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Critical Care Nurses' Involvement and Barriers in Palliative Care

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Abstract

Palliative care has identified the need for integrated components of comprehensive, intensive care for all critically ill patients concerning patient prognosis and family welfare. Critical care nurses are essential in increasing application systems integration, including decision-making with family members regarding care goals. The objectives are to determine the frequency of nurses' participation in palliative care (PC) and to identify the barriers nurses perceive to their involvement in palliative care. Convenience sampling was conducted, samples from 157 nurses working in the critical care unit at the public hospital using a self-administered questionnaire. The findings reflect the deep desire of critical care nurses to be involved in palliative care in ICUs in this part of the world. It will help to strengthen the practice of multidisciplinary PC treatment in the Critical Care Unit. The result of the study is intended to be shared knowledge that will lead to changes in the treatment of dying in all of these countries.

Keywords: Critical Care Nurses, Palliative Care, Barriers, Involvements, Public Hospital

Introduction

In Malaysia, when a patient is admitted to the hospital, family members are often seen by their side. Especially if the patient is in a critical condition, they will be on the patient's side. Despite working together to care for patients, family members will experience depression when dealing with crisis situations and unstable patients (Penrod et al., 2012). Nurses are people who always remain close to their patients and their families. When a patient is able to take his or her final breath, proper care can be given if the nurse and family member got along well.

Palliative care focuses on holistic therapy, including psychological and spiritual support, symptom control, care plan treatment, and preparing for death. Palliative care faces a tremendous problem when it comes to ensuring that people die with dignity. This may be essential for the full implementation of palliative principles and end-of-life care techniques in

intensive care units (Becker et al., 2018). Palliative treatment in intensive care units leads to substandard care. When discussing the prognosis of a patient who has been treated, physicians and nurses, in particular, face a tough scenario.

In a study conducted by Hussin and Hashim (2017) stated that communication between healthcare providers and family members especially nurses as essential aspect for the patient's condition need. In a situation involving end-of-life care in the intensive care unit, the family members must be informed of the patient's prognosis and care. One of the challenges faced by nurses in Malaysia is the absence of palliative care in the intensive care unit. The nurse's workload prevented her from providing palliative care in the intensive care unit. Staff shortage forces nurses to care for two patients, whereas ICU nurses should have a ratio of 1:1. (nurses: patients).

PC management improves the quality of life of patients and their families afflicted with a life-threatening illness through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other physical, psychological, and spiritual issues. Scheunemann et al (2019) conducted a study titled "Clinician-Family Communication Regarding Patients' Values and Preferences in Intensive Care Units" The audio study was recorded in the critical care unit's sitting room during family conferences involving family members, physicians, and nurses. The research on audio recorders is excellent. Studies conducted during family conference activities demonstrate the significance of nurse participation in this discussion.

Cc et al (2017) demonstrated that nurses with greater experience and proficiency had higher scores and a more favourable perception of family communication than less experienced nurses. The author concludes that nurses with greater clinical skills communicate effectively during end-of-life (EOL) care. There are additional studies conducted by additional authors. They discovered that inexperienced or junior nurses in critical care units had little or no ability to identify patients and family members during EOL situations. Experience influences a nurse's attitude and behaviour. The nurse's knowledge enables her to care for EOL patients.

Palliative care is medical care that emphasizes patients in critical situations to help improve service quality. The World Health Organization (WHO) says palliative care is an approach to improving patients' and experts' quality of life. Many reports had obtained in connection with the assessment of palliative care to measure treatment effectiveness. Mun et al (2016) stated that among the outcomes is the length of stay (LOS) rate that reduced hospital readings for hospitals and ICUs. Studies show that early detection of the goal of care and early treatment helps to positively impact patients by reducing the potential for ICU admission. In reducing LOS, critical care and hospitals implement palliative care structure and quality improvement programs in critical care units.
Nurses are individuals who are with the patient while they are in critical care. Nurses are the ones who often contribute to pain management for 24 hours patients need treatment. Therefore nurses need knowledge on pain management. Poor nurses are due to a lack of education and lack of skills. In a paper "To explore nurses' knowledge and barriers regarding pain management in intensive care units" by Wang & Tsai (2010), they conducted a study on barrier-related nurses in palliative care. The quality of care depends on the knowledge and skill of a nurse. This study was conducted on a group of nurses in China. Only one-third of

nurses in the critical care unit showed moderate pain knowledge management before knowledge enhancement activities were conducted in a cross-sectional study. The results indicate that nurses who provide palliative care when receiving instructions from a medical professional are the main barriers identified. The knowledge that nurses have in the unit is based on education level. Chong & Khalid (2014), in their study, concludes that barriers to palliative care management. In a survey conducted in several hospitals in Malaysia, there is a lack of knowledge and understanding of palliative care among health care providers. Focus on training and supportive policy is need to enhance the quality of palliative care services in Malaysia. Approximately half of the pediatricians and about one-fourth of nurses in this study agreed that they had only basic palliative care knowledge.

