

# Human Relationships in Palliative Care of Cancer Patient: Lived Experiences of Iranian Nurses

Leili Borimnejad<sup>1</sup>, Marjan Mardani Hamooleh<sup>2</sup>, Naimah Seyedfatemi<sup>1</sup>, Mamak Tahmasebi<sup>3</sup>

Department of Nursing, Center for Nursing Care Research, Iran University of Medical Sciences, Tehran, Iran<sup>1</sup>

Department of Nursing, Nursing Education Center, Tehran University of Medical Sciences, Tehran, Iran<sup>2</sup>

Cancer Institute, Tehran University of Medical Sciences, Tehran, Iran<sup>3</sup>

Corresponding author: Marjan Mardani Hamooleh. Department for Nursing, Tehran University of Medical Sciences, Iran. Phone: +982166941669; Email: mardanimarjan@gmail.com:

## ABSTRACT

**Background:** cancer patients require palliative care. Aim: the purpose of this study was to explore the experiences of nurses, who provide palliative care for cancer patients, within the context of Iranian culture. **Methods:** we conducted a hermeneutic phenomenological study. Semi structured in-depth interviews with 10 nurses were audio taped and transcribed. The transcriptions were then analyzed by Van Manen's method. **Results:** one of the most important themes that emerged was "human relationships", which also contained the subthemes of "comprehensive acceptance" and "psychological support". **Conclusions:** the results provide deep understanding of human relationships in palliative care of cancer patients in Iran. **Key words:** cancer, Iran, Nurse, Palliative care, Phenomenology.

## 1. INTRODUCTION

Cancer is one of the most important causes of death in the world. It is estimated that more than 15 million persons will experience cancer in 2020 worldwide (1). Cancer patients are unable to continue their lives as it used to be and the appearance of problems in all aspects of personal, familial, and social life eventually leads the quality of life to decrease (2). Therefore, to prevent such events, palliative care is followed for this group of patients. In fact, palliative care is a comprehensive approach that focuses on improving the quality of life in its final stages and usually it is provided for life-threatening diseases with unpleasant prognosis (3). Palliative care for cancer patients includes physical, psychological, social, and spiritual dimensions (4). The main objective of this type of care is to reduce the suffering through early identification of problems in these patients (5). On the other hand, human relationships in this type of care for cancer patients are mainly formed in the framework of nurse-patient relationship. In this respect, Mok and Chiu (2004) in their qualitative study in China described that one of the key elements of good palliative care is the nurse-patient relationship. These relationships provided by palliative care not only improve the cancer patients' physical and emotional conditions but also facilitate their acceptance of disease, lower their pain, and eventually lead them towards a good experience over the last stages of life (6). A phenomenological study carried out in cultural texture of Iran also showed that the nurse-patient

relationships are associated with altruism and support and in general the concept of care is regarded as sacred (7).

Iran is an ancient country located in the Middle East with more than 5000 years of civilization and a population of about 70 millions, mostly Muslim (95%) and with a life expectancy of 71 years(8). Cancer is the third cause of death in Iran, after the heart disease and road accidents as the two leading causes of fatality. Cancer occurrence in Iran is estimated to be around 48-112 and 51-144 cases per million for women and men, respectively (9). As mentioned, the rate of cancer is high in Iran however, despite widespread medical centers for treating cancer patients, palliative care centers in this country are very limited and at present there is only one palliative care center located in the capital of Iran (Tehran) which is affiliated to Tehran University of Medical Sciences. Unfortunately, the wrong cultural beliefs about cancer are still present among people indicating that the cancer taboo has not yet broken and many Iranians believe that cancer is equivalent to death and end of life (10). According to our literature review, we found that the number of researches in particular those associated with qualitative studies on palliative care of cancer patients in Iran is so limited, therefore it seemed rational to the authors of the present study to perform a research in this field. The purpose of our study was to explore the experiences of nurses providing palliative care to cancer patients within the context of Iranian culture.

