ORIGINAL ARTICLE

Nurses' Experiences in end-of-Life Care in an Intensive Care Unit at Tertiary Healthcare Setting, Lahore

MUHAMMAD BILAL¹, FARHAN MUKHTAR², SAMINA KOUSAR³, MANSOOR GHANI⁴, MEHDI HAYAT KHAN⁵

¹MSN Student, University of Health Science Lahore

²Principal/ Associate professor, University College of Nursing, The Islamia University of Bahawalpur

³Professor/HOD, Institute of Nursing, University of Health Sciences, Lahore

⁴MSN Program Coordinator, University of Health Sciences, Lahore

⁵Principal, Mustafa Kamal Institute of Nursing and Medical Sciences, Vehari

Correspondence to: Muhammad Bilal

ABSTRACT

Background: End-of-life care has emerged as an essential component of health care organizations. Now a day, end-of-life care is debated more intensively among patients and their families. Moreover, nurses working in the Intensive Care Unit perform their duties under extreme pressure. A reason for this extreme stress is a shortage of nurses and other healthcare resources. Patients' and family demands at the terminal stage of life further impact nurses' experiences of end life care. Thus, the current study was conducted with the aim of following objective.

Objective: To explore Nurses' Experiences in End-of-Life Care in an Intensive Care Unit at Tertiary Healthcare Setting, Lahore **Methodology:** A qualitative descriptive phenomenological research design was adopted to describe Nurses' Experiences in End-of-Life Care in an Intensive Care Unit at Tertiary Healthcare Setting, Lahore The target population was registered nurses who have been working in intensive care units for more than one year and are actively involved in the end life care. In depth interviews were conducted with a sample of 10 nurses until saturation of responses.

Results: Thematic analysis was carried-out. From the experiences of 10 nurses, 5 themes were extracted i.e. multifactorial influences of end life, financial issues, counseling, and communication, ignored care and administrative challenges for nurses. The results of the study revealed that ELC is influenced by religion and spirituality and nurses experienced problems in managing financial issues, communicating with patients and families.

Conclusion: Nurses need to encourage and participate in managing financial resources for patient care and they must also be involved in continuous education programs especially focusing on therapeutic communication and professional counseling. Furthermore, administrative policies must support nurses' sovereignty in their domain of practice.

Keywords: Intensive Care Unit, Nurses' Experiences, End life care, tertiary health care setting.

INTRODUCTION

Background: End-life care encompasses the self-esteem, spiritual desires, and decision making for a peaceful death for those who are terminally ill and are likely to pass away in a few days or weeks. It is care provided to relieve the sufferings of the dying patient through restored pain control, innovative care development, emotional and psychological support. Additionally, the personal choices of the patient regarding treatment and care are considered and valued (Friedel et al 2018). EOL care is essentially a care provided to minimize the sufferings and enhancing quality of life not only the prolongation of life span (Mauck, 2022).

Death is a natural phenomenon of life which cannot be avoided. With the development in technology, the life span of the population had prolonged, and large numbers of people require end life care. Providing end life care is very crucial which requires skills, knowledge, and commitment by the nurses (Tavares et al., 2017).

Pakistan is the 6th largest country in the world, but health care services are compromised. Significant attention is required towards end life care. In Pakistan, only 10% population can bear the expenditure of standard care. Public and private health care strategies are very poor. Low budget, scarcity of resources, and inappropriate priority setting result in deprivation of end life care. Ministry of Health of Pakistan proposed strategies in 2009 to uplift the health system but end-of-life care was ignored. In the private sector only basic end life care facilities are available in a few hospitals but formal and autonomous services are missing(Khan et al. 2015)

Not only developing countries are deprived of resources for end life care but also the developed world except a few countries in Europe, the end life care policies are lacking and the quality of care is also needed to be upgraded (Dalal and Bruera, 2017).

Furthermore, nurses do not have sufficient finance, proper skills, and knowledge to deal with the issues of end life care. It is suggested, that to meet the standard of care, indispensable administrative support, intellectual, and educational modifications for nurses are obligatory to tailor the latest circumstance (Ghaljeh et al., 2016).

