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Describing Perceptions and Experiences of Undergraduate Nursing Students Regarding Death and Dying in Palliative Care Setting

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Abstract

Background: Nurses in palliative care settings go through a wide range of experiences, therefore, they are able to provide an insight into death and dying related experiences explicitly.

Objective: This study aimed to explore the perceptions and experiences of nurses about providing palliative care to patients and their family members.

Method: A descriptive study design was used. The study was approved by the university ethics committee and the informed signed consent was obtained from the participants. Participants enrolled in the study (n=41) were divided into six groups for focus group discussion generated through using an interview guide. These discussions were recorded, transcribed and analyzed in themes, sub-themes and categories.

Findings: The study findings highlighted the following main themes: the attitude of nurses, ethical dilemmas and readiness of nurses for providing palliative care to their patients as well as families. In Pakistan, palliative care is in infancy and requires improvement in the infrastructure of the current health care system, which includes healthcare delivery policies, palliative care models and trained staff to support patients and their families. Pakistan is a way behind in multidisciplinary pain management approach and provision of morphine. Moreover, due to large and extended families, all family members do not have a clear picture of their patient's condition and this creates further conflict.

Conclusion: The participants highlighted the importance of preparing nurses for providing palliative care and dealing with dying patients and their family members. Thus, it is required that palliative nursing course should be included in medical and nursing curriculum.

Keywords: Undergraduate nurses; Palliative care; Death and dying; Qualitative study; Ethical dilemma

Introduction

Palliative care is an approach, which aims to improve the quality of life of patients with serious and incurable illnesses by providing holistic care [1]. The care is not only limited to the patient but extended to their family members as well and the care covers a wide range of services including the physical, mental, psychosocial, emotional and spiritual aspects [2-4]. Palliative care is recognized as human right as part of health therefore it is the health care system responsibility to develop palliative services. According to World Health organization 2018 around 40 million people are in need of palliative care each year in that 78% belong to low- and middle-income countries [5]. In Pakistan non-communicable diseases, including cancers have become the major cause of morbidity and mortality [6] indicating a high need of palliative care. However, health care system of Pakistan is not prepared to consider it as priority agenda. Moreover Pakistan health structure lacks trained staff and pain medication like opioids.

Palliative care is a multidisciplinary approach with nurses being in the forefront performing a special role in providing comprehensive care services to patients and their families from prevention to relief suffering and extend support to their family with grief [7]. Empirical literature identifies that nurses are needed to be educationally prepared through undergraduate and postgraduate curriculums [8].

In 2011, by considering the need of palliative care in Pakistan one of the private nursing universities introduced a course on the concept of palliative care to the ungraduate generic BScN students. The same course was extended to the post RN BScN students in 2015. The Post RN students are enrolled in the program bring almost 3 years of clinical experience. The course facilitates the learners to understand and relate the concepts of terminal illnesses and its associated practical issues in context of their physical, psychological, social, spiritual and sexual needs. To our knowledge this is the only private university in Pakistan introducing the concept of palliative care in their undergraduate nursing curriculum. In 2018 a group of faculty from palliative and oncology stream initiated the study within the course along with 41 enrolled students in the program. The aim of the study was to explore students (practicing nurses) perceptions and experiences regarding palliative care.

Methods

Design setting and participants

A descriptive research design was used to explore the perceptions and experiences of participants who were the undergraduate nursing students (n=41), caring for patients with death and dying in the palliative course in post RN BScN program. This program enrolls nurses with a minimum of two years of experience after they complete three years of diploma in nursing and one year of diploma in specialization in any filed. The course was offered from Jan 2018-April 2018; the current study was conducted after almost 3 months after exposure of theory, simulation and clinical. During the course practicing nurses shared their perceptions and experiences about providing palliative care to patients and their family members.

Data collection, analysis, and rigor

The data was collected through focus group discussions using a semi-structured interview guide with the probes to deepen the exploration. Two experts in focus group discussion were recruited to maintain the neutrality in the research. Field notes were taken and participants were observed for any non-verbal behaviors including silence, sighs, laughter, posture, etc., during the interviews. The focus group discussions were audio recorded and verbatim were transcribed and analyzed; themes, sub-themes and categories were extracted. The participants were encouraged to express their experiences explicitly.