## 2. METHODS

This qualitative study was performed using a hermeneutic phenomenological approach. A qualitative approach was chosen because it describes lived experiences, gives meaning to them and increases the understanding of human experiences (11). Hermeneutic phenomenological approach in our study, would allow participants to focus on their life experiences through description of their personal experiences of giving palliative care to cancer patients. Van Manen (2001) presented a phenomenological method based on elements of Husserl and Heidegger's philosophies (12). He proposed 6 research activities for conducting hermeneutic phenomenology research, which are used in this study:

Activity 1: Returning to the nature of the lived experience. Activity 2: Searching lived experience material everywhere in the life world. Activity 3: Reflecting on the essential themes that characterize the phenomenon. Activity 4: Describing the phenomenon through the art of writing and rewriting. Activity 5: Maintaining a strong and focused relationship to the phenomenon. Activity 6: Balancing the research context by considering the parts and the whole. During the first activity, the researcher should make sense of a specific experience by posing profound questions and having abiding concern about the subject. In our study, the research question was raised when the second author was really impressed by the experience of giving care to cancer patients. In the second activity, we searched the literature about the lived experiences of individuals from around the world to be able to guide our participants. In the third activity, we used thematic analysis to identify what signified the experience of giving palliative care to cancer patients. In the fourth activity, we provided an exhaustive description of the findings to present the experience of giving palliative care as it emerged. In the fifth activity, we tried to understand the experience of giving palliative care in a more humanitarian sense and not to settle for superficialities and falsities. In the final activity, we simultaneously considered the whole and the contextual data to comprehend the contribution of each part to the formation of the phenomenon.

### 2.1. Participants

We recruited a purposive sample of 10 baccalaureate nurses (7 women and 3 men). The nurses ranged from 27 to 44 years of age, and had worked in the cancer wards for 6-10 years. The participants had been working in a palliative care center at least 3 years. The main criterion for inclusion was the experience of giving palliative care to cancer patients, the phenomena under the study.

### 2.2. Interviews

We employed a face-to-face, semi-structured interview method, lasting 40-65 minutes, for data collection. Second author performed all the interviews in Persian and translated them into English after transcription. Since 2 participants were interviewed twice (due to their long stories or fatigue), a total number of 12 interviews were conducted. At the end of each interview session, the researcher thanked the participant and scheduled the next interview, if any. The recordings were reviewed after each interview. Each interview was transcribed verbatim by the Jet Audio Lyric Maker and converted to rich text format to be compatible with the MAXQDA software which was used for data management. The interviews were continued until no new theme emerged. Data saturation was obtained after all of

interviews. Our interviews were conducted using "What is the meaning of giving palliative care to cancer patients?" as the main research question. The participants were asked to describe their lived experiences in their own words. After the nurses answered the above question, further questions were asked to gain richer data, such as: "Would you explain more about this?", "What is the meaning of that notion?", and "Could you please give me an example in order to help us properly understand your point?"

### 2.3. Procedure

Analysis of data was followed by activities 3-6 of the methodology suggested by Van Manen. In the activity 3, each transcription was read several times and a short description was written using a holistic approach (macro thematic reflection). In this interpretive act, we expressed the overall meaning of the text. After understanding the whole, a selective approach was employed to isolate the thematic statements (micro thematic reflection). The transcriptions were hence read repeatedly to identify the statement(s) that seemed particularly essential to or revealing about the palliative care experience of the nurses. These statements were highlighted and treated as thematic statements. After extraction of general themes, similar themes were clustered.

The process of analysis included moving back and forth between the whole and the parts of the transcripts to increase the understanding and compare the text and critical reflection on it. Collaborative analysis was then performed by presenting the preliminary findings to the co-researchers. Free imaginative variation was employed to differentiate and verify essential and incidental themes. In the activity 4, we used the art of writing and rewriting to thoughtfully bring the assessed phenomenon into written words. For achieving depth, the results were written exhaustively. In the activity 5, the researchers tried to deeply understand the phenomenon studied and to avoid superficialities and falsities in the whole process of data analysis. In the activity 6, using the hermeneutic circle, the researchers repeatedly referred to the whole and the parts of the text to analyze how they were connected. In addition, the interviews transcribed and coded in an iterative fashion because coding in this fashion allows the interviewer to incorporate information learned from previous interviews into subsequent interviews. In our study, all the transcripts were read repeatedly and compared with the audio-taped interviews to confirm the accuracy of the data. The credibility of the results and interpretations were assured through prolonged engagement with the data during all stages of the study. The authors interpreted and analyzed the findings as a team. This tactic helped to reduce the effect of any particular researcher's preconceived ideas on the final outcome. Further, a member check for validation of the interpretation and classification of the interviews was conducted.

