

Caring for Dying Patients: Feelings, Thoughts, and Attitudes of Nursing Students, A Mixed Methods Study

Ölmekte Olan Hastaya Bakım: Hemşirelik Öğrencilerinin Duygu, Düşünce ve Tutumları, Bir Karma Yöntem Araştırması

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ABSTRACT Objective: It is thought that nursing students are not willing to participate in the complex care of dying patients. The aim of the study was to determine feelings, thoughts, and attitudes of nursing students regarding the care of dying patients. **Material and Methods:** A partially mixed concurrent dominant status design was used in the study. Focus group interviews were conducted to determine nursing students' feelings about and views of the care of dying patients. Five focus group interviews were conducted at the qualitative data collection stage. Frommelt Attitudes Toward Care of the Dying Scale was used to measure attitudes. **Results:** Four themes were identified in the qualitative data analysis: (1) feelings experienced while caring dying patients; (2) difficulties encountered while providing care to dying patients; (3) strategies of coping with the difficulties and (4) reasons for feeling incompetent in the care of dying patients. Nursing students reported they experienced intense sadness, desperation, and incompetence in the care of dying patients. The most common reasons for feeling incompetent were lack of experience, knowledge, and skill. Nursing students' mean total score on the Frommelt Attitudes Toward Care of the Dying Scale was 92.83±18.15. **Conclusion:** Nursing students were seen to have positive approach in the caring for dying patients, although they experienced difficulties and were often unable to cope with the situation. Nursing education curriculum for the care of dying patients should be included current training methods such as simulation and case-based learning to improve experience, confidence and competence of nursing students.

ÖZET Amaç: Hemşirelik öğrencilerinin ölmekte olan hastaların karmaşık bakımına katılmaya istekli olmadığı düşünülmektedir. Bu çalışma hemşirelik öğrencilerinin ölmekte olan hastaya bakım konusunda duygu, düşünce ve tutumlarını belirlemek amacıyla yapılmıştır. **Gereç ve Yöntemler:** Çalışmada kısmen karma eşzamanlı baskın statülü tasarım karma araştırma yöntemi kullanılmıştır. Hemşirelik öğrencilerinin ölmekte olan hastanın bakımına yönelik duygu ve düşünceleri odak grup görüşmeleri ile elde edilmiştir. Nitel verilerin toplanmasında beş odak grup görüşmesi gerçekleştirilmiştir. Tutumları belirlemek için Frommelt Ölmekte Olan Bireye Bakım Vermeye İlişkin Tutum Ölçeği kullanılmıştır. **Bulgular:** Çalışmada nitel verilerin analizi aşamasında dört tema belirlenmiştir: (1) ölmekte olan hastalara bakım verirken deneyimlenen duygular; (2) ölmekte olan hastalara bakım verirken karşılaşılan güçlükler; (3) güçlüklerle başa çıkma stratejileri; (4) ölmekte olan hastaya bakım verirken yetersiz hissetme nedenleri. Hemşirelik öğrencileri, ölmekte olan hastalara bakım verirken yoğun üzüntü, çaresizlik ve yetersizlik deneyimlediklerini ifade etmiştir. Yetersizlik duygusunun en önemli nedenleri deneyim, bilgi ve beceri eksikliği olarak belirlenmiştir. Hemşirelik öğrencilerinin Frommelt Ölmekte Olan Bireye Bakım Vermeye İlişkin Tutum Ölçeği puan ortalaması 92.83±18.15'dir. **Sonuç:** Hemşirelik öğrencilerinin, deneyimledikleri zorluklara ve çoğu zaman bu durumla başa çıkamalarına rağmen ölmekte olan hastaya bakım vermek konusunda olumlu bir tutum içerisinde oldukları belirlenmiştir. Hemşirelik öğrencilerinin tecrübe, kendine güven ve yeterliliğini artırmak için ölmekte olan hastaların bakımına yönelik hemşirelik eğitimi müfredatında, simülasyon ve olgu temelli öğrenme gibi güncel öğretim tekniklerinin yer alması önerilir.

