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Research

INTENSIVE CARE AND ONCOLOGY NURSES' PERCEPTIONS AND EXPERIENCES WITH 'FUTILE MEDICAL CARE' AND 'PRINCIPLES OF GOOD DEATH'

Abstract

Introduction: This study aimed to determine nurses' perceptions and experiences with 'futile medical care' and their opinions about 'principles of good death'.

Materials and Method: This descriptive and cross-sectional study was conducted in 11 state hospitals and 3 university hospitals in Ankara, Turkey. It included 856 nurses working in intensive care and oncology units. A questionnaire, which included demographics and futile medical care practices and the 'Attitudes toward Principles about Dying with Dignity Scale' were used.

Results: Participants were on average 30.49 ± 6.12 years old 92.3% were women, 61.7% were married and 62.7% had a bachelor's degree. Nurses defined medical care as futile when it was 'not affecting quality of life' (35.4%), 'not curing the disease' (46.8%) and 'prolonging the suffering of the patient' (42.9%). They stated that futile care was continued because of hospital policy (32.9%), doctor's decision (54.9%) or patient's or relative's decision (29.3%). Three of every four nurses stated that good death principles were not applied at their hospital. We found that attitudes toward death improved as nurses' education level increased ($p = .001$), and women had higher scale scores than men ($p < .001$).

Conclusion: Nurses were generally not satisfied with end-of-life care. Extending life, while ignoring the quality thereof, remains a major ethical dilemma for health professionals.

Key Words: Medical Futility; Attitude to Death; Terminal Care; Nurses

Araştırma

YOĞUN BAKIM VE ONKOLOJİ HEMŞİRELERİNİN "YARARSIZ TIBBİ BAKIM" VE "İYİ ÖLÜM PRENSİPLERİ" İLE İLGİLİ ALGILARI VE DENEYİMLERİ

Öz

Giriş: Bu çalışmanın amacı hemşirelerin "yararsız tıbbi bakım" ve "iyi ölüm ilkeleri" konusundaki algı ve deneyimlerini belirlemektir.

Gereç ve Yöntem: Bu tanımlayıcı ve kesitsel tipteki çalışma, Ankara'da 11 devlet ve 3 üniversite hastanesinde gerçekleştirildi. Çalışma, yoğun bakım ve onkoloji birimlerinde çalışan 856 hemşireyle yapıldı. Demografik özellikleri ve yararsız tıbbi bakım uygulamalarını içeren bir anket ile "Saygın Ölüm İlkelerine İlişkin Tutumlar Ölçeği" kullanıldı.

Bulgular: Katılımcılar ortalama 30.49±6.12 yaşında, %92,3'ü kadın, %61,7'si evli, %62,7'sinin eğitimi lisans düzeyinde idi. Hemşireler, "yaşam kalitesini etkilemediği" (%35,4), "hastalığı tedavi etmediği" (%46,8) ve "hastanın acısını uzattığı" (%42,9) için bakımı yararsız bulduklarını, ancak hastane politikası (%32,9), doktor kararı (%54,9) veya hasta yakınlarının kararı (%29,3) nedeniyle yararsız tıbbi bakıma devam ettiklerini belirttiler. Dört hemşireden üçü hastanelerinde iyi ölüm ilkelerinin uygulanmadığını bildirdi. Hemşirelerin eğitim düzeyi arttıkça ölüme ilişkin tutumların iyileştiği ($p = .001$) ve kadınların erkeklerden daha yüksek ölçek puanına sahip oldukları saptandı ($p <.001$).

Sonuç: Hemşireler genellikle yaşamın sonundaki bakımdan memnun değildi. Ömrü uzatırken yaşam kalitesini göz ardı etmek sağlık profesyonelleri için etik bir ikilem olmaya devam etmektedir.