Ethical considerations

The study was started after the approval from the ethics committee, Aga Khan University and the permission from the Dean of the school of nursing. Those participants who agreed to participate were given the consent form and they were informed that they would not be at any risk if they refuse to participate. At the beginning of the data collection we announced that if anyone feels emotionally instable might leave the session. Few students were observed getting emotional because of recently losing their loved ones in their families so they were allowed to leave the session but they did not because they felt relaxed and they found this discussion as grieving opportunity. The discussions were conducted in a friendly environment so participants do not feel threatened by the presence of the researcher. Individuals were given the freedom to express their true reflections, also is a requirement of this research. Individuals' confidentiality was strictly maintained by concealing their names and using codes according for focus group numbers. Entire data was saved on a computer and access to data was protected through a password. Participants' individual signed consent forms are saved in a lock and key.

Results

Through analysis of Six focus group discussions emerged the themes; attitudes of nurses, ethical dilemma, and readiness. Each theme with its sub-themes and categories are presented in Table 1 and supported through participants' verbatim.

Themes	Sub-themes	Categories
Attitude of nurses	For Patients	Lack of tolerance
		Task Focused
		Past Experiences
	For Families	Avoidance to talk
		Family not allowed
Ethical dilemma	Undignified death	Pain
		Last wishes
	Lack of empowerment	
	Infrastructure	Lack of policies
		Lack of resources
		Shortage of trained nurses
Readiness	Nurses readiness	Lack of training
		Lack of Competence
	Family readiness	Lack of comprehension
		Conflict amongst family members

Table 1: Sub-themes, categories, and sub-categories of the study.

Theme 1: Attitudes of nurses

Participants in the study reflected on their prior attitudes toward patient with end of life care. Moreover, this was further divided into two sub-themes; attitude for the patient and for families.

Sub theme 1: For patients

Their previously learned attitude in clinical settings the nurses were unaware of the need of the dying patients. During the course of COP they developed this insight that the patient should be given extra time and attention where possible, and highest amount of comfort should be provided to the patients in the form of relaxed meeting time with loved ones and being respectful of the patient even after the patient has died. The participants expressed:

One participant stated:

"Previously, we don't take the word 'palliative' that seriously, we say that if it is DNR then it is so…" (FGD 4)

Another participant said:

"Prior to this course We did not have any concept of palliative care … in our previous clinical experience …We learned that even dying the patient was trying to say something we were ignoring it; either we didn't try to listen or we were not much focused on her so that we were unable to hear what the patient was saying." (FGD 4)

Category 1: Lack of tolerance.

Participants shared that they were having poor tolerance regarding care to the dying patient.

A participant shared:

"I feel that usually we are not that much used to palliative care, maybe we have not learned it so well. May be we lack that time, tolerance and stamina which is required for the patient in palliative care?" (FGD 3)

Category 2: Task focused.

The participants shared that in their daily routine they are more task focused rather than paying attention to the patient's emotional needs. One participant shared;

"We often have excuses like we don't have time due to heavy workload that's why DNR patients were being neglected by us frequently." (FGD 2)

One of the participant said,

"when are assigned on three, four and five patients and one of them is a DNR patient then our priority is to cater the needs of other patients first before doing anything for the patient who is on DNR. ….. DNR is not our priority. But now they will be given priority by us." (FGD 2)

Category 3: Past experience of loss of loved one:

In FGD one, two, three and six prior experiences with dying person were shared. Some participants voiced that they were uncomfortable in situations of dying patients; they experienced feelings of helplessness and overwhelming emotions when dealing with palliative care patients. Few participants mentioned their experiences with family members.

Sub theme 2: For families

The participants also shared about the change in their attitudes for the families of dying patients after exposure with the concept. Change in attitudes for patients' family is categorized into; avoidance to talk and family not allowed.

Category 1: Avoidance to talk

The participants shared that they frequently avoid talking with the families of dying patients due to grieving and sadness. One participant shared her views;

"Just like today we were not able to respond to the questions of the attendants. I was feeling like crying same happens in real life. We have lack of words; we don't know what to say at that time." (FGD 1)

Category 2: Family not allowed.

