

Perception of Iranian nurses regarding ethics- based palliative care in cancer patients

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Abstract

Palliative care is still a topic under discussion in the Iranian healthcare system, and cancer patients require palliative care. Moreover, nursing ethics has an important role in caring for these patients. The purpose of this study was to identify the perception of Iranian nurses regarding ethics-based palliative care in cancer patients.

This study was done with a qualitative approach and by using content analysis. In this study, 14 nurses were selected through purposive sampling, and a face-to-face semi structured interview was conducted with each of them. After data collection, all interviews were transcribed and reviewed, and categories were extracted. At first, similarities in meaning were reviewed and based on centralization arranged in sub-categories. Then, relevant sub-categories were arranged in a category after a second review.

In general, original categories in the ethics-based palliative care in cancer patients encompass the following: "human dignity", "professional truthfulness" and "altruism". Human dignity has 3 sub-categories consisting of 'respecting patients', 'paying attention to patient values' and 'empathizing'. Professional truthfulness has 2 sub-categories consisting of 'truthful speech' and 'truthful action'. Lastly, altruism has 3 sub-categories consisting of 'complete and multi-dimensional patient acceptance', 'supportive behavior' and 'responsibility'.

Content analysis of ethics-based palliative care in cancer patients revealed the required conditions for this type of care based on the perception of nurses. The results of this study suggest that in nurses' point of view, human dignity, professional truthfulness and altruism all have important roles in ethics-based palliative care in cancer. The findings of this study will give nurses a greater knowledge about ethics-based palliative care in cancer patients, leading to a better understanding of the ethical needs of these patients, and may ultimately help improve the nursing practice.

Keywords: cancer, nursing ethics, nursing care, human dignity, palliative care

Introduction

Cancer is one of the major causes of death in the world. It is estimated that more than 15 million people will suffer from cancer by 2020 (1). This illness is a progressing problem in Middle Eastern countries (2). In Iran, cancer is the third important cause of death affected by factors such as genetics and the environment. Cancer occurrence in adults and in different regions of Iran is about 48 to 112 cases per million for females and 51 to 144 cases per million for males (3). Cancer causes physical and emotional malfunctions (4), and negatively affects the patients' lives. In this situation, patients require palliative care. Palliative care is offered for life threatening illnesses and is a comprehensive approach centralized on promoting life quality in its final phases. This type of care may prove helpful in confronting with chronic illnesses (5). Palliative care is a humanitarian need among cancer patients throughout the world (2) and its aim is to lessen patients' suffering by helping them figure out their pain, and physical, spiritual and ethical problems (6). Palliative care is important as it helps create a structured method in offering care and making patients feel good through availability of nurses, who in turn try to accept the patient and his or her emotional pleas. Factors such as focusing on professional laws in nursing highlight the importance of palliative care, and nurses' perception of this type of care in their work environment (7). In fact, palliative care for cancer patients is of a comprehensive nature (8), and humane cares generally employ a holistic approach concentrating on all dimensions of the patient (9). While caring for patients, nurses are constantly challenged by ethical issues since ethics in nursing calls for behaviors that would prevent harm to the patients from different aspects (10). Despite the emphasis on holistic, comprehensive and humane care, providing palliative care is really stressful for nurses (11) and results of a study show that from the viewpoint of nurses, adequate time is not allocated for this kind of care (12). Moreover, nurses' physical and mental fatigue is a burden to offering palliative care (13).

However, the major problem of the nursing system in Iran in offering palliative care to cancer patients is lack of a transparent framework for nurses, as palliative care does not receive serious attention in the formal education curriculum. It seems that one of the causes of this problem is lack of a comprehensive study in this field throughout the country, which restricts application of palliative care for these patients. The researcher's clinical experience shows that palliative care centered on ethics is present in patient care programs, and nurses offer this type of care. Although the

researcher believes that the majority of nurses working in cancer wards take ethical aspects into consideration, more nursing care is needed for palliative care centered on ethics. Reviewing texts, we found that there is a lack of studies on ethics-based palliative care for cancer patients in Iran, and that interpreting nurses' viewpoints and studying the involved factors closely can pave the way for a better offering of such care. It seemed suitable to perform such a research since identifying nurses' perceptions about ethics-based palliative care for cancer patients can lead to achieving the basic knowledge for offering related foundations to ethical care in nursing. These foundations help design studies on care and codify scales in this regard. The purpose of this study was to explain nurses' perception about ethics-based palliative care in cancer patients.

