

ORIGINAL RESEARCH

Caring at the end of life: Iranian nurses' view and experiences

Sedigheh Iranmanesh, Masoud Rayyani, Mansooreh Azizzadeh Forouzy

Razi Faculty of Nursing and Midwifery, Kerman Medical University, Kerman, Iran

Correspondence: Masoud Rayyani. Address: Razi Faculty of Nursing and Midwifery, Kerman Medical University, Kerman, Iran. E-mail: mrayyani@kmu.ac.ir

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Abstract

Nurses play a principal role in the caring for dying persons and their families. The nurses' working organization and social context may influence formation of their values and beliefs towards death and dying as well as their approach to the persons who are dying. This study thus conducted to examine nurses' view and describe their experiences regarding end of life care. A mixed method research was conducted to describe Iranian nurses' attitudes as well as their experiences in the field of end of life care. FATCOD questionnaire was used to examine 55 oncology nurses' attitudes towards caring for dying persons. Of these, 23 participated in qualitative part of study. In depth individual, audio-taped interviews were conducted. A latent content analysis approach also was used to explore nurses' experiences of caring for dying persons. The results showed a moderate positive attitude towards giving care to the people who are dying among the participants. They had no tendency to accept patients and their families as in charge decision makers or involve them in the care. Qualitative findings revealed two themes including: rewarding and disappointing experiences. The lack of palliative care units and its education as well as some cultural and professional limitations may have contributed to the formation of barriers and negative attitude towards some aspects of the care among nurses working with dying people in the Iranian context. Therefore, establishment of palliative care unit, incorporation of palliative care into undergraduate nursing studies, and cultural preparation through public education can improve quality of care at the end of life.

Key words

Caring for dying, Attitude, Iranian nurses, Experiences, Mixed method

1 Introduction

Human lives include a steady existential questioning and search for meaning. Death is an inevitable and natural phenomenon. The steady increase in organ transplantation requires physicians to define death and to determine when a patient is considered a dead body. Previously, brain death was considered the death of a brain in a living patient. Today, brain death is considered as the death of the patient^[1]. Death causes an existential crisis for many people, especially those who are facing a life-threatening disease. According to Sand and Strang^[2], the inevitability of death triggers an existential crisis that involves patients' and families' emotions and perceptions. This leads them to experience existential isolation. During the last few decades, the number of people living with life threatening diseases has increased. They need to lead a

meaningful life, even when they are at the end stage and may have only months to live. This invoked the establishment of palliative care units.

The philosophy of palliative care is to alleviate suffering and to improve the quality of life of patients who are facing death. Therefore, the values and beliefs of the nurses towards death and dying should be directed towards that philosophy. Personal motivation, which is a reflection of a nurse's attitudes towards giving care to people who are dying^[3], might be affected by the his or her beliefs and values about death^[4]. It might also be affected by his or her personal and professional experiences related to death and dying^[5]. The perception of caring for dying persons involves nurses having professional attitudes and skills in order to provide good care. This includes emotional and practical support^[6]. According to Keegan^[7] et al., the dying persons' relatives consider all aspects of care important towards the end of life. However, they pay special attention to the attitudes with which care is given and how it preserves the patient's dignity. Studies exploring the experience of being a family member of a dying person^[8,9] have revealed the family members' grieve with feelings of sadness and helplessness. They need active informational and emotional support from nurses.

The nurses' working organisation and social context also may influence the way they approach to the dying people. This occurs through the acquisition of caring attitudes and the development of caring behavior^[10]. Caring behavior is learned in both the institutional and social context. These can be transferred by narratives about people who embody ideal care. The concrete content of care depends on a person's capacities and on the prevailing cultural traditions in the community from which that person comes. Thus, the understanding of care from a single nurse's point of view and its content depends on the life story of that nurse^[11]. The nurses' understanding of care as well as his or her attitudes and behavior become more important in the context of palliative care, where a variety of feelings and experiences are evoked in the face of death. Different views on death are based on the differences in various cultures. The prospect of mortality could be both the foundation on which culture is built^[12] and the primary challenge in the search for meaning^[13]. So this study aimed to respond two questions: (1) "What attitudes do nurses in Iran have towards caring for dying people?" and (2) "What experiences do nurses in Iran have when caring for dying people?"

