fact that some medications for pain relief like morphine can cause respiratory depression, thus nurses have the challenge to administer these medications [23].

Nurses expressed that they are confused when providing two different types of care for various results, such as end of life care and curative care. End of life care is used to meet patients and their families' wishes and curative care is provided to improve the patients well-being [20]. Moreover, physicians' standards are different, thus meaning end of life care is different among physicians [25, 26].

### **Lack of involvement**

Nurses usually have close contact with patients and their families but the nurses on the other hand often are not involved in the medical decision-making process, thus nurses continually expressed how important it was for them to be involved in the decision-making and communicating with family members [23]. However, nurses claimed that it is important to be more involved in the decision-making process because, nurses know the patients better than other professionals [27].

### **Different cultures**

Different cultures of health care providers and patients may affect their feelings and the provision of end of life care. Thus, different cultures may lead to misunderstanding due to different beliefs and behaviours [26]. Moreover, nurses considered the patients belief about dying and death to be a large barrier to providing end of life care [22].

Communication with dying patients or their families, who have a different language, may affect nurses in providing end of life care [22]. Further, miscommunication between nurses and medical staff may affect the relationship with patients' families particularly when providing different opinions about plan of care and prognosis [21].

However, physicians often do not speak to the patient's families or they try to avoid the situation and thus, that can affect the relationship between physicians and families and it affects the end of life care [19, 24]. Yet, poor communication of physicians affects the end of life care and does not consider the dying patients' dignity [26].

### **Lack of knowledge or training**

Since no training or resources are available, nurses do not know how to improve end of life care [26]. Novice nurses felt the fear and challenge of dealing with dying, death and patient's family. Novice nurses were not well prepared; they need training or support from their colleagues in order to be ready [19, 28]. Moreover, lack of experience and knowledge of providing end of life care are considered a big challenge [28]. However, it was noted that some factors might affect end of life care, such as workload and lack of palliative care services (Aslakson et al., 2012).

Families' lack of medical knowledge is considered a barrier for nurses to provide end of life care [23]. However, patients' families are rarely considered, therefore nurses should be taking care of patients' families socially, emotionally, and spiritually [28].

Lack of policies or protocols may affect the provision of end of life care. Junior nurses are supported by nursing leaders; however, this is not enough to deal with the complexity of end of life care [18]. When lack of protocols or guidelines for end of life care is expressed, more education for nurses to improve end of life care and how to communicate with patients' families is required [23].

### **Lack of emotional support**

ICU nurses' emotions are affected due to daily basis exposure to critically ill patients [18]. Nurses, who provide end of life care are suffering emotionally, it may affect their spirit and feelings of hopelessness and depression. In addition, it was difficult for nurses to deal with family members who deny and refuse the reality of a patient's condition, this situation added to nurses' emotional stress. Further, nurses' emotions may be influenced by patients' conditions, such as level of alertness, age, duration of care and possibility of becoming an organ donor [29].

Nurses considered that the anxious families' reaction might affect their provision of end of life care and their emotions [29]. Further, the biggest challenge of providing end of life care is the patient's family and friends who frequently ask nurses for an update of the situation rather than a particular patient's partner. Usually dying patient's families are sad due to their patients' conditions and that may lead them to ask nurses continuously [21].

### **Feeling of unnecessary care**

Nurses often felt that when an intensive therapy should not be offered, the caring may be considered as futile [27]. The priority of care is provided for patients who may survive, that may affect the provision of end of life care [29]. Further, when the patient dies, the health care staff often considered the situation as unnecessary care because they feel that the care is ineffective [29]. However, nurses frequently mention unnecessary care as the most challenging part of ICU care [23].

### **Supporting dying patient in the ICU**

The second theme of this study was supporting dying patients and their families in the intensive care unit. These findings of support emerged with the following:

#### **Nurses' feelings of providing end of life care**

In order to support dying patients and their families, nurses need to be emotionally ready. Nurses' feelings may be improved due to having palliative care instead of curative care [23]. In addition, honouring self may improve nurses' feelings of providing end of life care [16]. However, the intimacy between nurses and team members is needed because it may create a feeling of security and safety among nurses [20].

#### **Comfortable care**

Nurses felt that they are responsible of providing care, comfort and protection to patients and their families. Further, pain relief and symptom management were considered important parts of end of life care. Besides, nurses are required to consider emotional and physical peace. Emotional peace may be achieved by meeting the patients' and families wishes and spiritual needs [20]. The provision of comfortable care includes taking care of hair, mouth, bathing, prevent pressure ulcer, provide spiritual support and administering sedation, analgesic and antimucolytics [18]. Moreover, nurses stated that they desired to maintain the comfort of dying patients [23].