Keywords: Death; nursing care; nursing student; terminal care

Anahtar Kelimeler: Ölüm; hemşirelik bakımı; hemşirelik öğrencisi; terminal dönem bakımı

The increasing number of patients requiring end-of-life care for various reasons, such as the increase in chronic diseases in worldwide, and life span extension, causes nurses and nursing students to en-

counter and provide care to more dying patients. It is important for the quality of nursing care to be maintained while this increased need for care is met.^{1,2} Nurses have a key role in the care of the dying pa-

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tients as they spend more time with the patients than other health care professionals. The knowledge, past experiences and feelings regarding the care of dying patients have a direct influence on the care provided by the nurses who are in direct contact with the dying patients. Nurses not being able to cope with their own fear and emotions while working with such patients may lead isolating themselves from the situation and cause them to experience negative emotions like sadness and incompetent.¹

Nursing students also often think that the care of dying patients is a disturbing practice performed unwillingly. Studies show that nursing students feel frightened, sad, nervous, frustrated, incompetent, and uncomfortable, and experience difficulties when providing care to dying patients.^{3,4} Studies also emphasize that curricula and clinical environments should provide nursing students with sufficient knowledge and skills necessary for the care of dying patients.³⁻⁵

Studies evaluating the experience of nursing students' in the care of dying patients is limited in the current literature. To know the care experience on dying patients during nursing education can be important to develop positive attitudes towards the care of dying patients. In this study, we aimed to determine nursing students' feelings and thoughts with the interviews and, to determine attitudes using the Frommelt Attitudes Toward Care of the Dying Scale towards the care of dying patients. We sought answers to the following questions: (1) What feelings are experienced by nursing students when they provide care to dying patients? (2) What are the difficulties of providing care to dying patients? (3) What are nursing students' attitudes towards the care of dying patients?

MATERIAL AND METHODS

DESIGN

This study employed a partially mixed concurrent dominant status design, which consists of two stages implemented simultaneously, with either the qualitative or quantitative components being more dominant.⁶ The qualitative component was more dominant in this study. The Frommelt Attitudes Toward Care of the Dying Scale was used to measure nursing students' attitudes towards the care of dying patients.

Focus group interviews were also conducted to determine their feelings about and views of the care of dying patients. Quantitative and qualitative data were combined to better understand the research problem and to confirm, disconfirm, cross-validate or corroborate the results.^{6,7} Scientific case studies investigate events which we cannot fully understand but to which we are not completely alien.⁸ Therefore, focus group interview method was used in the qualitative component of this study.

SETTING AND PARTICIPANTS

The study sample consisted of 75 nursing students (41 junior students and 34 senior students; (68 women, 7 men) during the 2015-2016 academic year in the Nursing Faculty of a university in Turkey. All junior and senior nursing students had completed their courses related to the care of dying patients and encountered dying patients in the clinical settings. They all participated in the quantitative component of the study. Thirty four (33 women, 1 men) of them agreed to participate in focus group interviews and were included in the sample for the qualitative component. None of the participants quit the study. Participants were informed about the purpose, procedure and confidentiality of the study prior to participation. The purposive sample revealed these characteristics: (a) Participants were junior and senior students in the faculty of nursing, (b) all participants had been trained in the care of dying patients, (c) all participants had practical experience in the care of dying patients.⁹ Data were collected using a semi-structured interview form developed by the researchers based on literature review, a descriptive information questionnaire form, and the Frommelt Attitudes Toward the Care of the Dying Scale.

Descriptive information questionnaire form: It consisted of three questions to determine the participants' sociodemographic characteristics (age, number of dying patients to whom they have provided care and willingness to participate in the care of dying patients after graduation).

Semi-structured interview form: It consisted of five open-ended questions. It was used in focus group interviews to determine participants' feelings about and views of the care of dying patients (feelings when

providing care to dying patients, difficulties encountered during care delivery, methods of coping with difficulties, status of feeling competent or incompetent in providing care and reasons for feeling incompetent). Interview questions were prepared in a descriptive manner and in a format which was suitable for reporting experiences and opinions.

