

NURSES' KNOWLEDGE ABOUT PALLIATIVE CARE IN AN INTENSIVE CARE UNIT IN SAUDI ARABIA

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Abstract

Background: Most patients die in hospital settings either in intensive care unit (ICU), emergency department (ED) or other departments. In Saudi Arabia, approximately 23,000 persons are diagnosed with cancer every year. According to the World Health Organization (WHO), palliative care is a holistic activity that involves physical, psychosocial and spiritual human needs to enhance quality of life for patients and their families. Palliative care is an essential aspect to be applied for patients with chronic diseases to improve their quality of life. Earlier studies have shown that physicians, nurses and nurse assistants who work in long-term care settings lack the knowledge to enforce palliative care principles due to lack of education. According to the WHO, health care professionals should be educated and trained to apply palliative care.

Aim: The aim of this study was to explore nurses' knowledge about palliative care in an intensive care unit in Saudi Arabia.

Method: Eight individual qualitative semi-structured interviews were conducted. Interviews were audiotaped and transcribed verbatim. Manifest content analysis was used to analyze the data.

Results: The palliative care concept was not familiar for most ICU nurses but it was applied in their daily work. Most nurses provided physical care at the end of life to keep the body intact. Some nurses highlighted that dying patients did not feel pain to be treated and did not have emotions to be supported.

Conclusions: Nurses had insufficient knowledge of palliative care and how to apply it in ICU setting. The provision of additional education in palliative care is recommended in order to improve the knowledge of palliative care among nurses.

Key words: Palliative care, Intensive care unit, Knowledge, End of life, Kingdom of Saudi Arabia

Introduction

According to the WHO, palliative care is a holistic activity that involves physical, psychosocial and spiritual human needs to enhance quality of life for patients and their families. It focuses on issues with life-threatening diseases, and it reduces suffering of pain and other symptoms in order to meet patients and their families' needs. It focuses on patients who experienced long-term advanced diseases and need specific care by comforting patients who are not responding to the curative treatment (1, 2, 3).

Palliative care can be either general care or specialised care. General or basic palliative care means the care that is delivered by all health care workers either in hospital settings, outpatient clinics or primary care centers to patients with life-long diseases. Health care professionals should be educated and trained to apply palliative care (2, 4, 5, 6, 7). The most common reasons for consulting palliative care specialised personnel are emotional support, depression, anger, management of several symptoms, control of pain and end of life care (8).

Palliative care in KSA started in 1992 at the King Faisal Specialist Hospital (KFSH) in capital city Riyadh. In addition, KFSH has a program for home health care services, consultation services, out-patient clinics and intensive management wards. KFSH established in 2002, a two-year postgraduate palliative training program (9, 10).

In 1998, palliative care was developed in Jeddah to meet the needs for patients with cancer. Likewise, in 2004, a new unit was established in National Guard Health affairs (NGHA) in Riyadh with two beds in order to improve the oncology department. Today, there are above 15 cancer centers in KSA that have palliative care units. In 2010 more than 500 patients received these unit services. Although, KSA may have the best palliative care services among the Middle East countries, there is a lack of provision of this care due to the low number of specialists, geographic location with a few patients with access to palliative care services and deficiency of opioids in the units (10).

Critical care or intensive care units are parts of hospital settings that apply continuum care for patients who have life-threatening or unstable medical conditions such as breathing problems, complications from surgery, infections and accidents (11).

In the United States, a fifth of all deaths occur in the ICU (12). In addition, the patients who experienced ICU admission are at high risk of developing psychological symptoms such as stress, depression, anxiety and pain which affects patients' quality of life (13). Most issues that are noted in the ICU include poor support for relatives of dying patients, not involving them in

treatment decisions and poor communication (1). Nurses' knowledge is a difficult term to define because nursing science depends on other sciences such as biological science and social science (14). Nurses need evidence based knowledge to perform the care. Nurses gain their knowledge through different sources, for example, through academic sources, personal experiences and practices. The academic source of knowledge includes theories and research which represent the scientific side of nursing (15). Carper classifies nursing knowledge in four types, which are empirical knowledge, personal knowledge, esthetics knowledge and ethical knowledge. Empiric knowledge is the scientific knowledge that can be obtained from observations and tests. Personal knowledge is based on individuals' thoughts. Esthetics knowledge is related to the art of creativity and values. Ethical knowledge is the knowledge that is used to distinguish between right and wrong actions (16).