Method

The present study is a qualitative study done through content analysis. This method is one of the approaches of qualitative research and also of qualitative data analysis (14). Content analysis analyzes written, spoken or visual messages in which raw data are summarized and then categorized. In conventional content analysis categories and their names are taken from the data (15). In the present study, conventional content analysis was used.

Setting and Participants

Participants were selected by purposive sampling method. In this research, sampling was done from nurses with maximum variation (sex, marital status, job experience) to the point of data saturation. The criterion to choose the nurses was having job experience in the adult cancer ward for at least two years. In this study, palliative care was not limited to a certain type of cancer or a certain phase of this illness, and participants were working in wards covering different ranges of cancer patients in different phases of the illness. From the 14 nurses participating in this study, there were 10 females and 4 males, whose ages ranged from 27 to 48. Nine were married, and the rest were single. Their job experience also varied from 4 years to 17 years. The research field was limited to centers related to Tehran University of Medical Sciences such as Cancer Institute, Palliative Medical Center and Valieasr Hospital.

Data Collection

Deep semi structured and face-to-face interviews were conducted with 14 nurses. The interview time was about 30 to 45 minutes, and each of

the nurses was only interviewed once. In general, 14 interviews were done. Before the interview, both the researcher and the nurses agreed on the time and place of the interview. At the beginning of the interview, the nurses were asked a general question: What is your experience in ethics-based palliative care for cancer patients? In order to attain more information, the interview continued with probing questions.

Ethical Considerations

To respect ethical considerations, a letter of introduction was obtained from the research department of the Tehran University of Medical Sciences. The interviews were recorded. The nurses were assured that all the information would remain confidential, and after implementation, all the audio files would be destroyed. If they wished, they could receive the audio files. They also were informed that they could abandon the study any time they wished, but no one did.

Data Analysis

The interviews were recorded, and written manuscripts were typed on the computer. Implemented texts of the interviews were reviewed and broken down into smaller meaningful units. Then, codes were unlocked to be placed in sub-categories based on their semantic similarities. Finally, the researcher and the participants agreed upon a shared semantic about categories. The researcher did his best not to involve his presuppositions in the data analysis procedure. To determine data accuracy, criteria such as credibility, conformability, and dependability posed a permanent clash between the subject and the data (16). Viewpoints of the research team professors were applied in the process of interviews and data analysis. Interview manuscripts, extracted codes and sub-categories were discussed by some nurses and 2 people who have a PhD in nursing. Modulation was used in data gathering (interviews and notes from the field) to determine data dependability. Furthermore, an outside observer, who was a researcher familiar with both clinical environments and qualitative research and was not the member of the research group, was used. There was an agreement on the findings. To determine conformability, all the activities are registered, and a report was prepared on the research process. To determine data transferability, data gathered from 2 nurses outside of the study who had conditions similar to those of the participants were discussed and verified.

Results

Three categories were derived from the deep descriptions of the participants. These categories consisted of eight sub-categories (Table 1).

Table 1: Categories and sub-categories

Categories	Sub-categories
Human dignity	- Respecting patients - Paying attention to patient values - Empathizing
professional truthfulness	- Truthful speech - Truthful action
Altruism	- Complete and multi-dimensional patient acceptance - Supportive behavior - Responsibility

Human Dignity

This category focuses mainly on ethics-based palliative care in the form of respect for patients, paying attention to their values, and empathizing.

Respecting Patients:

From the nurses' viewpoint, respect for patients is very important in ethics-based palliative care. Regarding aggressive patients, the way we look at them must be scrutinized. One of the nurses said:

"Some of the patients are nervous and aggressive, they curse at us and throw things at us, but we must ignore such things. We have to respect them because they cannot control their behavior, and accepting the illness is difficult for them." [Nurse 5]

Participants believed that they have to let the patients know that they are respected. One of the nurses said: *"In my opinion, palliative care for cancer patients means that the nurse can calm the patient with the respect he or she offers and by inducing a good sense of respect to the patient."* [Nurse 8]

Paying Attention to Patient Values:

Nurses believed that human dignity is formed through respecting patients' values. A participant said, *"Palliative care is not merely to lessen the physical pain.... No, there are other things such as respecting patients' values. For example, a patient may believe in prayers and think they can calm him down, so an attendant may want to bring a prayer. As a nurse, I have to let them bring prayers, or if they cannot enter the ward, I have to take the prayer to the patient in the ward."* [Nurse 4]

Another nurse clarified the necessity of constantly paying attention to the values of the in every moment of their lives: *"I try to give the best care to the patients till their last breath, when there is no hope for improvement... I think every moment is important to these patients, and we as nurses have to be aware of that."* [Nurse 2]

Empathizing:

Nurses believed empathy to lead to human dignity in ethics-based palliative care. *"If we try to walk in the patient's shoes or consider the patient*

as one of our relatives, empathy will be possible,” one nurse believed.

“We have to walk in the patients’ shoes, patients who suffer from deformity because of chemotherapy, patients who suffer from metastasis, or patients who are going to have prosthesis operations. I’ve always said those being hospitalized are like my sister, father, mother or one of my relatives.” [Nurse 11]

Another nurse highlighted the importance of empathy through unification with the patient’s feelings.

“Sometime, I go to medicate the patient, and it takes a rather long time. When my colleagues ask for the reason, I say I didn’t just medicate him. When he talked about himself, I cried with him, and I have no fear to say that I have cried with him because I think I helped him get relaxed.” [Nurse 13]

Professional Truthfulness

This category concentrates on professional truthfulness, which is in the form of truthful speech and truthful action.

Truthful Speech:

Nurses believed that patients also need verbal truthfulness in attaining ethics-based palliative care. A nurse said, *“We try to honestly tell the patients about medicines which cause hair loss in the first session, and we spend time on it, because patients may be shocked after the hair loss. That’s why we pave the way for the patient from the beginning.”* [Nurse 10]

One of the nurses emphasized the importance of not telling lies:

“It is said: Not to give information to the patients, but I don’t agree. I tell the truth as far as I can because nowadays everyone has access to the internet, and most of the patients are educated, so they can easily surf through the net.... I have to say that we must not tell lies to them.” [Nurse 13]

Truthful Action:

Nurses believed that ethics-based palliative care results from truthful action. One of them said:

“All a cancer patient wants is to receive good care. And if we fail to do that and do not work honestly, for example, not give a drug dose to a chemotherapy patient, he has been mistreated, and the nurse must be responsible both in this world and the next, because this action can lessen the life of the patient for one year.” [Nurse 9]

One of the nurses emphasized the importance of truthfulness in action. She said: *“We have patients in the cancer ward who receive especial care; cancer has spread throughout their body and we are almost sure that they will die in 2 or 3 days, but we ethically do not stop giving care and continue to work honestly for their well-being.”* [Nurse 3]

Altruism

This category emphasizes altruism in ethics-based palliative care, and is divided into the three

sub-categories of complete acceptance, supportive behavior and responsibility.

Complete and multi-dimensional patient acceptance:

One of the important aspects of ethics-based palliative care in altruism is complete acceptance. The nurse understands the patients, and accepts them with their special conditions. This is observed in one participant’s words:

“I have accepted that cancer patients have a special condition and agreed to work with such patients. I mean I have been taught to consider all aspects of the patients. So, we accept the patients and their special conditions. If cancer nurses can’t accept these patients and their conditions, how can we expect other people of the society to accept them?” [Nurse 5]

Focusing on services regarding complete acceptance in the patients’ final days, another nurse said:

“I have accepted all the conditions in working with cancer patients wholeheartedly. I mean if all nurses pay thorough attention to the patients, we can better serve them.” [Nurse 11]

Supportive Behavior:

Another aspect of ethics-based palliative care that is related to altruism is supportive behavior. The nurse is the listener, advisor and confidante. Supportive behavior is defined as the following from the nurses’ viewpoints:

“Sometimes a cancer patient is in search of a person to talk to, for example, a patient came and talked to me about his problem and asked me for a piece of advice. I can say my colleagues and I play a supportive role for cancer patients. The patients come to us not only as their nurse but also as a sister or a friend and ask for advice. I personally believe that I must protect cancer patients and give them the necessary guidance.” [Nurse 9]

Being a good listener, based on another nurse’s viewpoint, is a sort of supportive behavior in ethical palliative care:

