Original Article

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End of Life Holistic Care for Cancer Patients: A Qualitative Study

Nursing Section

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ABSTRACT

Introduction: Cancer is one of the most important causes of death in the world. Many cancer patients are hospitalised at the end of their life, requiring end-of-life care.

Aim: To elucidate the Iranian oncology nurses' experience of caring for dying cancer patients.

Materials and Methods: This qualitative study was conducted with a conventional content analysis method. Data was collected by semi-structured interviews, which were conducted with16 purposefully selected nurses who were providing end of life care for cancer patients in the oncology wards. Qualitative thematic analysis was used to analyse the data.

Results: Three themes emerged from the text including: patient-centered care, family-centered care, and personal and professional characteristics of the nurses. These three themes defined a more general class or category entitled; "holistic care".

Conclusion: The results of the study revealed that end-of-life patients require holistic care. Therapeutic relationships underlie professional holistic care and are essential for the end of life care. Proper education and professionally led supervision should be included in the curriculum of nursing education in Iran.

Keywords: Cancer, End-of-life care, Iran, Oncology nurses

INTRODUCTION

Cancer is a major public health problem worldwide [1]. About 7.9 million people die every year because of cancer all across the world [2]. About 70% of these deaths occur in low- and middle-income countries. It is estimated that by the year 2030 more than 26.4 million people will be affected by cancer and 17 million people will die as a result of cancer worldwide [3]. As the number of people expected to die from cancer increases, the need for a more effective and compassionate end-of-life care becomes more significant than ever before [4]. Therefore, with growing number of cancer patients, the demand for better quality end-of life care increases [5].

In end of life stage of cancer, patients have a growing need for more nursing care and a less need for medical treatments [6]. Thus, oncology nurses, who care for cancer patients, especially those who are at the end of life stages, play a vital role in caring for these patients. To undertake this role properly, oncology nurses require inclusive knowledge of care, skills, and a high standard clinical competence [7]. Some studies have showed that nurses with better skills and more experience are much more likely to affect dying cancer patients in a positive way than less experienced ones [8,9]. Besides, experienced nurses are likely to give patients and family members more emotional support during the particular stage of illness [4,10].

However, oncology nurses might experience various challenges when providing dying patients with what they consider to be a comfortable and dignified death [11]. Some researchers have indicated that nurses who care for dying people face cultural and individual challenges [11,12]. Most of the population in Iran is Muslim [13]. Like most Iranians, majority of nurses consider themselves religious and their beliefs are often, in an implicit way, integrated into their views on care [11,14,15]. Nurses are expected to pay attention to the patients' religious beliefs and dignity [11]. However, in Iran's health system, less attention is paid to the end-of-life care in health centers [16], and majority of people who are at the end of their lives spend their dying moments on oncology wards and intensive care units. In these settings, nurses are highly involved in the care of dying patients even though they have not received formal education about caring for such patients. Iranian nursing curriculum contains neither theoretical nor practical education about end of life or palliative care [17]. Therefore, nurses only provide routine care for end-of-life patients [18].

The nurses' experiences of care as well as their attitudes and behaviours become more important in the context of end of life care, where a variety of feelings and experiences are evoked in the face of death. Diverse views and experiences regarding the end of life care are based on the differences in cultures. This study aimed to elucidate the oncology nurses' experiences of caring for dying patients in Iran.

MATERIALS AND METHODS

Qualitative method with conventional content analysis approach was chosen for this study, because naturalistic paradigm and qualitative method believe that, reality is context based [19].

Ethical Consideration

This study was registered at Zahedan University of Medical Sciences with the code: (1396.99.R.ZAUMS.REC). The principle of confidentiality in this study was ensured for the participants and they were informed about the purpose of the study. The participants were also informed that participation in this study is voluntarily.

The topic of end of life patients and their experiences is an emotionally charged topic and may be a painful reminder of previous experiences. This risk was handled by the researchers' attentive and sensitive attitude towards the interviewees' emotional reactions. The researchers also gave the participants sufficient time to consider their participation in the study.