Apart from explaining the importance of palliative care to critically ill patients, palliative care was not implemented only at end-of-life care (EOL). The main barriers to palliative care for critically ill patients are the misunderstanding of care between health care providers and family members of the patient. Lack of experience, knowledge, and education need to be addressed to improve the quality of critical care for patients, especially in palliative care. Knowledge about palliative care is an additional area that requires injections to ensure professional care. In Malaysia itself, the emphasis on palliative care is not taken seriously, especially for patients in critical care.

Methodology

In a quantitative study, a non-experimental and descriptive cross-sectional study was conducted to identify nurses' involvement and barrier in palliative care at critical care units. The study was conducted at the General Intensive Care Unit (GICU), Coronary Care Unit (CCU), Paediatric Intensive Care Unit (PICU) and Neuro Intensive Care Unit (NICU) of Penang General Hospital.

Originally the population for this study was 178 trained nurses (N = 178). However, the population during data collection has been reduced. This is due to the staff deployment carried out for the entire hospital as a result of the Covid-19 pandemic crisis. The total respondants is 157 trained nurses.

Researchers use convenience sampling in data collection to facilitate better data collection. It is a technique where subjects are selected because of their convenient accessibility and non-probability sampling. The sample selected is a trained nurse and is in the critical care unit only.

A self-administered structured questionnaire adapted from the research paper: "ICU bedside nurses, involvement in Palliative Care Communication: A Multicentre Survey" (Anderson et al, 2016). This questionnaire containing 2 parts with 37 questions. Part 1 contains 5 questions on demographic data, personal factor and education level and working-related factor. Part 2 contains 3 sections which;

i. Section B: consist of 7 questions on the frequency of nurses' participation in palliative care that used Likert-type scales; never, rarely, sometimes, and often.
ii. Section C: consist of 11 questions that assessed the respondents' level of confidence in performing palliative nursing. Level of confidence measured with 1 is for not confident, 2: somewhat confidence, 3: confidence and 4: very confident. The level of

confidence were rated into ''very confident'' versus ''not confident,'' ''somewhat confident,''.

iii. Section D: consist of 14 questions of the barriers nurses perceived to their involvement in palliative care that measured with 5 points of Likert Scale of strongly disagree, disagree, neutral, agree, and strongly agree. The level of barrier were determine as ''strongly agree'' and ''agree'' versus ''strongly disagree'' ''disagree,'' and ''neutral''.

Validation of the questionnaires was done by using back to a back-translation. The original English version of the questionnaire was initially translated into Malaysia's national language, which is the Malay language, then the draft of the translation was translated back into the English language by Institut Terjemahan dan Buku Malaysia (ITBM). Meanwhile, the pilot study was conducted for 30 participants who are are undergoing advance diploma course from various critical care units to test the reliability of the questionnaire. Chronbach's alpha coefficients were 0.80, therefore, the instrument is considered reliable. As a general rule the Chrombach's alpha 0.6 – 0.7 indicates an acceptable level of reliability (Manerikar & Manerikar, 2015).

Prior to the data collection, this study was approved by the Ethics Committee of Universiti Tekhnologi MARA (UiTM) and register under National Medical Research Register (NMRR) through Clinical Research Centre (CRC). Questionnaires were put into an envelope with descriptions of related studies, including the study's purpose and informed consent to the participant. The envelope is distributed to the sister critical care unit (GICU, CCU, NICU and PICU). To ensure the participant's confidentiality, they were instructed to seal the complete questionnaire in the sealed envelope before handing it to the researcher. Each form and participant is marked with a numerical code to maintain confidentiality. One hundred fifty-seven questionnaires were distributed to four critical care units (GICU, CCU, NICU and PICU) and returned to the researcher.

All data collected was first collected and gathered in Microsoft Excel and then coded and analysed using SPSS (Statistical Package for Social Science) Version 24.0. Descriptive statistic was used to analyse the frequency of nurses' participation in palliative care and the barriers nurses perceived to their involvement in palliative care. Chi-square was used to determine the barriers nurses perceived to their involvement in palliative care between the intensive care setting.