Frommelt Attitudes Toward Care of the Dying Scale: It is a five-point Likert-type scale consisting of 30 questions. It was developed to measure attitudes towards the care of dying patients. The scale was adapted to the Turkish language and its validity and reliability were established by Cevik et al.¹⁰ Its Cronbach's alpha value was 0.73 and Pearson's coefficient was 0.94. The scale has an equal number of positive and negative response options: Definitely agree, Agree, Undecided, Disagree, and Definitely disagree. The items are scored on a scale of 1 to 5 (*Definitely disagree* = 1, *Definitely agree* = 5), the lowest score being 30 and the highest score being 150. The higher the score, the more positive attitude towards the care of dying patients.¹⁰

DATA COLLECTION

The study was conducted between December 29, 2015 and March 18, 2016 at a nursing school in Ankara, Turkey. Prior to data collection, participants were contacted to set interview times and locations. Nobody except the members of the research team was involved as a participant, observer or researcher during the research process. Five focus group interviews were conducted with 34 nursing students at the qualitative data collection stage. Each group consisted of 5-10 participants. One focus group interview was conducted with each group by the researchers (ZÖK, SK, AE, ÇCS, SŞÇ) using a semi-structured questionnaire. Each group was interviewed only once. None of the interviews was repeated or paused. A preliminary study was conducted with the first interview group to determine the clarity of the research questions. The research questions were not changed at the end of the preliminary study, and findings obtained in the preliminary study were included in the study. Before the interviews, participants were assigned numbers. They were seated in the interview room according to those numbers and administered the descriptive information questionnaire form and

the Frommelt Attitudes Toward Care of the Dying Scale. Afterwards, the focus group interview started. The names of the participants were not used and they addressed each other by their numbers during the interviews. A moderator and two note-takers were available at each interview. Interviews lasted about 35 minutes, and all interviews were recorded with a voice recorder. Each participant was asked the questions during the interview and they were given sufficient time to answer the questions. Moreover, 41 participants who were not included in the focus group interviews were administered the descriptive information questionnaire form and the Frommelt Attitudes Toward Care of the Dying Scale in the meeting hall of the faculty during the collection of the quantitative data. The data were analyzed after each interview. Since the data began to repeat themselves after the first 3 focus group interviews, it was decided that "data satisfaction" was achieved, and therefore, the qualitative part of the study was terminated after the fifth focus group interview.¹¹ Participants were not required to re-examine the data for confirmation or clarification after the transcription.

DATA ANALYSIS

Content analysis was used to evaluate the qualitative data. At this stage, the data obtained from the interviews were first conceptualized and then organized in a logical manner based on emerging concepts, with themes describing the data determined accordingly. Within this framework, an attempt was made to identify the content through analysis, thereby revealing facts that may be hidden within the data.¹² No software was used for qualitative data analysis. The data were examined using an inductive study design, and codes were extracted by three different researchers (ZÖK, AE, SK) during content analysis. By placing the codes generated during the transcript in appropriate sections of the code tree, the researchers detected five themes. The data were interpreted by association using the resulting themes. Positive and negative attitudes and experiences stated in a theme were numerically determined. In order to ensure the reliability of the study, the study question was clearly expressed and presented in a manner that was consistent with the other stages. Standards for Reporting

Qualitative Research (SRQR) were used to report the qualitative component of the study.¹³ IBM SPSS Statistics for Windows 20 (IBM Corp., Armonk, NY) was used to analyze the quantitative data. In terms of descriptive statistics, frequencies and percentages were used for categorical data while means and standard deviations were used for measured variables.

ETHICAL DIMENSION

The research was approved by the Non-interventional Clinical Studies Ethics Committee of the university (Project No: GO 15/317-25). Written informed consent was obtained from the participants according to the guidelines presented in the Declaration of Helsinki.

RESULTS

QUANTITATIVE DATA

The mean age of the participants was 22.33±1.6 years. They had provided care to an average of 1.7 dying patients before. Moreover, 49.3% of the participants wanted to provide care to dying patients after their graduation (Table 1). Participants' mean total score on the Frommelt Attitudes Toward Care of the Dying Scale was 92.83±18.15 (min: 60, max: 129) (Table 1).