2 Method

2.1 Design

There was an approval from the heads of oncology care unit in Valiasr hospital prior to the collection of data. This hospital supervised by Tehran University of Medical Sciences. A mixed method design as described by Creswell and Plano Clark was used to access the aim of study^[14]. The choice of combining qualitative and quantitative studies in this study was based on research questions that could not be answered by a single method. The field of mixed methods developed as a pragmatic approach focusing on research questions. It developed in order to utilize the strengths of qualitative and quantitative methods^[14].

2.2 Participants

In quantitative part of study, 55 staff nurses who were currently working in oncology care unit were considered as potential participants. Of these, 23 participated in qualitative part of study. All of participants were registered nurses with BSc degrees in nursing. Their mean oncology experience was seven years.

2.3 Procedure

In quantitative part of study, firstly, a questionnaire was designed to obtain background information which was assumed to influence on attitude towards death and dying. It was developed based on the experiences of a pretest among nurses and included 4 categories of the questions: 1) personal characters like gender, and age; 2) professional characters like previous education about caring for dying patients, years of nursing experience and years of working with people who are dying; 3)

previous experiences related to death within last 6 months such as experience of caring for a dying member in the family, experience of death of someone closed and experience of life threatening situation; 4) religiosity index consists of intrinsic (belief in God) and extrinsic (attendance to the religious services and activities) religiosity.

The degree to which participants considered themselves as likely or unlikely to care for people at the end of life was measured using Frommelt's Attitude towards Care of the Dying (FATCOD)^[15]. This scale consisted of 30 items designed to measure participants' attitudes towards providing care for dying persons. The questions were graded from 1 to 5 (1= strongly disagree to 5= strongly agree). Fifteen of the items were worded positively, and fifteen were worded negatively.

55 sets of questionnaire were distributed with a drop out of 5. In all collected data, 98 % of all questions were answered. The validity of scale has been assessed through a content validity discussion. Scholars of statistics and nursing care have reviewed the content of the scales from religious and cultural aspects of death and dying and agreed upon a reasonable content validity. The alpha coefficient for FATCOD was 0.78.

In qualitative part, the main approach to collecting data was based on a qualitative method of data collection. These comprised of individual interview. In depth individual, audio-taped interviews were conducted with the participants. The data analyzed with latent content analysis.

2.4 Qualitative data analysis

The participants were asked to describe their experiences of caring for dying people. As necessary, clarifying and encouraging questions were used such as: Can you explain a little more what you mean? Can you give me an example? The researchers, who were born in Iran, spoke the native language (Farsi). The interviews were read several times to get a sense of the whole. The text was extracted and brought together into one text, which formed the unit of analysis. The text was divided into meaning units that were condensed. The condensed meaning units were abstracted and labeled with a code. The various codes were compared based on differences and similarities and sorted into sub-themes. Finally, the underlying meaning, that is, the latent content, of the categories, was formulated into two themes.

2.5 Statistical analysis

In quantitative part of study, data from the questionnaires were analyzed using the Statistical Package for Social Scientists (SPSS). A Kolmogorov-Smirnov test indicated that the data were sampled from a population with normal distribution. Descriptive statistics of the sample and measures that were computed included frequencies, means and reliability. Pearson correlation was used to examine relationships among the measured factors and scores on the FATCOD.