Participants and Setting

The participants were 16 nurses working in the oncology wards of hospitals supervised by Zahedan University of Medical Sciences. The criterion for entering the study was at least 6 months experience of working in the oncology ward. The mean age of participants was 32 years.

Data Collection

In-depth, individual, semi structured and audio-taped interviews were conducted with the participants in their convenient time

and place. Participants were asked to narrate their experiences regarding caring for end of life patient. Clarifying and promising questions were asked from the participants, such as: "Can you explain more about…?" and, "Can you give an example?" The interviews were taped recorded, transcribe verbatim and analysed consecutively by the authors. All interviews were conducted in one session, according to the participants' requests. Each session lasted between 45-75 minutes. The sample size was determined by data saturation after the sixteenth interview. The study began in March 2017 and lasted till June 2018.

Data Analysis

Data were analysed according to the method proposed by Graneheim UH et al., [20]. Each interview was transcribed verbatim by the Microsoft Word immediately after the completion and was reviewed several times to get a general understanding of the participants' statements. The interview text was then converted into sematic units. Each sematic unit consisted of related words and sentences. The sematic units were condensed while ensuring that, their contents are retained. Each condensed sematic unit was then labelled with a code. The codes were classified into specific classes (themes) and subclasses (sub-themes) according to their similarities and differences. Data analysis was carried out simultaneously with data collection. Data collection was continued until data saturation, where the collected data was repeating the previous data, leading to no new class or code.

Credibility

In this research, the criteria of Graneheim UH et al., were used to strengthen the study [20]. In order to determine the acceptability of the data, the researcher maintained a long term engagement with the subject and the data, and the views of research team members regarding the interview process and data analysis were considered. Interviews and codes were extracted and sub-themes were shared with some of the participating nurses (p) and two nursing professors familiar with qualitative research. In order to determine the reliability, the data were presented to a foreign observer familiar with both the clinical environment and the qualitative research, who was not a member of the research group, to resolve the ambiguity of coding and formulation of classes. In order to determine the confirmability of findings, all activities were recorded and a report of the research process was prepared. Also, to ensure the data transferability, findings were shared with two non-participant nursing students who had similar situation as the participants. The data analysis was approved.

RESULTS

The participants included 16 expert nurses with the mean age of 32 years, and a minimum of 9 months and maximum of 12 years (mean = 6 years) work experience in the oncology wards. Also, 75% of the nurses were married, and all of them had a bachelor's degree in nursing. Three themes were resulted from the data analysis including; patient-centered care, family-centered care, personal and professional characteristics of the nurses. These three themes formed a more general class or category entitled; "holistic care".

The theme and sub-themes are described in more detail below [Table/Fig-1].

Sub-themes	Theme	Main class or classes of common themes
Cultural and religious care and beliefs Helping to accept the status quo Paying attention to the wishes and needs of the patient Emotional relationship with patient Attention to human dignity	Patient-centered care	Holistic care
Helping the family to regain their caring role Supporting the family	Family-centered care	
Individual characteristics Professional characteristics	Personal and professional characteristics of the nurses	

[Table/Fig-1]: Main theme and sub-themes.

1: Patient-Centered Care

Most participants (P) pointed to the importance of patient-centered care for the end-of-life patients.

1.1 Cultural and religious care and beliefs: The nurses referred to their cultural and religious beliefs in their care experiences. One participant stated: "I consider my cultural beliefs and behaviours in the care of patients. For example; at the end of life, patients want to write a will or solicitation letter for their family and friends, and I let them do so." (p5).

Another participant said: "I respect the religious beliefs and culture of patients. I help them to pray. I had a patient, who couldn't say his prayers without help, so I helped him to pray. That was more effective than any medicine, it made him calmer." (p2).