“I feel when I listen to patients; they will know that somebody supports them, a person who can be a good listener for their problems. A cancer patient definitely needs support.” [Nurse 6]

Responsibility:

Another aspect of ethics-based palliative care in altruism is responsibility, which is connected to nurses’ observance of ethical issues. According to one of the nurses, feeling responsible is so important that its absence may cause a sense of guilt:

“In this ward, you can perform routine and ordinary work, write reports and then go home, and nobody will know. But if you’re not responsible for what you did for these patients, then what? Ethically speaking, it is impossible to simply pass by.... If I don’t feel responsible in my job, I will feel guilty.” [Nurse 12]

One of the nurses asserted that the physical inability of patients is a stimulus for improving his sense of responsibility:

"You may want to take a short rest in the middle of your job, as is customary in other wards, but here you have to feel more responsible because seeing a physically powerless cancer patient provokes you not to rest and relax." [Nurse 1]

Discussion

Findings of this research showed that the nurses believed ethics-based palliative care for cancer patients can be divided into three categories: human dignity, professional truthfulness and altruism. Participants believed human dignity to be possible through considerations such as respect for patients, paying attention to their values, and empathy. In this regard, Baillie in England found that human dignity is an important concept in nursing which covers all human aspects and makes nurses see the patient as a thorough human. This concept is related to the values and social thinking of the people (17). In this respect, Lam stated that the importance of human dignity in the nursing profession is to protect it in ethical codes as a duty and to consider it as a right in human rights framework, and it is the nurse's responsibility to protect human dignity (18). Furthermore, this finding agrees with the statements in the Bagheri et al. study that human dignity is a central phenomenon in protecting patients, and is defined as being seen as a human being and respecting yourself and others (19). Our findings seem to be in line with the Mahmoodi Shan et al. results that confirmed respecting patients is among important ethical concepts that should stand out in a nurse's job (10). Since individual expectations related to human dignity are formed based on a person's viewpoints (20), if patients' dignity is preserved, they feel more powerful with a positive mental picture (21). Participants say that the patient must receive the best care till the last moment. This is in line with Aramesh's view that one of the prerequisites for human dignity is the right to live and die respectfully in the last phases of life (22). The findings of qualitative studies conducted by Kvale and Bondevik in Norway and Zagheri et al. in Iran indicated that respecting the patient and promoting this respect is of high importance (23, 24). Even in the case of aggressive patients, nurses in our study believed in respecting them because they thought that in ethics-based palliative care, it is possible to calm the patients through respecting them. Moreover, they believed that palliative care is not just lessening physical pain but respecting patients' values as a basic component of their human dignity. Lacey and Sanderson in Australia and Meran and Spath-Schwalbe in Germany also have mentioned supportive roles such as respecting human dignity in cancer patients (25, 26).

Nurses believed that empathy has a key role in preserving human dignity in palliative care. They also believed that one must consider the patient as one's relatives. Empathy with the patients, considering them as one's relatives and walking in their shoes is among important ethical concepts. Qualitative studies done by Mahmoodi Shan et al., Jo and Doorenbos, and Heijkenskjold et al. in Iran, Korea and England showed that considering the patient as one of your family members helps respect the patient's dignity (10, 27, 28). Empathy with patients is an ethical practice that can accelerate their recovery process (29) and lead to preservation of their dignity (30). Despite all the attempts made to preserve human dignity, there are situations that can weaken or threaten human dignity, such as disrespecting patients and not considering them as human beings (27, 28). It seems as if palliative care is mixed with preserving patients' dignity, and because the nurses in the present study believe in this ethical principle, they take it into consideration.

Another finding of the study showed that the nurses believed in professional truthfulness in ethics-based palliative care. They considered truthfulness in speech and action to be necessary for nurses, so much so that they believed in giving truthful information to the patients and explaining about the medication. The results of Kvale and Bondevik's study in Norway emphasized that giving truthful information to the patient is of high importance (23). In situations where telling the truth is vital to make the patient cooperate, although some disadvantages are probable, the truth must be told to suffer the fewest drawbacks (31). Nurses believed giving truthful information to the patient may lead to a better confrontation with the illness. Although learning that one has cancer is distressing and may initiate unpleasant reactions, giving correct information to the patient can help them better confront the cancer (32). Some resistance may be seen upon revealing to the patient that they have cancer, but not telling the truth is disrespecting their rights and is considered deception (33). Participants in the study declared that they spent time on giving truthful information to the patients and emphasized the importance of this ethical issue. Listening to the patients and getting to know them is the consequence of giving information and makes one sensitive to the patient's individual needs (34). Nurses believed that actions such as not giving medicine to the patient are inconsistent with truthful action. In another study, one of the important ethical implications of the nursing profession was being truthful (10). Participants believed even if the patient's death is imminent, the nurses must continue to act truthfully. However, a study showed that in America, the offered care to dying patients such as cancer patients is not suitable, and some invasive