Carper's work was criticized by Schultz and Meleis (17). As a result of this critique, nursing knowledge was identified as clinical, conceptual and empirical knowledge. Clinical knowledge results from combining personal and empirical knowledge while providing care and solving patient problems. Conceptual knowledge is a reflective knowledge that defines concepts and examines the relationship between the concepts within a theory. Empirical knowledge is the use of tests, experiments and study phenomena, to measure the effectiveness of action in the practices (15).

According to Ganem, Shaikh, Abo Alia, Al-Zayir & Alsirafi, patients with cancer are not the only ones who need palliative care. There are other conditions rather than cancer to be treated with palliative care such as sickle cell diseases, peripheral arterial diseases, end stage renal diseases and acute liver diseases (18). It is important to identify nurses' knowledge, thoughts and experiences about palliative care, and to highlight the importance of applying palliative care in the ICU. The aim of the study was to explore nurses' knowledge about palliative care in an intensive care unit in Saudi Arabia.

Method

A qualitative method is a systematic process that is used to explore social and human problems. Qualitative researchers study the natural setting of things in order to make a science of phenomena by several means such as case studies, interviews, experiences and life stories (19). Using a qualitative design helped to gain deep understanding about nurses' knowledge regarding palliative care in an intensive care unit.

Sample and setting

Eight nurses from the Eastern region in Saudi Arabia, who worked in an ICU teaching hospital, were interviewed. The eligible participants were chosen by the ICU supervisor based on the inclusion criteria of the study. All interviews were conducted in 2013 by the

first and second author. Each author conducted four interviews in separated rooms. The interviews took place in the ICU department in one day during participants' duty time. The participants were two males and six females who worked in medical, surgical and pediatric ICU. The participants' experiences were between seven months and 25 years. Some participants had diploma while others had bachelor degrees in nursing. All participants were coded in order to protect their confidentiality. The inclusion criteria for this study were nurses working in the intensive care unit who could speak the English language.

Data collection

An interview is a face to face conversation between the researchers and the participants (19). Semi structured interviews were conducted, with open ended questions to gain rich information from the participants. According to Polit and Beck a topic guide is necessary to have when conducting semi structured interviews, and the purpose of using this guide is to cover research area with all participants. Open-ended questions were used to guide interview processes and follow up questions were asked based on participants' responses (19).

The interview guideline questions were obtained from two sources; from valid questionnaires to measure nurses' knowledge about palliative care and through intensive reading of studies about applying palliative care in an ICU (20).

The ICU supervisor arranged a suitable place and time for contacting interviews. Each interview started with greeting, smiling and thanking the participants in order to build a comfortable environment that allowed the participants to talk freely. The study was briefly explained to the participants prior to obtaining the verbal agreement. The recording process started after obtaining participants' verbal agreements. All interviews were audio recorded and stored by the authors' cell-phones which were locked by passwords to maintain participants' privacy. The interviews lasted between 15-20 minutes. The first question was "What is palliative care for you?" Some participants could not recognize the palliative care term and two other concepts, end of life and dying were used instead.

Pilot study

The interview questions' sufficiency in answering the aim of the study was evaluated after two interviews, and no new questions were added to the interview guideline questions. These four pilot studies were included in the study. A pilot study is a scale to evaluate the possibility of using, changing and improving the research method (19).