The participants shared that in real life usually the families of the dying patients are not allowed to stay in ward. A participant said,

"… If we talk about Pakistan then it is not in practice to involve the family in the dying process of the patient. In future we will focus on patient and the attendants. During their last moments, we should allow the members to stay with the patient." (FGD 1)

Another participant also shared:

"Before having this course we didn't realize the importance of the communicating with family members of the palliative patient and we never acknowledged how they are feeling. We only treat the patients and were concerned with our task. We now realize that they must be worried about their dying family member…… (FGD 2)".

Theme 2: Ethical dilemma

The participants shared the few dilemmas like that could be considers harmful for the patient on the other hand in end of life principles could be considered as dignified death Such as, allowing the family to give holy water to a dying patient, patient needs morphine but nurses are concern about patient may get addicted to morphine. In addition in some instance nurses are feeling powerless to make decision to provide comfort care to patient and family because of hospital policies and procedures. This theme further divided into 3 sub themes like undignified death, lack of empowerment of nurses and infrastructure of the hospital.

Sub theme 1: Undignified death

The participant's acknowledged that their dying patients should die with dignity which means withdrawal or withholding of life-preserving treatment according to the patient's choices. And its responsibility to provide comfort care to the dying patient and if their choice not being catered then the death would be undignified.

Category 1: Pain.

In terms of pain management, participants shared few ethical concerns and one participant described:

"… We looked for heart rate which was thirty seven before administering morphine. The patient was in pain but with that heart rate administering morphine could cause harm. But not giving morphine could result in pain" (FGD 5).

Category 2: Last wishes.

Patients last wishes were important for the nurses which are exhibited by their quotes like one participant shared:

"My patient was dying he asked for some water, I was unable to provide a sip of water due to the patient breathlessness… After two to three hours the patient died so it was something to reflect that giving him sip of water could have satisfied the patient last wish" (FGD 3).

Sub theme 2: Lack of empowerment

The participants felt that they are not empowered in terms of announcing a patient's death. The doctors announce it.

Nurse student shared that "we shouldn't have to wait for doctors to announce a patient's death" (FGD 4).

Another participant shared:

"Sometimes (the patient) is already dead but we fear to announce that because it is not a part of our job as a nurse, we have to wait for the doctor to come and announce" (FGD 4).

Sub theme 3: Infrastructure

In terms of infra-structure the participants had the following concerns.

Category 1: Lack of policies

A participant shared:

"In our experiences working as staff nurses when our patient die we immediately start working for the death certificate and discharge summary. We asked attended to submit patient dues instead of providing time to them to grief… It is as if we just want to drive them out of the hospital, it is that kind of situation" (FGD 4).

Category 2: Lack of resources.

"We have limited resources such as no specific room for the patients who are dying, I think family needs some privacy to spend time with their love ones to grieve once the patient dies. Also, there is lot of emotional burden, which require psychological service" (FGD 6).

Category 3: Shortage of trained nurses

The participants in all the FGDs talked about lack of training as one of the ethical dilemma which obstructs them to provide holistic palliative care to their patients and families.

Theme 3: Readiness

The theme of readiness is further divided into two following subthemes as follows:

Sub theme 1: Nurses' readiness

Participant shared that few nurses are not ready to handle patients in palliative care because of lack of training and lack of competence.

Category 1: Lack of training

Participants shared that they are not well trained in terms of palliative training. One participant shared;

"Chronic illnesses like cancer are prevailing and there is a need for people to deal with it. Without training, we won't be able to provide them with the kind of comfort which they deserve" (FGD 6).

Another participant shared:

"This course was effective to make us more prepare to deal end of life patients and we haven't had a course in palliative care before this." (FGD 2)

Category 2: Lack of competence

Participants shared that they lack the competency to care for their dying patients and their families. One participant described, "When I handled dying situation for the first time that was scary because the caring of dying patient is very challenging" (FGD 2). Another participant shared:

"We are helpless. I mean we do not have that much skill [to give them comfort]". (FGD 1).