Caring is a core of nursing and it becomes more important and obvious in intensive care units where nurses devote themselves to the care of those who are in pain. In ICUs, all possible measures are taken to guard the life of a patient. Different kinds of technical instruments are being used in intensive care units and it is expected that nurses must know the proper utilization of these instruments and they must utilize psychological and holistic approaches in the caring of sick. But, in the past, the focus of attention has remained only on the wellbeing of the patient and their families, and nurses who take part in aggressive management and are involved in the process of death and dying are ignored (Betriana and Kongsuwan, 2019).

Furthermore, nurses spent more time with patients and their family. They face a situation that needs therapeutic treatments and sometimes termination of treatment. Continuous existences with the dying patients develop anxiety and stress among the intensive care nurses (O'Connor, 2016).

Deaths in intensive care units are very frequent. It is reported that every 5th person who died in hospital took his last breath in the intensive care unit. These high mortality rates become the cause of anxiousness and stress. Nurses feel psychologically distressed and irritated due to the none progressive nature of end life care. The center of attention of the doctors in intensive care units is mostly disease specific while nurses in the health care team have to perform diverse roles since they have to provide care holistically. Nurses provide care to the patient till the end of their life which create anxiety and feeling of desperation and nervousness among the nurses(Mani, 2016).

Objective of the Study: To explore the Nurses' Experiences in End-of-Life Care in an Intensive Care Unit at Tertiary Healthcare Setting, Lahore

Study Question: This study aims to answer the following question: What are the Nurses' Experiences in End-of-Life Care in an Intensive Care Unit at Tertiary Healthcare Setting?

Significance of the study: It has been reported that nursing education lacks a specific curriculum regarding end life care. Therefore, finding extracted from the experiences of nurses working in ICU can be utilized in nursing education to improve the

curriculum of trainee nurses. Secondly, the findings of this study could help in developing evidence-based practice, improving current deficiencies in the health care system.

Literature Review: Critical care nurses face many ethical and moral challenges that may cause burnout and stress which leads toward compassion fatigue, depersonalization, emotional turmoil, low morale, job dissatisfaction, and even the decision to leave the nursing profession (Friedel et al., 2018).

Care of the patient at the end of their life is the main component in intensive care units. Researchers propose that death frequency in intensive care units is high. Termination of treatment is very communal in intensive care units and the role of nurse's increases when the treatment of a patient is concluded because it requires specific care to alleviate suffering at the end of life. Similarly, communication and counseling of attendants of dying patients is complex (Ranse et al., 2016).

Many studies focus on the stress of patients and families related to end life care but data related to nurses' experiences and workplace stress regarding end life care is lacking and it is important to study nurses' experiences to develop strategies to minimize workplace tension and enhance nursing care of terminally ill patients (Johnston et al., 2012).

Studies suggest that even with the development in technology and improvement in the health care system death ratio in intensive care units is very high and nurses who are dealing with these situations have a lot of concerns. As intensive care nurses are dealing with dying patients consistently, it creates depression and anxiety among nurses (Kisorio and Langley, 2016).

End of life care is a challenging task and nurses have to devote themselves to the care of dying people. Many barriers have been identified which hinder the care in the intensive care unit. These barriers varied based on education level, training, and credibility of the institute (Friedenberg et al., 2012).

Death and dying is an inevitable phenomenon that causes stress not only to the family of the deceased person but to the staff nurses who are working in the intensive care unit. Dealing with dying patients and their families is painful and stressful. It had been observed in different studies that nurses while providing end life care develop an emotional bond with the patient so their death creates psychological distress in them (Rushton et al., 2016).

Challenges for nurses in Intensive Care Unit: Nursing is considered one of the hectic and demanding professions and nursing professionals are very much prone to stress, as it has been accepted universally (Lee and Akhtar, 2011).

Intensive care nurses reported that it is also a source of stress for nurses to hide the information from the patient and their families due to any reason. The other source of stress for nurses is unnecessary, ineffective and expensive treatment offered to dying patient, which increases the financial burden of the families (Ferrell, 2016 Velásquez, 2015).

Tension and anxiety are very common among intensive care nurses as they work with critically ill patients and their condition switches frequently according to which immediate decisions have to be taken without knowing the prognosis and outcomes of the decision. (Cronqvist et al., 2006).