Data analysis

According to Polit & Beck a transcription means to convert the oral data to written transcript (19). The

transcription was done by adding the nods, silence periods and phone rings. According to Kvale & Brinkmann the interview transcription is the first step in data analysis for qualitative research (21). The recorded data was transcribed verbatim in word documents. During the transcription process the participants were coded from P1 to P8 to protect their identities.

The qualitative content analysis is a method used to interpret written data, and it can be either latent or manifest based on the depth of the interpretation. In this study, the manifest content analysis was used which maintains the level of interpretation and to present participants' thoughts without changes (22).

The transcript data was read several times and discussed in order to highlight the important meaning units that were related to the aim of study. Finally, the narrative text was divided into meaning units which were constructed by coding. The similar codings were placed under categories and theme.

Ethical Considerations

Ethical principles are essential guidelines for researchers to protect the human rights for the participants. The ethical principles in a qualitative research are autonomy (independence), beneficence (doing well), non-beneficence (preventing harm) and justice (fairness) (19, 23). Verbal information about the study was given to all participants before the interview.

According to Benner and Ketefian, it is important to obtain informed consent prior to starting the interviews. Participants' names were not disclosed for confidentiality purposes. Participants were informed that it was an optional participation. Participants' autonomy was met by giving them the right to refuse to answer any question or to withdraw from the study without consequences (24). The participants' thoughts were respected by presenting their own words without changes during transcription and analysing the data.

Results

Eight nurses were interviewed for this study, two males and six females who all worked in the intensive care unit. The findings are presented below. The five themes are; nurses' knowledge about palliative care, nurses' thoughts and experiences during end of life care, nurses' thoughts about the nursing roles in the ICU, nurses' experiences about communication in the ICU and nurses' thoughts regarding team work in the ICU.

Nurses' knowledge about palliative care

Source of knowledge

Four nurses studied palliative care during their education but it was not in a specific course, and two of them admitted that the palliative care knowledge was mainly

gained from clinical experiences. The palliative care concept was not recognized by some nurses, but it was applied in nurses' daily work. The need of studying and improving palliative care was highlighted by some nurses.

"I got that one from the experience". (P2)

"We are mostly doing palliative care subconsciously, and we use palliative care but we did not use the concept". (P7)

"All of us would like to know more about palliative care". (P5)

Nurses' experiences about supportive care

The nurses personally defined palliative care as supportive care that can be given to patients and their families holistically. The supportive care included providing a peaceful death, supporting patients and their families emotionally, providing a comfortable environment, administering pain medications, relieving patients' symptoms, allowing families to visit their patients any time and giving same quality of care for all patients.

"Emotionally the parents will be there but in the night we will be like parents. We will act as parents because we will be here". (P2)

"Palliative care is ... supportive care...how we support patient, how to support the family". (P7)

Furthermore, one nurse said that palliative care is to provide comfort and support care for patients by their families:

"Family coming here for visiting, as well as what we are doing, they should...comfort him or her or showing us their support to her". (P4)

On the other hand, one nurse believed that the physical care for patients with brain death was the only one to be given.

"Nothing, that's only a matter of time... the brains died already". (P3)

Nurses' thoughts and experiences during end of life care

Nurses' thoughts about applying palliative care in the ICU

There was no specific palliative care unit in the ICU, but it was applied for most of the ICU patients as mentioned by some nurses, mainly the pediatric ICU nurses.

One nurse supported this statement and added that doctors, co-nurses and nurses applied palliative care services in the ICU. These services were applied for patients who were not for resuscitation, terminally ill, patients with chronic conditions and ventilator dependent patients. One nurse believed that palliative care should be applied for all terminal ill patients and it should be practiced by all health care professionals:

"... We don't have any palliative teamwe are the ones doing... Some patients they are chronic patients ... I think they need palliative care ... also the patients who already DNR". (P7)

Physical care at the end of life

Most nurses agreed that the end of life care is the physical care that focuses on keeping the body intact through positioning, bathing, changing clothes and linen, mouth care, suctioning, nasogastric tube feeding, back care and giving medications:

"We are giving complete nursing care to that patient as to any other patient" (P2)