Sub theme 2: Family readiness

In the theme of family readiness participants narratives are following.

Category 1: Lack of comprehension.

Participants shared that in our context family members are no well prepared to understand the patient's condition including the medical jargons and treatment choices.

One participant shared:

"There were two brothers of the patient, they had signed DNR but they did not know what was meant by DNR" (FGD 2).

In this context one participant shared:

"Because we were informed beforehand that patient is DNR code. When attendants were asking us to perform CPR we were feeling helpless" (FGD 2).

Category 2: Conflict amongst family members.

The participants shared their perception regarding conflicts with the family members of their dying patients. In context to Pakistan, most of the time male elder attendant signs for the DNR. Moreover, due to large and extended families all family members don't know the clear picture of their patient condition.

One participant shared:

"… I was in an oncology department in which the patient had nine offspring so each of them visited the patient one by one. DNR was signed. When the patient's condition deteriorated the other son shouted a lot. He said that my patient's condition is worsening and you people are doing nothing. At that, time staff was confused… CPR was done, and patient was intubated and mechanical ventilator started and continued till the family was able to resolve the conflict and took appropriate decision for their patient" (FGD 2).

Discussion

Participants in the study revealed that the field of palliative care is in infancy in Pakistan, and do not have enough resources, infrastructure, polices, models and trained staff to support patients and their families for palliative care. Moreover, due to the lack of hospital policies nurses and other health professionals neglect the grieving family members of dead patients as well as hospitals are lacking grief room for family. Similar findings are been reported in studies that capriciousness of human and logistical resources, financial constraints, and limited infrastructure challenges delay or prevent patient from receiving palliative care [9-12]. In regard to palliative pain management, Pakistan is worth discussing, Pakistan is way behind in multidisciplinary pain management and provision of morphine to reduce burden of chronic pain by providing pain education and training to health care professionals [13]. In the study participants also had a lack of clarity on the use of morphine administration such as in condition of slow heart rate with severe pain at the end of life. They felt using morphine seems hastening death. Similar findings are supported by literature that lack of training can cause misconception regarding morphine such as it accelerates death [14-19]. Another study finding was: that the nurses who had been specifically prepared to deal with the terminally ill patients in palliative care units reflected a more positive attitude toward caring for the dying than those who don't have trainings specifically regarding palliative care [20,21]. The participants in the study shared that while dealing with decision about care of dying patients, they found serous conflicts within the family members of their dying patient. In regard to, family's decision making about code status of do not resuscitate (DNR) and later resistance to change code by other family members was a common unrealistic expectations. Health care providers felt pressured to forcefully change code decision in spite of presence of legal documentation signed by another close family member. In context to Pakistan, due to large and extended families all family members don't know the clear picture of their patient condition, such as when one attendant signature for the DNR others would create conflict with health staff to change decision. The view is supported by literature that extended families in Pakistan are highly connected to their members that there is no confidentiality except the patient, this cultural phenomenon takes away the individual person or patient autonomy [22]. Therefore in times of confronting medical decision-making regarding end-of-life care, there is a need to emphasize the differences in social and cultural values and norms and provide advocacy for dignified death [23,22]. Providing timely communication with simple language with no medical jargons, and effective counseling to attendants and appropriate preparation for undesirable outcomes can prevent hospital related violence [24]. In addition, nurses need to be prepared to deal with families in educating them about the patient's reality, given that families do not tend to accept and understand the poor prognosis of patient with disease like cancer [25].

Conclusion and Recommendation

Providing quality palliative care to dying patients is important for nurses. Therefore, it is important to be included in the nursing curriculum for achieving competency in palliative care for all graduates. Moreover, creating a supportive platform for nurses and patients' families to promote the culture of sharing ethical concerns in palliative care through ongoing dialogues is needed. Health care institutions need to develop infrastructure such as comprehensive policies for palliative patient and space such as providing a lounge with a counselor for the grieving process. Furthermore, administrative and institutional level decisions are required in governmental and non-governmental institutions to support palliative care initiatives and the availability of opioids for pain management in context to Pakistan.

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