METHODOLOGY

Study Design: In this study, a qualitative inductive phenomenological research design was adopted to describe the Nurses' Experiences in End-of-Life Care in an Intensive Care Unit at Tertiary Healthcare Setting, Lahore

Study population: The study population for this study included Intensive care nurses who were actively involved in the end life care in tertiary care hospitals, Lahore.

Research setting: This study was conducted in Shalamar Hospital, Lahore. Separate rooms of the hospital were utilized with the permission of the administration for peaceful, discreet, and distractions free interviews.

Duration: The duration of the study was 9 months.

Samples Size: There is no strict rule to address sample size in the phenomenological study therefore data is collected until saturation. Initially, it was estimated to collect data from 20 intensive care nurses, but data saturation was achieved in the 8th sample size, however, 2 extra participants were interviewed to confirm data saturation therefore a total of 10 participants were interviewed.

Sampling techniques: Non-probability Purposive sampling technique was adopted. As Yin, (2011) described that purposive sampling is the process of data collection based on the richness and significance of information with respect to the research question.

Sample selection criteria:

Inclusion criteria:

- All nurses working in ICU.
- Those who were involved in providing end-of-life care.
- Who have experience of more than one year.
 - Both genders will all age groups

Exclusion criteria:

- Foreign qualified Nurses
- Those who were certified to end-of-life care.

Data collection tool: An interview guide was developed and utilized as a tool for data collection. The primary researcher developed the interview guide from his own experience, an extensive literature review done which was then reviewed by the experts. The first part of the interview consisted of demographic data related to participants' characteristics including Name/code, Age, Gender, Qualification, Experience and Years after qualification.

Last part of the interview guide comprised of questions that focused on exploring the experiences of intensive care nurses regarding end life care. The interview guide had consisted of eight open-ended questions with planned and unplanned probes. Moreover, field notes were noted to record verbal and nonverbal gestures and expressions of participants.

Interview Process:

- Face-to-face in-depth interviews were conducted to obtain the required data. All the essential information was given to the participant for their voluntary participation. Demographic data including gender, education, nature of duty, and their qualification were taken during the collection of data. Permission was obtained from IRB-UHS, the concerned hospital Director, head of the departments, and participants. Once permission was allowed, the date and time of the interview were arranged and scheduled according to the feasibility of participants.
- Semi-structured interviews were carried out with the participant. Such sorts of interviews allowed the participant to express their feelings easily. Participants were facilitated in every aspect in which they could explore their experiences and feelings freely. Each interview was about 30 to 35 min duration.
- Interviews were tape-recorded with the consent of participants and then transcribed verbatim. Transcriptions were confirmed with the tape recorder.

Data Analysis: Qualitative research data analysis started simultaneously with data collection. Therefore, analysis of the data was started at the time of its collection. A Six steps inductive data analysis approach developed by Braun and Clarke (2006) was utilized to analyze the data. All the audio files of interviews were given anonymity with pseudo names and saved on a personal PC. Interviews were transcribed verbatim. Interview transcriptions were read and re-read word by word and sentence by sentence several times and relevant ideas were recognized. Secondly, all the relevant content from transcripts was extracted according to the interviewed questions. Important phrases, sentences, words were labeled or highlighted for coding. Categories and subcategories were developed based on the meaning, concepts, connectivity, and relevancy between codes. Finally, the data was presented in plain text and table form

For summarization, the following steps were used to analyze the data.

- 1. Transcription: From audio into written form
- 2. Coding: Process of labeling important information
- 3. Categories: Categories based on the essence of data.
- 4. Themes: Essences of categories, the main idea of the data, essence in form of categories and subcategories, and whole report.
- 5. Define themes
- Write up

Ethical considerations: The study was followed by the ethical principles of the WMA Declaration of Helsinki made at 64th WMA General Assembly, Fortaleza, Brazil, in October 2013. The health, well-being & rights of Subjects will be the prior consideration.

- The procedures were explained to the participants clearly and written informed consent was obtained.
- The research was conducted in a friendly environment.
- The confidentiality of the information was assured and maintained.
- The study was approved by the Institutional Ethical Review Board of UHS and the relevant hospital.
- Any harm to the participants was avoided.