QUALITATIVE DATA

We evaluated the data using four themes: feelings experienced while providing care to dying patients; difficulties encountered while providing care to dying patients; ways of coping with these difficulties and reasons for feeling incompetent in the care of dying patients.

Theme 1: *Feelings experienced while caring for dying patients*

The participants were found to experience positive, neutral or negative feelings while providing care

to dying patients. The students were mostly found to feel intense sadness, desperation, and incompetence while providing care (Table 2). Participants' statements contributing to these findings are given below.

"...since that situation is the only situation where we feel desperate, frankly I do not feel like a nurse. I feel very incompetent. I can do nothing. My feelings smother my professionalism. The moment of death is what I am afraid to see most. I feel sorry that I am incompetent, and it is the only place I do not feel like a nurse" (5th Group K9).

Only five participants stated they felt happy with the thought of being beneficial for dying patients. One of the participants expressed this feeling in the following way.

"When it comes to my feelings... it was very weird, because the patient is totally dependent on you and cannot fulfill his/her own needs. And this has made me a person who is very emotional and disturbed. I felt a lot of responsibility while caring for the patient, but I was also happy because I could help him" (3rd Group K1).

Theme 2: *Difficulties encountered while providing care to dying patients*

The participants had the most difficulty in establishing communication with patients and family while providing care to dying patients, because they were negatively affected emotionally (Table 2). The participants' statements contributing to the findings are given below.

"... we also had patients and patients' relatives that we could not communicate with. Any silence is usually a disturbing silence. I did not like it much" (3rd Group K4).

Theme 3: *Strategies of coping with difficulties encountered while providing care*

TABLE 1: Participants' descriptive characteristics.

Characteristics (n=75)	Descriptive statistics
Age (year)	22.33±1.6 [mean±SD]
Number of dying patients provided care by the nursing students	1.7 [mean]
Willingness to participate in the care of dying patients after graduation (number of the nursing students giving answer "yes")	37 / 49.3 [n / %]
Total score of Frommelt Attitudes Toward Care of the Dying Scale	92.83±18.15 [mean±SD]

TABLE 2: Themes and subthemes.

	n	%*
Feelings experienced while caring for dying patients (n=33)		
Feeling intense sadness and pity	27	81.81
Feeling desperate, helpless and incompetent	22	57.57
Feeling anxious / fear	15	45.45
Feeling a great responsibility	6	18.18
Feeling sympathy for the patient	5	15.15
Feeling happy	5	15.15
Feeling the patient as a family member	5	15.15
Feeling professional satisfaction	4	12.12
Difficulties Encountered While Caring for Dying Patients (n=33)		
Having difficulty in communicating with patients and their families	14	42.42
Trying to provide care despite intense sadness and desperate	14	42.42
Trying to maintain treatment and care, knowing that death is unavoidable	9	27.27
Providing care to patients who do not know what they have been diagnosed with	6	18.18
Witnessing the sadness of patients' families	5	15.15
Strategies of Coping with Difficulties Encountered While Providing Care (n=24†)		
Trying to maintain communication	11	45.8
Trying to provide the best care	6	25.0
Trying to maintain care without internalizing the process	5	20.8
Leaving things to time	4	16.6
Requesting assistance from nurses, teachers and friends	3	12.5
Avoiding communicating with patients	3	12.5
Involving patients' families in care	2	8.3
Trying to forget the experience and the process	1	4.2
Trying to relax by crying	1	4.2
Reasons for feeling incompetent (n=28)		
Lack of enough experience	16	57.1
Insufficient knowledge or skills	12	42.8
Belief in the inability to cope with psychological aspects	2	7.1

* Percentages were calculated using n, n multiplied. † Nine participants reported that they had no strategies to cope with the problems.

Students' strategies of coping with difficulties encountered while providing care are presented in Table 2. In terms of coping strategies, the participants were found to continue to communicate and provide care to ensure the maximum benefit to patients. The participants' statements related to the findings are given below.

"I choose to talk and not to avoid because the patient is expecting something from me. If you ask how I deal with my own feelings, it is by crying. I try to be strong there, but that strength disappears when I leave" (4th Group K4).