### 2.4. Ethical considerations

The ethics committee of Tehran University of Medical Sciences approved the study. The data collection was carried out after obtaining verbal consent and a signed informed consent form from the participants. The nurses were given verbal and written information about the study. They had the right to withdraw from the study at any time during or after the interviews and could ask the researchers to return their audio-taped interviews. The interview setting was a quiet location in the palliative care center, on the basis of participant convenience and preference.

### 3. RESULTS

In this study, the main theme of “human relationships” was consisted of two sub-themes including the “comprehensive acceptance” and “psychological support”. In other words, the experiences of participants indicated that the human relationships in palliative care given to cancer patients bear two entities of “comprehensive acceptance” and ‘psychological support’ together. Here are some examples of the interviews presented to give the readers the opportunity to make a better judgment on the results provided with more details.

#### 3.1. Comprehensive acceptance

One important aspect of human relationships in the palliative care of cancer patients was the issue of comprehensive acceptance. Nurses could understand the patients and accepted them with their particular conditions. This is evident in the narratives of the participants:

*I have accepted the particular conditions of a cancer patient and agreed to deal with this group of patients; I have admitted that the patients in this place spend the end-stage of their lives; I have learned that a patient must be accepted as a human. If as a nurse I reject accepting a cancer patient, I should not expect the other members of the public to accept such patient.* These were statements mentioned by a female nurse with 10 years’ work experience.

*A cancer patient, even in the last days of life, has feelings indignant to man, understands the reactions shown by a nurse, and needs the nurse’s acceptance. I think this characteristic is specific to cancer patients’ ward, where a nurse with all her heart and soul understands a human who is facing the final days of life. I used to work in ICU and giving care to patients who were also spending the last days of their lives but this place is different because the patients are fully conscious.* These expressions were made by a female nurse with 7 years’ work experience. *By working in cancer patients ward I have accepted that it doesn’t matter if the cancer patient has just one day left to live in the world but what is important is to extend the useful load of this day into one month and even longer for the patient.* These were remarks mentioned by a female nurse with 6 years’ work experience.

#### 3.2. Psychological support

Another aspect of human relationships in the palliative care of cancer patients was related to psychological support. Nurses listened to patients and gave them advice to ease their problems. Here are some examples of psychological support expressed by our participants in their narratives:

*Sometimes cancer patient are looking for someone to trust in order to decrease the load of their excitement through self-expression. For example, one patient came to me seeking for consultation over a problem and asking what decision is better to make to solve the problem... I can tell you that I and my colleagues in this place are sponsors for cancer patients and they do not come to us only as a nurse but they refer to us as a sister or a friend and seek counseling. I personally think that I have to support cancer patients and give them necessary guidance.* These expressions were made by a female nurse with 8 years of work experience while talking with great enthusiasm.

*When I listen to a patient and sit next to him, he realizes that there is someone acting as his patron, a person who is the listener of his problems. Although many cancer patients of this place know that they will die soon but I think I can help them. Sometimes I come to the conclusion that the patient is just one step away from*

*the cemetery but it does not cause me to leave the patient alone, instead, I try to be with patient under any circumstances to increase the patient’s tolerance against cancer.* These were some comments made by a male nurse with 9 years work experience.

### 4. DISCUSSION

In present study, the human relationships in palliative care of cancer patients were revealed as the nurses described their experiences. On the other hand, this study introduces the human relationships as a key aspect of experiences found by the Iranian nurses while providing palliative care to cancer patients. The experiences of nurses participating in this study suggest that the human relationships as one of the aspects of palliative care for cancer patients consisted of two sub-themes referred as “comprehensive acceptance” and “psychological support”. Several studies have mentioned the role of human relationships in caring for cancer patients and those at end-stages of life. The results of a qualitative study in the United Kingdom showed that the social relationships are considered as the center of palliative care for patients with life-limiting conditions (13). Also, in another qualitative study carried out in the USA to examine the factors associated with the palliative care offered to patients at end-stage of life, the dominant theme revealed was the issue of relationship (14).