RESULTS

Introduction: The demographic data is presented below in the form of a percentage and frequency chart.

Table 1: Demographics of Participants Demographic

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Demographic	%	N
Male	40	04
Female	60	06
Highest Level of Education		
Diploma	20	02
Diploma (With ICU specialty)	20	02
BSN (Generic)	30	03
BSN (Post RN)	20	02
BSN (Post RN+ Specialty in ICU)	10	01
MSN		
	00	0
Age Ranges		
21-30	30	03
31-40	60	06
41-50	10	01
51-60	0	0
61 or over	0	0

Overview of thematic analysis results: A total of five themes were extracted. Which were Multifactorial influences of end-of-life care, financial issues, counseling and communication, ignored care, and administrative challenges for nurses.

In the theme Multifactorial Influential of end life care, it was discussed that end life care is influenced by many factors particularly sociocultural values, religion and community education. The second theme was financial issues. It was the main concern of all the participants that affordability is a major problem, and many patients were deprived of care due to the scarcity of resources.

The third theme was communication and counseling. It was stressed by participants that proper counseling and communication are pivotal for end life care. It was noted that there are many flaws in communication and counseling. The fourth theme was ignored care. Almost all the participants described that there is a big difference between the care of a dying patient who is DNR as compared to the full-code resuscitated patient. It was discussed that care for the DNR patient is compromised due to multiple factors.

The fifth theme was administrative challenges for nurses. This theme has been discussed under three categories, the administrative support, working environment, education and training regarding end life care.

Theme 1_ Multifactorial influences of end life care: After analyzing the data collected from intensive care unit nurses who actively take part in terminal care, it was explored that end-of-life care has multiple spheres, and it is influenced by multiple factors. During the interview, it was stressed and discussed by the

participants that the provision of end-of-life care is a challenging task. Social factors have an inordinate influence on end-of-life care. Our society and culture are stirred richly by cultural values and customs.

It was highlighted by the intensive care nurses that attendants place their standards on them and try to force them to adopt those standards. It was stated by three nurses as:

Theme 2: Financial issues: Various issues were identified by the participants. In the provision of end-of-life care resources have a central role. Pakistan is a developing country and the budget for health care is very low and end-of-life care support is being neglected. Intensive care nurses in this study stressed on the scarcity of resources and discussed that lack of resources is a major barrier to the provision of end-of-life care. End of life care in the private sector is very much expensive and unaffordable for many people.

It is reported by the participants that some families agreed to terminate the treatment due to the unavailability of resources. All participants of this study highlighted the shortage of resources by stating:

"Affordability and resources are a big issue in providing endof-life care" (6 females and 4 male) (ID1,2,3,4,5 6.7,8,9,10).

Theme 3: Counseling and communication: In the care of dying patients, counseling and communication have an integral role. Most of the participants in this study stressed the need for prompt and continuous counseling and discussed that proper counseling and good communication can avert various issues. It was highlighted by the participant that counseling should be started as early as possible and the prognosis should be explained and communicated properly to prevent a disastrous situation. It has been observed that a good understanding among health care providers and patients, and their families results in a positive outcome. Participants described misunderstandings in ICUs as the consequence of poor counseling and miscommunication.

Theme 4: Ignored Care: The intensive care unit is technologically very sophisticated and requires specific knowledge and training to operate machinery. When workload increases but the staff ratio remains the same, it becomes very difficult and almost impossible to provide optimal care. The response of the four nurses is quoted below:

"The staffs are every sensitive and provide efficient care. Sometimes, due to overburden and staff shortages, it becomes difficult to provide standardized care " (two male and two female) (ID 5, 6, 8. 9).

End of life care is considered sometimes futile care. Most of the study participants described that, comparatively, more focus is given to the patient who has more chances of survival as compared to the dying patient. It was thought that the care of a well-prognostic patient will have a positive outcome which will create satisfaction among the health care providers. Care of the terminally ill patient produces anxiety and builds a perspective that the care of dying patients is useless. Participants stated as:

Theme 5 Administrative challenges for Nurses: Intensive care nurses work in a multifarious environment and face many challenges. These challenges are of different kinds and nurses have to encounter them. Some challenges are associated with death and dying, and nurses can overcome them through refined knowledge and commitment. Nurses also confront problems with health care administration that are related to the care of the patients but cannot be overcome without the support and facilitation of the administration. It is pointed out that administration did not provide support related to end life care. Furthermore it is discussed that working environment is also not conducive due the lack of encouragement from administration. Participants also discussed that formal education and training related to end life care was lacking. Under this theme, administrative support, working environment and education and training related to ELC being discussed.