3 Results

3.1 Participants

A descriptive analysis of the background information (see Table 1) revealed that the participants belonged to the age group of 20-40 years with a mean age of 28 years and were mainly female (82.6%). The majority had a Bachelor of Science degree in nursing (91%) with 1-10 years' experience of working in hospitals (65%). All participants claimed that they were not educated in caring for people who are dying. Almost 88% of respondents stated that they had 1-5 years of experience of caring for people at the end of life. Regarding previous experience of death and dying, 46.5% had the experience of death of someone closed, 29% had the experience of care for a dying member in the family and 53.9% had experienced a life threatening situation within last 6 months. Considering religiosity (see Table 1), while 89% of respondents reported that they always experience God existence in their daily life, 24.2% claimed that they attended to the religious services daily. Of participants, 68.4% stated that they attended to the religious activities like pray daily.

Table 1. Most of the background characteristics of the sample

Variable	%
Nursing experience (year)	
1-10	65
10-20	28
More than 20	7
Experience of working with dying patients (year)	
1-5	88
5-10	12
More than 10	0
Palliative care education	
Yes	0
No	100
Experience of death of someone closed (within last six months)	
Yes	46.5
No	53.5
Experience of a life threatening situation (within last six months)	
Yes	53.9
No	46.1
Experience of care for a dying member of family (within last 6 months)	
Yes	29
No	71
Attendance to the religious services	
always	24.2
often	50
sometimes	25.8
Never	0
Personal experience of god existence	
Always	89
Often	9
Some times	2
Never	0

3.2 Quantitative findings

Descriptive analysis (see Table 2) indicated a moderate positive attitude towards giving care to the people who are dying among the participants (mean=3.87). Most of the nurses in this study were likely to giving care and emotional support to the persons at the end of life and their families as well. They acknowledge care of the people at the end of life as a worthwhile experience. Most of the participants had not tendency to involve the persons who are dying and their families in the care and accept them as in charge decision makers. They also reported themselves unlikely to talk about death with persons at the end of life and even educate them about death and dying. Furthermore, they stated that they are not likely to

give the honest answer to the dying persons about their conditions. Among demographic characters, the experience of caring for a family member who is dying ($r=0.315$) found positively correlated with attitude towards giving care to the people at the end of life. A positive correlation was found between intrinsic religiosity (belief in god) and participants' attitudes towards caring for dying people ($r=0.261$).

Table 2. The scores of some items of FATCOD questionnaire

Scale	Scale items	Mean	SD
FATCOD	Attitude towards caring for dying patients and their families	3.87	0.36
	Giving nursing care to the dying person is a worthwhile learning experience.	4.88	1.20
	The family should be involved in physical care of the dying person.	2.25	1.24
	Dying people should be given honest answers about their conditions.	2.14	1.25
	The dying person and his or her family should be the charge decision makes.	2.44	1.11
	Families need emotional support to accept the behavior changes of the dying person.	4.91	0.58
	I would be uncomfortable talking about impending death with the dying person.	4.77	1.32
	Educating families about death and dying is not a nursing responsibility.	4.64	1.25
	I would be uncomfortable if I entered the room of terminally ill person and found him or her crying.	4.52	0.97

3.3 Qualitative findings

3.3.1 Rewarding experiences

The nurses described that caring for dying improved their own personal ways of life: personally and professionally. They experienced that working with patients in the oncology wards required them to be closer and more compassionate to them compared to care giving work in the other wards. Iranian nurses expressed that they learned to be compassionate in a process that took several years.

“As soon as I want to shout at my children, I remember my patients and I think that I should not be angry. I learnt to be patience.”

Religious beliefs seemed to give insights into the need to be compassionate. Values and religious beliefs and practices gave new meaning to nurses' professional lives. Their spiritual foundation and religious beliefs assisted them in a positive way to cope with and provide meaning to the caregiving work on the oncology unit. They also referred to specific religious beliefs that guided their practice or their approach to patients. One of them talked about her belief in a life after death, a circular process of life and death as a divine order, and that such a belief facilitated forming caring relationship with people at the end of their lives:

Really, I am not afraid to get close to a person who is near to the death, because I believe that death is just a bridge between this earthly life and the life after death.