The first sub-theme in our findings was the comprehensive acceptance. Based on the experiences of Iranian nurses over human relationships with cancer patients, the nurses comprehensively accepted and understood the cancer patients under any circumstances because of their specific conditions. As Abraham (2012) also stated, the palliative care for cancer patients is a comprehensive care (15). Likewise, in another qualitative study, the degree of understanding over the rehabilitation of cancer patients among 21 Korean nurses working at cancer wards was investigated. The semi-structured interviews applied were conducted with nurses in the focused groups. Two major themes found in the study were comprehensive nursing activities and active involvement with patients while sharing feelings was demonstrated to be one of the sub-themes of such engagement (16). The results of a study involving 14 cancer patients showed that the palliative care for cancer patients is a process of continuous search to know and understand such patients. In addition, our nurses described that the type of palliative care offered to cancer patients must be specific. Similarly, in a hermeneutic phenomenological study by Valente and Teixeira (2009) in Brazil in which 17 nurses participated, it was concluded that the type of caring given to patients at their end-stage of life should be unique and specific (18).

The second sub-theme of our findings was the issue of psychological support. Our study showed that cancer patients trust nurses and love them like their sisters or advisers. In fact, trust is an important element of nurse-patient relationship in the field of palliative care. The results of a qualitative study in China indicated that when relationships between nurses and cancer patients are formed based on trust; the patients do not consider the nurses only as care providers but regard them as part of their families or a good friend. In addition, the nurses who build up the relationships based on trust, show a holistic approach towards patient care, get familiarity with their unstated needs, and provide them with comfort without being asked to do so (6). The findings of the present study revealed that the nurses

who offered palliative care to cancer patients were good listeners. Other researchers described that when providing patients with palliative care, it should be noted to consider their personal and social needs as allocating time to listen and understand the patients could provide the opportunity to know them and make a stand for developing a better communications (19). In an ethnographic study, a semi-structured in-depth interviews with 10 Sri Lankan nurses showed that the cancer patients initially need the nurses' support to have their physical pain and complications alleviated(20). Also, the results of a study in Australia confirmed that offering support to cancer patients improves their communications (21). The findings of another study showed that cancer patients need to receive support more than other patients (22). Moreover, another study reported that support is one of the important approaches to cope with cancer and play a crucial role in improving the patients' quality of life (23). Similar to the experiences of Iranian nurses concerning the human relationships in palliative care of cancer patients in which the issue of psychological support was emphasized, the qualitative studies conducted in other cultures have also confirmed these findings. In a qualitative study while the Korean nurses expressed their experiences associated with giving care to cancer patients, the importance of clinical support for this group of patients was highlighted (16). Likewise, the results of another study reported from the State demonstrated that providing the cancer patients with support improves their ability to withstand disease (24). In a qualitative study carried out in Iran also demonstrated that cancer, as a stressful event, affects patients emotionally therefore, the psychological support of cancer patients by nurses is of prime importance (10). Other researchers in their study also pointed out the emotional role of nurses in caring of cancer patients in Israel (25). Despite the cultural diversity of the studies, similar results are observed therefore it could be concluded that the issue of psychological support is one of the essential elements of palliative care for cancer patients which is globally a focus of attention in nursing but what makes this essential element in the Iranian culture different from other cultures is the strength of human relationships in which the members of the society are considered as the organs of one body who share their agony and happiness. These relationships even become stronger when an individual is suffering from an incurable disease. Therefore, it seems that, our nurses in the field of palliative care of cancer patients have a single body and this leads them towards comprehensive acceptance and psychological support of cancer patients.

## 5. CONCLUSION

Our results provide deep understanding of experiences obtained by the Iranian nurses over human relationships in palliative care of cancer patients. These findings also show that the relationship between nurses and cancer patients is a close connection in a supportive atmosphere with comprehensive acceptance of patient. On the other hand, given that this is the first study on the palliative care of cancer patients conducted in the cultural context of Iran, the results obtained in this study could reveal some aspects of palliative care of cancer patients in this society. This study was performed on a limited number of nurses. The small sample size and the nature of the study limited the ability to generalize the findings. However, as with all qualitative researches, the results were not intended to be

generalized. Nevertheless, the findings of this study add to the body of knowledge in this area.