interventions are performed that are in vain, and threaten the patient's quality of life in the remaining years (35). It seems that what makes ethics-based palliative care more meaningful is that nurses mix their clinical function with a supreme humane concept such as truthfulness. They must try to preserve this ethical attribute and beware of vices such as lying to the patients.

Nurses' explanations showed that altruism is one of the major aspects of ethics-based palliative care that is possible through the patient's complete acceptance, supportive behavior and responsibility. The results of another study in Iran showed that caring for patients is done with altruism (36, 37). As the nurses mentioned, they accepted and understood the patients and their special situation. A qualitative research conducted by Ohlen et al. in Germany also showed that for cancer patients, receiving palliative care is a process of a continual quest for understanding (38). With regard to complete acceptance, the participants pointed to the uniqueness of these patients' situation. The results of a phenomenological study conducted by Valente and Teixeira in Brazil showed that nurses consider caring for patients as something unique and especial (13). In the researcher's viewpoint, what propels the participants to completely accept the patient is the essence of the nursing profession that views human beings holistically. Nurses offer palliative care while considering this important issue. Another finding of the study showed that nurses' supportive behavior in ethics-based palliative care leads to altruism, in such a way that the patients consider them as their sisters, friends or advisors, as well as good listeners. In fact, palliative care is a basic supportive view of patients (34) as cancer patients need more care compared to other patients (39). The findings of qualitative studies conducted by Valizadeh et al., Chang and Park, and Rhondali et al. in Iran, Korea and the U.S. emphasized that supporting cancer patients is vital as it helps them better deal with their illness (40-42). As nurses in this study focused on supportive behavior, studies conducted in other cultures have verified these findings, too. We can therefore say that from the nurses' viewpoint, supporting the patient is of great ethical importance in palliative care.

Another finding of the study showed that nurses consider responsibility as an important component of altruism in ethics-based palliative care. Failure to fulfill one's responsibilities will cause a sense of guilt, as seeing the patients' inability makes nurses forget their own basic needs such as rest. Responsibility is a fundamental concept in nursing that is reinforced through conscientiousness and a lack thereof can hurt the patient. Responsibility calms

the conscience and neglecting it arouses a sense of guilt (10). Studies done in Iran and England showed professional responsibility as an important factor in caring (24, 43). One of the factors in palliative care may be that nurses ethically and legally consider themselves responsible for the patients, and believe this responsibility to be very important. Despite cultural diversity in the above-mentioned studies, the results are almost the same; therefore, paying attention to ethical issues is a basic factor in palliative care that is observed internationally in nursing. What differentiates this basic factor in Iranian culture from other cultures is the nature of human relations in the former, in that it considers all human beings as different organs of a single body who share prosperity and sorrow; this is intensified when somebody suffers from a severe illness. Consequently, it seems as if the nurses in our study consider themselves as one with the patient. This view leads them to preserve human dignity, professional truthfulness and altruism. It is recommended to explain the ideas of other people involved in caring for patients. This study did not cover general palliative care for cancer patients. It is recommended that in further studies, ethics-based palliative care be examined separately for cancer patients.

Conclusion

This study depicted only a small portion of the broad world of ethics-based palliative care from the viewpoint of the nurses and showed that ethical concepts have a pivotal role in palliative care. Although some concepts derived from this study can have different interpretations, the results showed that nurses care about concepts such as human dignity, professional truthfulness and altruism in ethics-based palliative care, and factors such as respect for patients, paying attention to patients' values, empathy, truthfulness in speech and in action, supportive behavior, complete acceptance of patients and responsibility are important to nurses. On the other hand, because this is the first qualitative research done on ethics-based palliative care for cancer patients in Iran's cultural context, the results may reveal some aspects of this kind of care in our society.

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