Nurses need to offer themselves sincerely and give dying patients and their families certain attention. Moreover, touch is useful to communicate gentle care, sincerity, good wishes and warmth to dying patients and their families [16]. On the other hand, humour may be used in some sad situations [23].

### **Maintaining dying patients' dignity**

Protecting dignity for dying patients includes physical care, privacy maintained, comfort and quality care [20]. Patients and families have the right to information and truth as well as involvement in the decision-making process [17]. Moreover, dying patients need to have a good look such as hair combed, hands are out and smell nice [30]. However, nurses are responsible to be patient advocates, such as maintaining the legal position and safety provisions for patients [30].

It was essential to maintain patient's dignity after death and provide care with high respect [20]. Further, nurses considered the deceased as a human being, thus care such as cleaning, dressing the body and respecting the deceased is continued [16].

### **Care of dying patient's family**

Caring for patient's family was noted as a significant part of care for dying patients [20]. Nurses must frequently inform family members about the patient's health care situation and assure their understanding [31]. Family members desire accurate and continued communication. However, it is felt that building a good relationship with family is important because it may lead the family to trust in nurses for information [23, 25].

Supporting family's religious beliefs must be considered because it may help the family to access their spiritual value [28]. When a patient is dead, nurses should provide a peaceful bedside scene and private place for a patient's family to cry [24]. Moreover, it was thought that caring of the dying patient's family was important. The patient's family needs to be supported and educated about moving from aggressive to comfortable care [18]. However, in order to understand the family's thinking, it is important to listen and realise what a family's reflection is. Further, a systematic dialogue with the family members and avoidance of giving uncertain expectation were recommended [28].

Nurses, it was noted, have a desire for good memories for the family in the patient's final moment [23]. Therefore, nurses may support in creating memories for family members to keep, such as having a patient's hand print, gathering a patient's hair, bands and identity [18].

### **Patient's environment in the intensive care unit**

Nurses thought that when the ICU is not created for dying patients, single rooms are required because it may help nurses to dignify death. Single rooms are an ideal environment for dying patients because they provide privacy, space and quietness. It helps to reduce patient and family exposure to others who are dying or have

died [18, 20]. Yet, nurses found that a familiar and calm environment may support dying patients to be at peace [31].

Having a designated contact with one of the family members is supportive [21]. Nurses are needed to contact a patient's family to visit and spend time with their patients [16]. Further, it is important to support the family presence because family members may provide care and improve the dying patient's emotion [19, 24]. However, it is found that nurses are responsible for assuring that patients are not dying alone and provide emotional support particularly when family is not present [20, 31].

Nurses may modify the patient's bedside environment from intensive care to be more homely, such as removing clinical equipment, changing hospital bed sheets with different colours, dimming the light and putting up pictures [18]. Moreover, providing temporary space around dying patients is significant. It provides chances for family members, relatives and friends to be with their dying patient [16].

## Discussion

The result of this literature review has emerged insights of ICU nurses' experiences about end of life care in both: ICU nurses' challenges of providing end of life care and supporting dying patients and their families.

### Intensive care unit nurses' challenges of providing end of life care

The ICU nurses' experiences of providing end of life care showed many obstacles that may affect the quality of end of life care. The result indicated that providing end of life care might be a struggle for nursing care and the personality of nurses. Many challenges of providing end of life care were identified. All these challenges may increase nurses' frustrations.

Because, non-technical or palliative care is not explicitly supported by critical care policy, critical care nurses are left without obvious guidelines to deal with dying patients [11, 12]. The result indicated a need for a particular protocol or guideline for end of life care. It is evidenced by Ranse, Yates [18] and Espinosa, Young [23]; they stated a lack of policies or protocols of providing end of life care. Earlier, three studies indicated a similar need for more end of life care education, standardised procedures and protocols [10, 32, 33]. When a basic guideline or protocol was not available, nurses may provide end of life care based on their experiences. This may affect the quality of end of life care. Moreover, the author suggested that guidelines or protocols are needed to guide the provision of end of life care in the ICU. For instance palliative care approach, may help nurses to get confidence and guide them in how to support dying patients and their families.

Twigg and Lynn [34] stated that many nursing colleges include some end of life care in the course's content. Further, the result indicated that lack of knowledge and

experiences are considered to be a big challenge to providing end of life care [28]. However, nurses usually contact dying patients and their families more than other professions [35]. Therefore, the author thought that not only are the guidelines or protocols needed but also that nurses must be well educated, prepared and trained about end of life care or palliative care approach. The nurses may face dying or death in any hospital setting, therefore, end of life care courses must be well involved in the nursing curricula in order to improve the quality of end of life care.