### Acknowledgments

*The authors are grateful to all the nurses in this study who were willing to share their experiences with us. This research as part of the second author's PhD thesis supported by Tehran University of Medical Sciences.*

### CONFLICT OF INTEREST: NONE DECLARED

### REFERENCES

- Higginson IJ, Costantini M. Dying with cancer, living well with advanced cancer. *Eur J Cancer*. 2008; 44: 1414-1424.
- Landier W. Adherence to Oral Chemotherapy in Childhood Acute Lymphoblastic Leukemia: An Evolutionary Concept Analysis. *Oncol Nurs Forum*. 2011; 38: 343-352.
- Van Mechelen W, Aertgeerts B, De Ceulaer K, et al. Defining the palliative care patient: A systematic review. *Palliat Med*. 2013; 27(3): 197-208.
- Miyashita M, Nakamura A, Morita T, Bito S. Identification of quality indicators of end-of-life cancer care from medical chart review using a modified Delphi method in Japan. *The Am J Hosp Palliat Care*. 2008; 25: 33-38.
- Schneider N, Lueckmann SL, Kuehne F, et al. Developing targets for public health initiatives to improve palliative care. *BMC public health*. 2010;10: 222.
- Mok E, Chiu PC. Nurse-patient relationships in palliative care. *J Adv Nurs*. 2004; 48: 475-483.
- Nikbakht Nasrabadi A, Emami A. Perceptions of nursing practice in Iran. *Nurs Outlook*. 2006; 54: 320-327.
- Navab E, Negarandeh R, Peyrovi H. Lived experiences of Iranian family member caregivers of persons with Alzheimer's disease: caring as 'captured in the whirlpool of time'. *J Clin Nurs*. 2012; 21(7-8): 1078-1086.
- Mousavi SM, Pourfeizi A, Dastgiri S. Childhood cancer in Iran. *J Pediatr Hematol Oncol*. 2010; 32: 376-382.
- Valizadeh L, Zamanzadeh V, Rahmani A, et al. Cancer disclosure: Experiences of Iranian cancer patients. *Nurs Health Sci*. 2012; 14: 250-256.
- Streubert HJ, Carpenter R. *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia, PA: Wolters Kluwer Health, Lippincott Williams & Wilkins, 2010.
- Van Manen M. *Researching lived Experience: Human Science for An Action Sensitive Pedagogy*. London, ON: The University of Western Ontario, 2001.
- Hyde V, Skirton H, Richardson J. Palliative day care: A qualitative study of service users' experiences in the United Kingdom. *Nurs Health Sci*. 2011; 13: 178-183.
- Nelson JE, Puntillo KA, Pronovost PJ, et al. In their own words: patients and families define high-quality palliative care in the intensive care unit. *Crit care med*. 2010; 38: 808.
- Abraham JL. Integrating Palliative Care Into Comprehensive Cancer Care. *J Natl Compr Canc Netw*. 2012; 10: 1192-1198.
- Chang HK, Park YH. Cancer rehabilitation from the perspectives of oncology nurses in Korea. *Nurs Health Sci*. 2012; Oct 29.
- Ohlen J, Wallengren Gustafsson C, Friberg F. Making Sense of Receiving Palliative Treatment: Its Significance to Palliative Cancer Care Communication and Information Provision. *Cancer Nurs*. 2012; Oct 9.
- Valente SH, Teixeira MB. Phenomenological study about the nurse's home care for families of terminally ill patients. *Rev Esc Enferm USP*. 2009; 43: 655-661.
- Edwards A, Pang N, Shiu V, Chan C. Review: The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliat Med*. 2010; 24: 753-770.
- De Silva BS, Rolls C. Attitudes, beliefs, and practices of Sri Lankan nurses toward cancer pain management: An ethnographic study. *Nurs Health Sci*. 2011; 419-424.
- Jones R, Regan M, Ristevski E, Breen S. Patients' perception of communication with clinicians during screening and discussion of cancer supportive care needs. *Patient Educ Couns*. 2011; 85(3): e209-e215.
- Stenberg U, Ruland C, Miaskowski CH. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology*. 2010; 19: 1013-1020.
- Weibull A, Olesen F, Neergaard MA. Caregivers' active role in palliative home care—to encourage or to dissuade? A qualitative descriptive study. *BMC Palliat Care*. 2008; 7: 15.
- Rhondali W, Burt S, Wittenberg-Lyles E, et al. Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study. *Palliat Support Care*. 2013; 10: 1-8.
- Admi H, Zohar H, Rudner Y. "Lighthouse in the dark": A qualitative study of the role of breast care nurse specialists in Israel. *Nurs Health Sci*. 2011; 13: 507-513.