Anahtar Sözcükler: Tıbbi Yararsızlık; Ölüme İlişkin Tutum; Terminal Bakım; Hemşireler

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INTRODUCTION

With the ageing population around the world, an increasing number of people are getting accustomed to living with serious chronic illnesses towards the ends of their lives. Consequently, this phenomenon demands the creation of modalities to improve not only health, by preventing disease and disability, but also the quality of remaining life, enabling people to live well and, when the time comes, die well (1). The primary aim of caring for terminally ill patients is to provide high-quality health care during their last period of life and to make the process of death as good/comfortable as possible. However, the substantial impact of medicine on health/life makes it easy to forget that death is also a natural part of life. This results in life expectancy becoming the standard in evaluating the success of health care, and causes attempts to extend life through futile care, regardless of the outcome (2). 'Futile medical care' refers to the provision of all possible medical care or treatment to a patient, even when there is no reasonable sign of a cure or benefit (3-5). The rate of futile care in intensive care units (ICUs) is estimated to be approximately 40%–60% (6).

The term was first defined during cardiopulmonary resuscitation in the 1980s and entered the medical literature in the 1990s within the concept of bio-ethical problems. The American Medical Association stated that the meaning of the term 'futile' depends on the values and goals of a particular patient in specific clinical circumstances. Moreover, they used the term 'medically ineffective interventions' instead of 'medical futility', in the new version of the 'Code of Medical Ethics' (5,7). Although futile care has been discussed in medicine over the years, dilemmas and differences in opinion on the starting, ending, or continuing life support attempts are still commonly experienced in practice. Difficulties in determining who will participate in decision making, the idiosyncratic character of each case and the standards of application make futile care problematic (4,8). The diverse criteria for defining this phenomenon and care providers' different opinions on this issue reflect the subjectivity of personal judgements, which are rooted in one's emotions, personal beliefs and culture (9).

Another significant term, 'good death', enables caregivers to consider the needs of the people being prepared for their impending deaths. The Institute of Medicine defines good death as one that is 'free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards'. Perhaps, one of the vital components of this concept constitutes dying with dignity, and it is opined that the stakeholders' perspectives might categorise this concept into other themes of good death (10).

Nurses who provide terminal health care can also provide a good death and prevent futile medical care (8). In a recent study, 16 articles (published from 1994 to 2015) that focused on nurses' perception of futile care were reviewed (9). It concluded that because nurses play a key role in patient care and end-of-life decision making, and can significantly influence the attitudes of patients and their families, understanding their experiences about futile care is the first step toward designing effective care programmes in ICUs. Despite the growing interest about futile care and the considerable amount of research on nurses' perceptions thereof, research on Turkish nurses' perceptions towards futile care is lacking. Considering the subjectivity of this phenomenon, it is important to understand Turkish nurses' opinions and experiences on this issue, which may reflect cultural differences and practices. The aim of the present study was to determine nurses' perceptions and experiences with 'futile medical care' and opinions about 'principles of good death' in Turkey. The research questions were as follows:

What are the reasons nurses think that the medical care is futile?

What are the reasons nurses continue the care despite considering it to be futile?

What do nurses think about 'principles of good death'?

MATERIALS AND METHOD

Design and Settings

This descriptive and cross-sectional study comprised nurses working in the intensive care and oncology units of 11 state hospitals and three university hospitals in Ankara between June 2012 and February 2013. Sampling was not done and the entire sample universe was included. Nurses who worked in oncology units or ICUs for at least one year were included in the study. Of the 1419 nurses, 856 participated in the study (60.3% response rate) (Table 1).

Table 1. Distribution of Nurses According the Hospitals

Hospitals	Total n	Unfilled	Reject	Unavailable	n (%)
Government Hospitals					
1	102	2	27	21	52 (50.9)
2	212	11	29	54	118 (55.6)
3	51	1	18	15	17 (33.3)
4	98	3	15	42	38 (38.7)
5	108	10	7	6	85 (78.7)
6	181	9	9	61	102 (56.3)
7	41	1	2	5	33 (80.4)
8	82	1	12	10	59 (71.9)
9	57	3	7	5	42 (73.6)
10	50	3	3	9	35 (70.0)
11	50	1	14	13	22 (44.0)
Government University Hospitals					
A	121	1	9	32	79 (65.2)
B	152	5	28	40	79 (51.9)
C	114	4	5	10	95 (83.3)
Total	1419	55	185	323	856 (60.3)