The nurses' personal experiences also contributed to the development of being compassionate. They described how their own experiences of having a family member with cancer had affected their approach to these patients. One experienced nurse who had children of her own claimed that insights gained as a mother made her understand the feelings of a mother of a baby with cancer:

I am a mother and I am not able to see even a small sore or a little blood on my baby's hand, so maybe that is why I am very kind with babies and their mothers.

Nurses experienced that relations with dying persons made them change the way they looked at their own lives. They discovered that they had changed their views on many things. Witnessing people's suffering made them re-examine their own attitudes towards life and accept that incurable disease and death are parts of life.

"I can say that I realized what is important in life and some of the things I thought were important are not. That is why I am really satisfied."

An important part of the nurses' descriptions of rewarding experiences was the positive feedback and acknowledgment they received from many patients they cared for, and from their family members. This included a caring relationship where nurses felt that they had been able to meet personal needs, share their life stories, and comfort them. The acknowledgment from the family members often continued even after the death of the families' loved ones. The nurses gained personal strength and a feeling of being valued from these appreciations.

"When a patient acknowledges me, I feel that I am a positive human being because I can do something to save another one's life".

They expressed this as being rewarding, gaining an inner strength, and being more patient with their own personal problems. Participant nurses commented about their inspiring experiences, whereby they have been witness to the special situation. Two nurses explained about their vitalized experiences and how they got energy from being witness to the dying persons- families' relations.

"It was really surprising to see how kind those two girls were towards their stepmother and how they took care of her."

Some nurses stated that since working with end of life persons, their fear of death decreased and their acceptance of death increased. They felt that it is their different view on life that leads them to have a different view on death as well. They explained their experiences as a self-transcending, unifying force, which finds meaning in life, disease and death as commented:

"Now this earthly life is so unvalued for me due to what I have seen here. I believe that death will come to me sooner or later."

3.3.2 Disappointing experiences

The participants elucidated another key intervening condition as the lack of autonomy among nurses towards the dying persons who they have cared for. They emphasized that nurses in spite of spending a lot of time with dying persons and being the most informed of their needs, are not able to intervene in the decisions made to provide the dying persons wellbeing as indicated.

"We spend a lot of time with patients but we cannot decide about their environment, their food and their clothes."

The lack of palliative care to focus on people's special needs during the process of death and dying was found to be the other barrier in the participants' narrations. They described that in the oncology unit they just use chemotherapy or other life- saving strategies which leads dying persons to face an uneasy death.

"Actually we just try to extend their life with chemical drugs, even if we see how they suffer from those drugs and how many difficulties they have."

Palliative care, however, provides them an opportunity to help persons to overcome the fear and sadness as natural responses to death. One of them expressed her own experience with a person who was close to death, but still expected something to be done for her. It was difficult for her to accept her own death.

“She was at the end. Her eyes were insistent with me to understand. I felt terrible that I still could not do anything for her.”

They explored that dying persons in an oncology unit are not able to choose their treatment and have no authority to decide about the sedative drugs, while in palliative care, the persons and their families have the right to participate in every decision making process:

“They at least should be able to use sedative drugs, but the physician is the one who decides even about using sedative.”

The text also revealed frustration about the tension between telling the truth and the cultural code of always preserving hope. Some nurses were frustrated at not being allowed by physicians to tell the truth about diagnoses. On the other hand, there were also some who felt that patients would not be prepared to hear that they had an incurable disease, and that disclosure could hasten their death. One argument for being open and telling the truth was that the person with cancer could then accept the disease and fight it instead of denying it. Telling the truth could also provide an environment where nurses could educate clients and their families. Such openness could facilitate discussion about how to reduce or even stop the progression of cancer and help patients to overcome fear and sadness:

In the last moments he still was not able to accept that he was near to death, so he held my hand and appealed to me to do something for him.