Results

The socio-demographic characteristics of the critical care nurses were showed in frequency and percentage and were present in table 1. Hundred fifty-seven nurses (n=157) were eligible to take part in this study. They are consisting of critical care nurses working in GICU, CCU, NICU and PICU. In this study, a total of 157 nurses were distributed questionnaires completed and returned a response rate of 100%.

In the table showed that 78 (49.7%) of the participants' age was within range of 20 to 30 years, 75 (47.8%) age within 31 to 40 years while only 4 (2.5%) age within 41 to 50 years. Most of them were female (n: 140; 89.2%) while 17(10.8%) were male nurses. The majority of them had diploma in nursing (n: 153; 97.5%) while there 4 (2.5%) nurses who had degree in nursing.

More than half had 1 to 9 years experiences in nursing (n: 105; 66.9%), 49 (31.2%) had working experiences between 10 to 19 years, while 3 (1.9%) of the nurses had experiences in the nursing profession between 20 – 29 years. As their experiences working in intensive unit; 59 (37.6%) of the participant had one-year experience in critical care nursing; 73 (46.5%) had 2 years working experience, 19 (12.1%) had 3 years working experience; 5 (3.2%) had 4 years working experience while only 1 (0.6%) had6 years working experience in intensive care unit. Half of the participants involved in this study were from GICU (n: 80; 51.0%), 26 (16.6%) of them were from PICU and 26 (16.6%) were from CCU and 25 (15.8%) were from NICU.

Table 1
Characteristics of the Respondents (n=157)

Variables	Frequency	Percentage
Age (years old)		
20-30	78	49.7
31-40	75	47.8
41-50	4	2.5
Gender		
Female	140	89.2
Male	17	10.8
Education level		
Diploma	153	97.5
Degree	4	2.5
Year in Nursing (years)		
1-9	105	66.9
10-19	49	31.2
20-29	3	1.9
Year in ICU (years)		
1	59	37.6
2	73	46.5
3	19	12.1
4	5	3.2
5	1	0 .6
Working Area		
PICU	26	16.6
CCU	26	16.6
NICU	25	15.8
GICU	80	51.0

The frequency of nurse involvement in different types of palliative care varied widely (Table 4.3). Many reported ''often'' engaging in discussing discuss with family patient's goal of care (n: 42; 26.8%) followed by discuss with physician prognosis of the patient (n: 38; 24.2%). While only 22 (14%) of the participants often consult with physicians regarding palliative care, 26 (16.6%) discuss with family prognosis of the patient and 26 (16.6%) participate in palliative care consultation with family.

Around 30 (19.1%) of the participants revealed that they never attended family meetings; 30 (19.1%) of them never participated in palliative care consultation with family and 16 (10.2%) of them had never consulted with physicians regarding palliative care.

Table 2
The Frequency of Nurses' Participation in Palliative Care.

Variables	Never	Rarely	Sometimes	Often
Did you discuss with physician patient's goal of care?	12 (7.6)	23 (14.6)	91 (58.0)	31 (19.7)
Did you discus with family patient's goal of care?	9 (5.7)	31 (19.7)	79 (50.3)	38 (24.2)
Do you discuss with physician prognosis of the patient?	7 (4.5)	42 (26.8)	66 (42.0)	42 (26.8)
Do you discuss with family prognosis of the patient?	12 (7.6)	45 (28.7)	74 (47.1)	26 (16.6)
Did you consult with physicians regarding palliative care?	16 (10.2)	57 (36.2)	62 (39.5)	22 (14.0)
Did you attend family meetings?	30 (19.1)	48 (30.6)	49 (31.2)	30 (19.1)
Did you participate in palliative care consultation with family?	26 (16.6)	37 (23.6)	68 (43.3)	26 (16.6)

Table 3 portrayed the barriers nurses perceived to their involvement in palliative care discussions. There were five choice of nurses perceived to their involvement in palliative care discussions; strongly disagree, disagree, neutral, agree and strongly agree.

Most of the participants strongly agreed and agreed that they needed more training in palliative care (n: 132; 84.1%); 43.3% (n: 68) of them agreed and strongly agreed that the physicians did not ask for their perspective in palliative care; 39.5% (n: 62) agreed and strongly agreed that their involvement in palliative care discussion was emotionally exhausted while 38.9% (n: 61) agreed and strongly agreed that it was hard to get coverage for their patients, so they can attend family meeting; as the most perceived barrier to their involvement in palliative care discussions.