1.2. Helping to accept current conditions (Status Quo): Nurses' experiences showed that, they should understand patients at the end of life and help them to accept death and their status quo. One of the nurses said: "Some patients become aggressive about taking medication and say; I'm dying, so why do you give me drugs? I talk to them and tell them; you are here right now and you can give us your requests. There are healthy people like me who may have sudden death in an accident, I do not have a guarantee to survive, but maybe you're lucky. I may not be alive tomorrow due to a sudden accident, but you may still be alive 6 months later, so this time is an opportunity that you can use any way you want." (p4)

Another nurse said: "I tell the patient that you should live your normal life alongside your illness. I tell him about a nurse who has cancer but still works in the department and lives a normal life." (p16)

1.3 Paying attention to the wishes and needs of the patient: One of the clinical nurses described her experience as follows: "If the patient has severe pain, the first thing I care about is reducing the patient's pain. I will do it immediately. Patients should not suffer from physical pain at the final moments of their life. When the patient's pain is resolved, he or she will become comfortable." (p11)

Nurses believed that, patients would need mental support at the end of their life more than ever before. "I understood that, at the end of life, patients are deeply focused on the anxiety and fear of death, and they are afraid of loneliness. At this time, I sit next to them, and I begin to talk to them; I continue to speak to them and they talk about their feelings." (p12)

One of the nurses who had started her career in oncology ward said: "In the first days after my graduation, a 28-year-old woman who was diagnosed with leukaemia asked me to look after her three-year-old daughter and say goodbye to her at the end of her life, but I did not notice that she died at the end of the shift and I did not see her daughter. This bitter experience always remains in my mind, and I wish I could go back to that time and grant her wish." (p15)

1.4 Emotional relationship with patient: A nurse said: "I try to spend more time with the patients. Sometimes, I sit and talk to them, then they start to talk and express their feelings." (p15). Another nurse said: "Communicating with the patients is very important. They are sometimes depressed and sometimes aggressive, so I provide the right condition for conversation. For example, when I take their medicine to their room, I do not leave the patient's room quickly. I am the first to talk and I continue to talk to the patient." (p14)

1.5 Attention to human dignity: Nurses referred to dignified death in their caring experiences. "It's very hard to see a human dying. They're sometimes of our own age. I always pay attention to their

independence and their participation in decision-making with regard to treatment." (p13)

2. Family-Centered Care

Family-centered care included two sub-themes; "helping the family to regain their caring role" and "supporting the family."

2.1 Helping the family to regain their caring role: One of the nurses, in regard to her own experience with the family's presence on the patient's bedside, stated: "The law and regulations of the unit and hospital do not allow entry to this unit, but when I see the patient at the end of his or her life, I provide the condition and let one member of his or her family to come in and stay next to him or her." (p14)

Another nurse, in relation to the participation of family in the care of patient, stated: "I teach the patient's family simple procedures to help the patient, so I try to make them involved in the care of their patient. They feel good when they can do something for the patient at the end of his or her life." (p16)

"There are cases where, patients have some conditions and cannot make decisions for themselves," says another participant nurse: "In my opinion, the family is the patient's voice, so the family should be involved in decision-making for the patient." (p5)

2.2 Supporting the family: The participating nurses pointed to the family support after the patient's deaths in their interviews. One of the nurses in regard to the supporting of family after the patient's death said: "When a patient dies, I do not expel his/her family from the department. Most of them like to be alone with the patient for a while. I shut the curtain of the patient's room, and try to keep the area quiet." (p1)

Another nurse in the context of sympathising with the patient's family after death described her experience as: "I sympathise with them, I say I have seen your suffering and I understand you." (p6)

3. Personal and Professional Characteristics of the Nurses

This theme consisted of two sub-themes of; individual characteristics and professional characteristics of the nurses.