The result illustrated that both providing aggressive medical management without benefit and poor prognosis may frustrate nurses. Nurses may face emotional distress when providing care in these two situations, as well as it may obstruct nurses' ability of providing optimum care. However, Espinosa, Young [23] mentioned that nurses usually have close contact with dying patients and their families but are not involved in the decision-making process. The author suggested that physicians must share with nurses and other staff the decision-making responsibilities because nurses know the dying patients and their families more than other professions.

Further, it is found that miscommunication between nurses and medical staff may affect the relationship with patients' families particularly when providing different opinions about plan of care and prognosis [21]. Nurses must be more involved in the decision-making process in order to avoid different plans and improve end of life care.

Effective teamwork in the ICU may help to avoid different opinions about the plan and increase the consensus among team members. In teamwork, different staff will perform decision-making process and that may improve their communication and increase their satisfaction and awareness of the process. The teamwork may help nurses to cope with end of life care and reduce their emotional distress. The result indicated that the intimacy between nurses and teamwork environment is needed because it may create a feeling of security and safety [20]. Furthermore, Hansson, Foldevi [36] mentioned that the health care team includes different professions who plan, coordinate and provide interventions. From the teamwork, a holistic view of patients' situations may emerge. Yet, thinking and discussing patients and their family members' situations in the team help to view patients from a holistic perspective [37]. The author suggested that it is very important to have effective teamwork in the ICU and include palliative care because it leads to perform thoughtful decision-making from a holistic point of view. Effective teamwork may help to provide optimum care and meet the needs of dying patients and their families.

Wu, Chen [6] noted that the ICU environment does not improve the quality of life and patients' satisfaction. Further, the findings indicated that the ICU environment might affect nurses' provision of end of life care due to many tasks and crowded situations [16]. Patient's privacy was not considered in the ICU environment [17]. However,

it is important to support the family's presence because family members may provide care and improve dying patient's emotions [19, 24]. Therefore, single rooms are an ideal place because they provide space, privacy, quietness and reduce the exposure to other deaths [18, 20]. The author suggested that the ICU environment must be well structured with particular single rooms for dying patients. Single rooms may help to maintain space for family presence and quietness. It also allows dying patients to be with their families, relatives and friends. Single rooms may help nurses to provide end of life care effectively and meet dying patients' and their families' need.

### Supporting dying patients and their families

Intensive care unit nurses are required to assess and evaluate patients and their families' needs by using holistic care [38]. The result of this study illustrated nurses' roles in supporting dying patients and their families. Nurses have a main role that may maintain dignity and peace for dying patients and their families in the ICU. Firstly, nurses' roles toward dying patients include providing comfort care, emotional and physical peace, pain relief, symptoms management, spiritual support, privacy, calmness, space for family and friends, maintenance of safety and being a patient advocate. In addition, McCallum and McConigley [20] stated that emotional peace may be achieved by meeting the dying patients' and their families' wishes and spiritual needs.

Secondly, nurses' roles toward dying patients' families include building a good relationship, providing dialogue, listening and realising their thinking, providing spiritual support, frequently informing family members about their dying patients situations, providing good memories, educating them about the move from aggressive to comfort care and providing a peaceful and private bedside scene. The author suggested that all these cares above might help nurses to support dying patients' families and meet their needs.

Bersten and Soni [39] stated that the responsibilities of nurses are different among health care systems and hospitals, but the most important factors may consist of flexibility and improvement of care. Thus, the author suggested that ICU nurses needed to be flexible and improving their care by following their guidelines and evidence-based resources. Moreover, nurses must consider that dying patients' quality of life is different because quality of life is individualized. Thus, flexibility and improvement are needed, as well as, thinking and discussing the dying patients and their families' situations in the team. In effective teamwork, ICU staff may gain knowledge from each other and that support may improve the quality of end of life care.

### Conclusion

This study set out to describe the ICU nurses' experiences about end of life care in two areas. Firstly, ICU nurses' challenges of providing end of life care may affect the

quality of care. The lack of knowledge, protocols, procedure and ineffective teamwork regarding end of life care may frustrate ICU nurses. The provision of end of life care may affect nurses and nursing care. The author recommends that having courses about end of life care or obvious guidelines like palliative care approach is essential, as well as, integration of effective teamwork regarding end of life care in the ICU., particularly when it found that nurses have significant roles in supporting dying patients and their families. Moreover, it was stated that single rooms were recommended in the ICU. Further studies are needed to clarify issues concerning end of life care in the ICU and include the dying patients' perspective.

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