However, most of them were disagreed (strongly disagreed, disagreed and neutral) the statement of they do not have time for bedside discussions of prognosis (n: 146; 93.0%); their managers do not support their involvement in the discussions (n: 141; 89.8%) and the physicians have negative reaction to palliative care (n: 136; 86.6%) as their perceived barrier to their involvement in palliative care discussions.

Table 3
The barriers nurses perceived to their involvement in palliative care

No	Barriers nurses perceived to their involvement in palliative care discussions	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
24	I need more training in palliative care	1 (0.6)	1 (0.6)	23 (14.6)	99 (63.1)	33 (21.0)
25	Physicians do not ask for my perspective in palliative care	2 (1.3)	19 (12.1)	68 (43.3)	52 (33.1)	16 (10.2)
26	Involve in palliative care discussion is emotionally exhausted	12 (7.6)	31 (19.7)	52 (33.1)	57 (36.3)	5 (3.2)
27	I am unsure of my role in discussing prognosis in palliative care	10 (6.4)	47 (29.9)	63 (40.1)	33 (21.0)	4 (2.5)
28	I am not sure how to bring up the prognosis and goals of care with families	7 (4.5)	52 (33.1)	60 (38.2)	35 (22.3)	3 (1.9)
29	I do not feel that physicians support my involvement in these discussion	4 (2.5)	77 (49.0)	36 (22.9)	37 (23.6)	3 (1.9)
30	Physicians have negative reaction to palliative care	25 (15.9)	76 (48.4)	35 (22.3)	18 (11.5)	3 (1.9)
31	Families have negative reaction to palliative care	11 (7.0)	59 (37.6)	57 (36.3)	27 (17.2)	3 (1.9)
32	It is hard to get coverage for my patients, so I can attend family meeting	3 (1.9)	38 (24.2)	56 (35.7)	55 (35.0)	5 (3.2)
33	I am not invited to family meeting	9 (5.7)	47 (29.9)	58 (36.9)	33 (21.0)	10 (6.4)
34	I do not have time to attend family meeting	15 (9.6)	73 (46.5)	37 (23.6)	30 (19.1)	2 (1.3)
35	I do not know when and where family meeting occurring	25 (15.3)	59 (37.6)	46 (29.3)	25 (15.9)	3 (1.9)
36	I do not have time for bedside discussions of prognosis	24 (15.3)	82 (52.2)	40 (25.5)	11 (7.0)	0
37	My managers do not support my involvement in these discussions	27 (17.2)	66 (42.0)	48 (30.6)	14 (8.9)	2 (1.3)

Discussion

In this research finding revealed that most respondents reported that their engagement in discussions of prognosis, goals of care with physician and family, and participate in palliative care consultation with family was very important to the quality of patient care. The involvement of nurses in family discussion and prognosis is very helpful in increasing the emotional strength and acceptance of family members to the condition of loved ones. Nurses are individuals who are closest to the patient and have the trust of family members in end-of-life care situations.

This research finding result is similar to (Anderson et al., 2016; Festic et al., 2012; Fox, 2014). The authors further stressed that this engagement had provided them on specific roles that the critical care nurses can play in discussions of prognosis, goals of care, and palliative care as a result of their training and physical proximity to patients. Because of the nurses' proximity and constancy at the bedside, they are also key conveyors of important family dynamics that influence decision making such as individual and group identities, family relationships, moral convictions, values, cultural beliefs, and spiritual context. The authors further illustrated these roles are coordinating communication between family and clinicians, identifying information gaps and needs of the family, providing emotional support, and reinforcing and clarifying information about prognosis and treatments.

Discussions conducted with family members involve patient care, patient prognosis as well as treatment that given to the patient as long as the patient is in the critical care unit. The nurse is an important individual as a reference for family members who need a clearer explanation after receiving the explanation from the physician. The nurse is also the one who always accompanies and is by the patient as long as the patient receives treatment in the critical care unit. Therefore, they are the most appropriate individuals to participate in discussions with the family and the physician. This is because they are more aware of the patient's current situation and condition.

Statistics also shown few nurses never attended family meeting and never participate in palliative care consultation with the family. The most prominently cited obstacles to the participation of nurse participants were inadequate nurse education, doctors not requiring nursing participation, and the emotional toll of participation in discussions.