Administrative support: Nurses work in a stressful environment and they need support from the administration regarding end-of-life

care. However, the majority of the participants were agreed that the administration did not support them regarding end-of-life care. Administration mainly focused on the resuscitated patient while care of the DNR patient was not encouraged and appreciated. Although some participants discussed that some kind of support is provided by the administration but that is not sufficient. Participants stated as:

"The administration does not provide us with any specific support regarding end-of-life care." (Three participants were male and two were female)(ID 3, 4, 6, 8, 9)

"Yes, they support us, but sometimes problems occur and deficiencies are there and the system needs to be improved ". (One male participant) (ID 6).

DISCUSSION

The current study revealed that there are many factors influencing ELC which include sociocultural, religious values, and education level of the community. These findings were supported by (Baliza et al 2015).

The findings of the study conducted by Menace et al. (2018) are also relevant to the current study which highlights that the practices and choices of end-of-life care differ in different parts of the country. The justification for this difference is considered as a diversity of cultural and religious values.

Another study conducted by C Shilnall et al (2015) stated that religion is the main factor utilized by families to deal with the stressors associated with end-of-life care. Religion provides excellent coping mechanisms regarding end-of-life care. These finding are parallel to current study.

Current also revealed that the education of families plays an important role in the provision of end-of-life care. It was discussed that families with proper education regarding end-of-life care experience positive aspects of care giving and support the health care providers, but lack of education at the community level is witnessed which creates challenges for health care providers. These were supported by (N Lalani et al 2019).

A study conducted by Manda-Taylor et al. (2017) is relevant to Current study which highlighted that the health care budget in developing countries is very low, and supplementary support is mandatory to provide standard care. Without additional support and funding, the provision of standard care is not admissible.

A study conducted in Pakistan by (Khan, 2017) also projected the finding of the current study that along with other issues affordability is a major challenge in Pakistan for ELC.

Current revealed that advancement in technology had positive impact, but this advancement also enhances the cost of treatment in the intensive care unit, which unfavorably influences the financial status of the families, parallel finding was highlighted by (GM Pittoni, et al. 2016).

While in contrast to the current study developed countries have sufficient resources and well-defined mechanisms to provide care. The health care system in western countries is very well established and organized. They have a well-established reporting system and their budget for the health sector is specified. (J. Carlet, et al 2014)

In short, the findings of the current study point out the fact that families of dying patients face a limitation of resources, which is congruent with the findings of other studies conducted in developing countries, while in contrast to the findings of studies conducted in developed countries.

Administrative challenges for nurses: It was revealed in the current study that participants were not satisfied with the working environment due to the non-cooperative attitude of the physician and lack of support, appreciation and encouragement by the administration. These findings of the current study were relevant to the previous study E Ferrand, et al (2013), which indicated that nurses working in intensive care units in France were dissatisfied with the environment due to different perceptions and discrepancies with physicians.

Current study indicates that training and education regarding end-of-life care were deficient and improvements are desirable which is relevant to the study conducted by (N Bekkema et al 2014)

CONCLUSION

It is concluded that end-of-life care is a challenging task for the nurses working in ICU as well as for patients and their families. Decision making regarding end-of-life care is richly influenced by cultural customs and religious values.

Nurse's counseling and communication play a vital role in relieving stress, tension, and anxiety. Education and training regarding end life care was absolutely lacking. The administration does not support intensive care nurses regarding end-of-life care. **Recommendations:** Nurse's adequate education, appropriate counseling, cost-effective treatment modalities, giving proper training, and sufficient administrative support may help nurses and families to reduce their miseries, difficulties, and challenges.

Limitations of the Study: The current study was conducted in private hospital in Lahore. The experience of public hospital nurses may not be pertinent to the current study and the implications of this study for other parts of the country are not applicable.

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