4 Discussion

The overall aim of this study was to describe nurses' views on and experiences of caring for dying people in the cultural contexts of Iran. According to the qualitative findings, the lack of palliative care to focus on people's special needs during the process of death and dying was a barrier in the participants' descriptions. Quantitative results showed that none of participants had educated in caring for people who are dying. The results also indicated that the Iranian nurses did not have positive attitudes towards caring for dying people. It could be related a lack of palliative care education, and lack of specific training among Iranian student nurses. Kwekkeboom et al. ^[16] as well as Mallory ^[17] reported that nursing education, including courses dealing with death and dying, has a positive effect on nurses' and student nurses' attitudes towards death and caring for dying people. The importance of education is further elaborated on by Miyashita et al. ^[18], who state that palliative care education affects nurses' attitudes towards care and helps them develop strategies to alleviate the communication difficulties between nurses and patients.

The results showed that Iranian nurses were not likely to talk with patients about death. Furthermore, Iranian nurses were frustrated with the lack of organizational support and that they were not allowed to tell the truth to the persons and their families. Miyashita et al. ^[18] concluded that autonomy has a positive impact on nurses' attitudes towards caring for dying people. The lack of autonomy among Iranian nurses could be related to public healthcare views on the nurses' profession. According to Emami and Nasrabadi ^[19], the Iranian public views the nursing profession as less than professional. Emami and Nasrabadi ^[19] stated that nurses working in Iran described their profession as socially undesirable.

Iranian nurses felt that even if they would be allowed to tell the truth, the cultural context, expressed in kinship relationship, would not be accepted. They found that patients and their families were not prepared to hear about incurable diseases. A disclosure could hasten their death. This finding should be considered in the cultural context prevailing in Iran. The individual is viewed as a part of the family. The society values people's mutual dependency and harmony within the family rather than the individual's autonomy ^[20, 21]. Iranian family ties become more obvious when a person becomes sick. Professionals in the health care system may hesitate to tell the patients and families grave news. They believe that it could strike the whole family and temporarily paralyze their lives.

Based on the qualitative and quantitative findings, nurses viewed and experienced caring for dying people as a worthwhile learning experience that developed them personally and professionally as well. The nurses' development could be interpreted as part of the mutuality or reciprocity that existed in the caring relationships with dying persons. Maturity and growth are important elements in relationships between patients and nurses during end-of-life care^[22-24]. An asymmetry in caring relationships could potentially be unethical if it is not balanced with reciprocity^[25]. Personal and professional development can be the main strategy that nurses use to cope with the challenging work that they do. Wengström and Ekedahl^[26] claimed that professional development is a coping process that nurses use when caring for persons with cancer.

According to qualitative and quantitative findings, nurses' personal experiences had positive effect on their attitude as well as their experiences of caring for dying persons. Based on Dunn et al.^[5], nurses' personal motivation to care for dying people is affected by their personal and professional experiences related to death and dying. Barrere et al.^[27] found that experience with family members who were dying positively change attitude towards caring for dying people. Previous death experience was correlated negatively with a positive attitude towards caring for people at the end of life^[28].

The quantitative findings indicated that belief in God positively affected nurses' attitudes towards caring for dying people. Nurses also experienced that religious beliefs gave them insights into the need to be compassionate. This corresponds with Lundmark's results^[29]. That study found a positive correlation between religiosity and spiritual care to people who are dying. Schoenrade suggested that a belief in the afterlife permits an individual to reconcile the positive and negative aspects of death. By enhancing the perspective of death, such beliefs allow individuals to accept the negative aspects of death^[30].

5 Conclusion

The results in this study suggests that education about caring for persons at the end of life should be included in the education of registered nurses as being of utmost importance for the attitudes towards death and care at the end of life. Nurses should be offered opportunities to reflect on their experiences, feelings, actions and reactions to death and caring for dying people in their families in order to enhance the possibilities to utilize personal experiences as a part of positive and constructive learning. This requires access to professional supervision for re-interpreting their personal and professional experiences. The nurses in this study were supported by their own philosophical foundation, but they also needed support from the socio-cultural and organizational context. Professional care for dying people is potentially a learning process that developed the nurses' personal and professional life when supported by teamwork, reflective practice and counseling based on nurses' personal and professional histories.

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