Jarrad & Hammad (2020), discussed and summarized that some of the predictable examples of factors that could play a role in the manifestation of these problems and more are: shortages of staff, frequent newcomers needing supervision and training, lack of management support, inter-personnel conflicts, stressful accreditation procedures, penalty systems, lack of job protection and noticeable lack of personal achievement. In addition, there are high patient acuities, suffering and mortality, hopelessness, lack of control, family abuse, high sense of scrutiny, high workloads in the shadows of lack of satisfying atmosphere and lack of rest and leisure activities for compensation and stress ventilation.

Discussions regarding the purpose of treating these patients are very necessary to ensure that family members are mindful of the treatment and preparing to care for their loved ones. This will help to launch recovery from the patient's own family members with constructive engagement.

Another objective of this study was to identify the barriers nurses perceive to their involvement in palliative care. The result described that more than half participants strongly agreed and agreed that they needed more training in palliative care. The key justification for investing in training in palliative care is to ensure that clients and families receive quality palliative care while improving voluntary experience.

In a study by Horey et al (2015), they examine the effect of preparation and support for volunteers in palliative care, on clients of palliative care programs, and on volunteers themselves. It also sought to raise awareness of international differences in the use of volunteers and to identify the existence of any reliable tools to measure effectiveness or determine impact .The clause Support For Palliative Care Volunteers can have major resource consequences for palliative care organizations, and as volunteers can significantly expand the scope of a program;

Most of the participants strongly agreed and agreed that their involvement in palliative care discussion was emotionally exhausted and that it was hard to get coverage for their patients, so they can attend family meeting.
Nursing is known as a stressful job since it is associated with complex job demands and needs, and high expectations, excessive responsibility, and minimal authority have been identifed as

the main stressors (Jacobs & Lourens, 2016). Work stress is an important cause of nursing job dissatisfaction and may affect choices to stay at work or leave. Palliative care nurses often encounter stressful circumstances linked to death and dying in their caring position. Burnout or loads of work and the task of work are potential stressors for nurses in palliative care. In this case, critical care nurses say that they are unable to attend family meetings and engage in palliative care because they have little time to attend.

The findings were in congruence with results of previous studies by Peters et al (2012) Stress was associated with manpower shortages and the deterioration of support structures in critical care unit. Job stress for critical care nurses in PC treatment was due to busy times with less manageable workloads, shift work, and shortages of workers in 564 England, with the relief of staff with additional demands. These challenges have been stressors for nurses in Canada, too. Few research on the views of palliative care nurses in Australia have been performed also.

In this study, the participants also agreed and strongly agreed that the physicians did not ask for their perspective in palliative care. Another quality indicator analysis by De Roo et al (2013) enhancement across five European countries found that the barrier in PC was influenced by the characteristics of individual professionals or education level with experience and motivation, and also organizational background, such as leadership, culture of change, team environment, resources (including time) and facilities. Main challenges included modifications inconsistent with the philosophy of local treatment and lack of expertise.

The majority of participants disagreed (strongly disagreed, disagreed, and neutral) the statement of their managers do not support their involvement in the discussions and the physicians have a negative reaction to palliative care. Routine and a role of family discussion activities in the Critical Care Unit in Malaysia is the involvement of the in-charge nurse of the patient in the family meeting. This is because important information about the patient throughout receiving treatment is known by the in-charge nurse.

Unfortunately, several recent non-US qualitative studies by Dy et al (2017) have examined and engaged in perceptions of obstacles and facilitators of quality measurement, several of which correlate well to the content of this survey and support the validity of its content. The quality assessment study found that the primary perceived facilitators were organizations (leadership and resources, including time) and characteristics of individuals (education level and expertise).

Conclusion

The findings reflect the deep desire of critical care nurses to be involved in palliative care in ICUs in this part of the world. It will help to strengthen the practice of multidisciplinary PC treatment in the Critical Care Unit. Critical care nurses may also facilitate palliative care by collaborating with other health care providers to define exact unit requirements for patient referral and by ensuring that appropriate patients are referred to. Palliative care is more likely to be incorporated into critical care if nurses provide guidance to the critical care team on palliative care's benefits and regularly advocate for it. Critical care nurses will become champions of palliative care because they can do all these things regularly.

In order to fully understand how these variables function in palliative care environments, further research is needed. Importantly, employers and managers have a vital role to play in providing palliative care nurses with education and training to promote their growth and to help reduce their vulnerability and the effect of occupational stress.

This study's findings indicate that the principles of critical care nurse engagement in PC conversations and decisions remain unclear, indicating a need to strengthen coordination between health care staff, patients, and their families. Aspects of right treatment, the role played by families, and ethical questions were all raised. The study's result is intended to be shared knowledge that will lead to changes in death treatment in all of these countries.

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