3.1 Individual characteristics: One of the nurses said, "I enter the patient's room with smile. The patient may be depressed, angry, etc, but I try to be kind to him and be happy." (p9)

Another nurse stated: "The patient says; "I have pain. Do you understand what pain is?" Many patients say this. However, the nurse should understand and be patience. The patient in this situation is sensitive, so I let them say whatever they want." (p2)

3.2 Professional characteristics: Nurses referred to the importance of professional characteristics of the nurses in the end-of-life care. One of the nurses said: "In the end-of-life care, I must have the necessary skills and abilities, and use the experience of others. I had just started to work and did not have the necessary skills. I was very stressed when I first became ill at the start of my work. I just liked to finish work as soon as possible, but my colleagues helped me a lot. After that, I tried to use my colleagues' professional experiences more often." (p15)

One of the nurses said, "Nurses in the oncology wards should have the professional skills. I teach the beginners in the morning shifts, and I try to familiarise them with the ward and characteristics of the hospitalised patients. I supervise them, teach them how to work with the equipment, and create conditions in which they could update their knowledge and, if necessary, work in other shifts with another experienced nurses." (p5)

DISCUSSION

In this study, the nurses' experience of end-of-life care in cancer patients was explained. In fact, all care efforts were based on holistic care.

Holistic care is an approach that focuses on all aspects of patient's existence. Gill F et al., in their study considered essential care for cancer patients [21]. Iranmanesh S noted that holistic care at the end of life for cancer patients facilitates a dignified and comfortable death process [15]. However according to Ghaljeh M et al., providing holistic care in the oncology departments has numerous challenges [11]. As Rafii F has shown in his study, nurses in Iran have become accustomed to routine care and focus only on core tasks, and refrain from performing tasks that are not done routinely [22].

In the present study, nurses referred to the patients-centered care in their experiences. Their perception was that every patient has a set of values, and nurses in end-of-life care should pay attention to cultural and religious values, wishes and needs of patients, as well as their human dignity. As the findings of Zheng RS et al., showed, care should be taken at the end-of-life to respect the values of dying patients [23,24]. Believing in values and respecting the beliefs can shape the care process and how the patient responds to care. Such care provides satisfaction and dignified death. A dignified and comfortable death is the ultimate goal of end-of-life care.

Another theme was family-based care. This type of care focuses on the role of family support. Nurses' experience showed that if nursing care is provided in a comprehensive and qualitative manner, support should be provided for not only the patients but also for their families. In fact, in the end-of-life care, family members of the patient need the nurses' support as their patients do, and nurses can never be held responsible for supporting family members during the bitter and unforgettable experience of death of their loved ones [25]. The results of Zheng RS et al., study showed that families play an important role in patient care at the end of life [23].

Moreover, Walker W et al., showed that most families need support when their relatives die. The family's presence at the patient's bedside leads to their satisfaction [26]. After death, it is important to pay attention to the patient's family. Providing enough time for the family to stay with their dead patient and grief in a decent and calm condition can considerably help the family [27]. The results of Mitchell M et al., study in Australia showed that family-based care increases the collaboration and support [28].

In any case, the nurses at oncology wards are the first to deal with the family of end-of-life patients, and are the first to face the grief of the family. In other words, they see the suffering of the patient's family. Therefore, supporting the family of these patients is a professional duty in end-of-life care. However, studies show that nurses pay less attention to how they perform their duties towards patient's family [29]. Nurses in critical care units do not welcome family-centered care [30]. In fact, in support-based care, although to support the family is one of the criteria but it is not considered because it does not clearly exist in the patient care protocol.

Participants in their experiences expressed that, the nurses' personal and professional characteristics affect the quality of end-of-life care. Findings of Allahyari FS et al., study showed that, nurses with a personality trait such as patience show more commitment towards their profession, and undertake their tasks more appropriately [31]. McEvoy L et al., in their study emphasised on the importance of individual characteristics appropriate to the profession, as they believed this factor is a prerequisite for the provision of holistic care [32]. The findings of Kaya N et al., study also revealed that nurses are more capable of identifying patients' needs and providing better care [33].

LIMITATION

In this study, the views of other healthcare workers, such as physicians, about their experience of end-of-life care were not evaluated. Considering that, end-of-life care is provided by a team of healthcare professionals, understanding the perception of other team members is also important.

CONCLUSION

This would improve nurses' experience of caring for dying patients and helps them to achieve a realistic view of their profession.

Future recommendation: It seems that more research is needed to explain the psychological support of nurses in oncology wards, models for participatory decision making, expression of nurses' beliefs about death and dying, palliative care for end-of-life patients, family involvement in care be done.

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