One nurse said that health care workers did not provide unnecessary treatment such as intubation and medication. While another nurse admitted that patient's life was expanded by giving medications that kept the body alive:

"Like if there is no intubation, the doctor will not intubate any more, like no chemical support or drugs to given like atropine" (P8)

"It will give her more time, few hours" (P3)

Pain management at the end of life

Four nurses believed that dying patients feel pain, while two nurses disagreed. Pain assessment methods vary from one nurse to another. Some nurses were guided by changes in vital signs such as tachycardia and high blood pressure while other nurses observed the discomfort measure that caused pain. Except one nurse who linked the pain assessment with patients' abilities to talk. The first nurses' response regarding pain focused on physical pain which can be treated by identifying the cause of it.

"The physical pain is depended on the cause of pain, and I treat the cause of pain" (P7)

"I think they do not have pain" (P3)

"When they are intubated and how they express to us... they have pain or whatever.. Patients, they cannot talk" (P5)

One nurse emphasized that dying patients have pain and should be treated with respect as human beings:

“Respect him as a human ... being. You should also take care of him or her even though she is dying... still, yes she has pain” (P4)

Emotional and spiritual care at the end of life

Applying psychological support in ICU was decided based on patients' conditions. Two nurses pointed out those dying patients felt psychological pain.

One of them mentioned that keeping patients in a comfortable position and assuring that patients are relaxed, are measures to relieve emotional pain. The other nurse explained that giving patients hope was an emotional support which allowed patients to live their lives as normal persons.

Some nurses admitted that psychological support cannot be given for intubated patients, while others mentioned that psychological care is not applicable for dying patients because those patients did not have feelings or emotions:

“You can give full hope to them” (P6)

“For the psychological condition there is nothing to be done ... he cannot feel what is happening”(P3)

A pediatric nurse stated that psychological support was given to families rather than patients because pediatric patients may not have emotions. Nurses in pediatric ICU allowed parents to visit patients at any time and to touch their babies:

“Emotionally, I am not sure ... They can touch the baby... so they can express their love to the child” (P2)

Spiritual care took place at the end of life care. Some nurses indicated that praying and listening to the Quran helped in comforting patients and assisted families to accept patients' conditions:

“We have this digital Quran that can be played 24 hours The patients can pray even when they intubated” (P6)

Nurses' thoughts about the nursing roles in the ICU

Nurses could not explain patients' conditions to relatives, and this inability was referred to the hospital policy and protocol which emphasized that doctors were the one who explained patients' conditions rather than nurses. As a result, nurses had limited roles in giving detailed information of patients' conditions. As well, nurses were not able to take decisions regarding the patient's

treatment plan. Medications administration for all conditions required doctors' orders which means that nurses were not allowed to administer any medication without an order. Although, nurses are limited, one nurse mentioned that they were able to discuss patients' conditions with doctors:

“The protocol here is that the nurses are not allowed to disclose any information regarding the patient. It is the sole responsibility of the doctor” (P8)

“The relatives ask more and more in details and in depth, we are not allowed to do so” (P1)

“I will interfere ... final decision will be to the physician. He will decide” (P3)

Nurses' roles were described as the process of carrying out doctors' orders even though nurses knew the effectiveness of management:

“It will not change ... this will not be my decision. It will be the physician's and the consultant's decision”. (P3)

Nurses experiences about communication in the ICU

All nurses stated that either doctors or nurses answered relatives' questions. Nurses were required to answer simple questions about patients' conditions, but the major ones were referred to the doctors. There was an exception with critical and dying patients. In these conditions, the direct contact would be between the doctors and relatives where nurses had no role in this process. As well as delivering bad news, it was not the nurses' duty but nurses were present while delivering the news for documentation purpose. Further, nurses listen to patients and their families while verbalizing their feelings. Relatives' questions were answered in a nice way and simple words were used in order to comfort, support and assure the relatives. The main challenge that nurses faced while communicating with patients and their relatives was speaking and understanding Arabic language, but one nurse referred the effectiveness of communication based on the situations and family acceptance of patients' conditions:

“Whatever is the answerable we do answer to the patients and the relatives but for the major parts ... we will refer to the doctor”. (P1)

“I will support the parents, I will try to explain ... in simple words, I will try to comfort them”. (P7)

“The language barriers, I cannot speak Arabic well ... So we ask help from doctor to talk with patients”. (P5)

Nurses' thoughts regarding team work in the ICU

Two nurses defined team work in the ICU as the cooperation between nurses during break period and busy time. On the other hand, one nurse mentioned that the team work in the ICU is a collaboration between nurses, physicians, and respiratory therapists.

The discussion about patients' conditions took place within the ICU team where each member had the opportunity to present his or her point of view, but the final decision is for the doctors. ICU team members are nurses, physicians, respiratory therapists and interns:

"I will tell him my point of view. RT will tell his point view. The charge nurse also will tell her point view, but the final will be physician and the consultant to interfere". (P3)

"We are helping each other ... especially if there are some days that are very busy". (P4)

Discussion

A qualitative research design was used to explore nurses' knowledge about palliative care in the ICU. According to Polit and Beck a qualitative method is a scientific research method that allows researchers to collect and analyze information that is relevant to the research topic (19). Using an interview approach in a qualitative design helped in being part of participants' experiences. The answers in the quantitative research are concrete which limit the ability of participants to express themselves, while the semi-structure interview in the qualitative research gives the participants the opportunity to share their experiences and thoughts. A qualitative method was seen as suitable to be used in this study rather than a quantitative method (25).

The participants worked in the medical, the surgical, and the pediatric ICU departments. The selection of participants had two impacts on the study, positive and negative. The positive impact for random selections was the variation of participants' answers that led to different perspectives within the same department. On the other hand, participants' autonomy might be harmed by this selection because they may not be able to refuse the supervisor's request that could have a negative impact of the selection.

In the present study, some nurses mentioned that they gained their knowledge about palliative care mainly from their experiences and thoughts which is supported by the basic classification of nursing knowledge (14, 16). The general review about nurses' knowledge in this study varied from one nurse to another. Some nurses had knowledge regarding palliative care application in the ICU while other nurses lack this knowledge in certain areas such as providing emotional support for unconscious patients.

The palliative care concept was not familiar for most nurses, but its content was applied in the ICU. Nurses' interest to get more information about palliative care was observed in order to provide high quality of care for patients and their families.

Most nurses provide physical care for dying patients as any other patients but not the emotional support or managing the pain. Conscious patients were treated holistically while dying patients were treated based on physical basis. One nurse said that unnecessary management was not applied according to the department policy and another one from the same department confirmed giving unnecessary treatment at the end of life.

Nurses act as advocates for their patients and this requires education (26). The interviewed nurses missed the advocate part in their work as giving unnecessary treatment for dying patients although nurses knew its effectiveness.

Nurses communicate with patients, families and other health care professionals. The communication in this study, as highlighted by the interviewed nurses, was between nurses and families through answering questions and listening to their feelings.

Dealing with nursing as a unique professional may lead to several benefits such as to empower nurses to make decisions, act independently, be involved in the treatment plan and to take part in teamwork.

Conclusion

This study shows that nurses lack some knowledge about applying palliative care within the ICU setting in KSA. The main lack was noticed in applying emotional care and pain management for dying patients. On the other hand, nurses showed good physical care and spiritual support for those patients. Nurses had limited roles in the ICU due to department policies which was presented as their inability in administering medications, making decisions and communicating with families. Nurses faced challenges in communicating with patients and their families due to language barriers.

Future Studies

There is a need for large-scale studies regarding nurse's knowledge about palliative care in the ICU by using both qualitative and quantitative methods. These studies should focus on team approach and educational interventions. There is also a lack of studies that describe families' perceptions and experiences about end of life care in ICU.

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