Theme 4: Reasons for feeling incompetent regarding the care of dying patients.

The most common reasons for feeling incompetent regarding caring of dying patients were not having enough experience, knowledge, or skill (Table 2). The statements of the participants are given below.

"I have a lack of experience. If the Ministry of Health has a certificate program, I would like to participate" (2nd Group K2).

"I am emotional. I have to have more experience to cope with this issue" (5th Group K9).

DISCUSSION

Nursing students are emotionally affected and experience difficulties or avoid providing care to dying patients.¹⁴⁻¹⁸ Studies report that nursing students ex-

perience negative emotions such as sadness, vulnerability, helplessness, fear, anxiety and suffering when providing care to dying patients and at the death of the patients.^{14,16-20} Similar to literature, the findings of this study indicate that nursing students most often feel intense sadness, despair, incompetence, fear and anxiety in the care of dying patients. The majority of the participants stated that they felt incompetent in providing care to dying patients, which was mostly due to lack of experience and knowledge/skills. Research shows that basic nursing education including dealing with death and care of dying patients reduce nursing students' anxieties and that the more educated nursing students are, the more positive attitudes they have towards the care of dying patients.^{15,21} Therefore, effective training methods such as case discussions, role-play and drama, and more specific teaching contents for the care of dying patient should be used in basic nursing education to teach nursing students how to overcome the feeling of incompetence, to improve positive attitudes and communication skills, and to enhance knowledge and experience.^{17,22-25}

Nursing students have difficulty in providing care due to fear of being incompetent, of failing in the care of dying patients and, of inability to communicate with patients and families.¹⁸ In the study by Osterlind et al., students stated that they did not know what to talk to dying patients and their families about.¹⁴ In our study, most participants mainly expressed that they have difficulty in communicating with patients and their families and, difficulty in trying to provide care despite intense sadness and desperate. Most participants also stated that they tried to cope with difficulties in the care of dying patients by trying to maintain optimal communication and continuing to provide care in order to provide the maximum benefit to patients. An important strategy implemented by nursing students to cope with difficulties and to prevent burnout, is to confront and accept their own feelings and maintain effective communication with patients and their families.^{17,19} Nursing students therefore need support in order to improve communication skills in the caring of dying patient during basic nursing education and clinical practice. Current education methods should be integrated into basic nursing education to provide nursing students with the opportunity to have emo-

tional experiences and to improve their communication skills. Simulation teaching strategies widely used in nursing education nowadays can be included in basic education in order to allow nursing students to gain those skills necessary for the care of dying patients.²²⁻²⁵

Providing care to dying patients not only lead to negative emotions but also evokes various positive emotions. The occupational satisfaction felt by nurses for providing care to people needing care in their last days of life may be the reason why they prefer to work in this field.²⁶ This study found that 15.5% of the participants felt happy to provide care because of the benefits to patients and, 49.3% wanted to provide care to dying patients after they graduated, despite the negative feelings they experienced during their provision of care. Participants' mean score (92.83 ± 18.15) on the Frommelt Attitudes Toward Care of the Dying Scale also supports these findings. The mean total score indicates that participants have a mildly positive attitude towards providing care for dying patients, which is consistent with the results reported by the studies.^{3,6,27}

CONCLUSION

The results indicate that nursing students find it difficult to provide care to dying patients and experience various challenges while doing so. Nursing students are emotionally affected, have difficulties in maintaining communication with patients and their families, and feel incompetent. The strength of this study lies in the fact that it shows that nursing students have a positive approach to providing care to dying patients despite the fact that they experience difficulties and are often unable to cope with the situation. In line with these results, we recommend that nursing education curriculum for the care of dying patients be improved and that up-to-date and effective training methods such as simulation method and case based learning be included in nursing education to provide nursing students with the opportunity to gain experience and to improve confidence and competence.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct con-

nection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: Zeliha Özdemir Köken, Sevilay Şenol Çelik; **Design:** Zeliha Özdemir Köken, Sabri Karahan, Atiye Erbaş, Çiğdem

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