QUESTIONNAIRE

The questionnaire comprised three parts. The first part included socio-demographic questions, while the second part included questions that determined the participants' futile care practices (whether they had practised or were practising futile care, the reasons why they think it is futile and the reasons why they continued the care despite considering it to be futile). A group of patients receiving futile care was neither specified nor defined in this study. The last part of the questionnaire comprised questions about their opinions on good death. We used the 'Attitudes

towards Principles about Dying with Dignity Scale', which consists of 12 items based on the principles of good death as mentioned by 'The Debate of the Age Health and Care Study Group'. This scale was used and validated by Duyan on social work students (11). The item–total score correlation varied between 0.480 and 0.743, while the internal consistency coefficient of the items was found to be 0.892. Participants rated the importance of each principle using a five-point Likert scale: strongly disagree = 1, disagree = 2, neither agree nor disagree = 3, agree = 4 and strongly agree = 5. Each item on the scale was designed to be a positive statement.

The total score from the scale can range from 12 to 60, with higher scores denoting higher adoption of good death principles and lower scores denoting otherwise. Cronbach's alpha value of the scale was found to be 0.92. The portion regarding good death included two close-ended questions that determined whether nurses had previously thought about good death and whether their hospital considered good death principles.

Data Analysis

Data were coded and analysed using the Statistical Package for the Social Sciences version 16.0 for Windows. When two groups with non-homogeneous data were compared, the means test and the Mann–Whitney U test were applied to determine the significance of their differences. Moreover, one-way ANOVA for comparing multiple groups, Tukey's HSD test for determining differences between groups and Kruskal–Wallis analysis of variance test were applied when the data were not homogeneous.

Ethical Considerations

This study was conducted in accordance with the principles of the Declaration of Helsinki. The study protocol was approved by the Republic of Turkey Ministry of Health Turkey Public Hospitals Authority (28.05.2012-12237). Ethics approval was obtained from the Ethics Committee of Ankara University (27.09.2012-588). Written permissions were obtained from the 14 hospitals included in the study, and written informed consents were obtained from participants after explaining the aim of the study.

Table 2. The Reasons Why Nurses Think the Care Is Futile and Why They Continue the Care Despite Considering It to Be Futile (N = 856)

	n	%
Reasons to think the care is futile		
Care did not improve the life quality	303	35.4
Intensive care was given to terminal cancer patients	454	53.0
Care just prolonged life span without any other benefit	273	31.9
Care did not have possibility of curing the disease	401	46.8
Care given to patients with brain death	255	29.8
Care extended the period of pain, ache or discomfort of the patient	367	42.9
Care caused more harm than good	41	4.8
Reasons for continuing the futile care		
Hospital policy	282	32.9
Decision of the doctor	470	54.9
Decision of the custodian	251	29.3

RESULTS

On average, nurses participating in the study had an age of 30.49 ± 6.12 and had been working for 8.97 ± 6.84 years. Among the participants, 92.3% were women, 61.7% were married, 46.6% had children, 62.7% had a bachelor's degree, 70.4% were from state hospitals and 68.5% worked in ICUs.

The reasons why nurses think the care as futile is summarised in Table 2. Nurses stated that they continued the care despite considering it to be futile because of hospital policy (32.9%), doctor's decision (54.9%), and patient's or relative's decision (29.3%) (Table 2).

Table 3. Nurses' Opinions About "Principles of Good Death"

Principle Number	Principle	Mean	Standart Deviation
3	To be afforded dignity and privacy	4.21	1.06
7	To have access to any spiritual or emotional support required	4.16	1.01
9	To have control over who is present and who shares the end	4.09	1.05
8	To have access to hospice care in any location, not only in hospital	4.08	1.05
4	To have control over pain relief and other symptom control	4.06	1.04
10	To be able to issue advance directives which ensure wishes are respected	4.01	1.04
11	To have time to say goodbye, and control over other aspects of timing	3.91	1.12
6	To have access to information and expertise of whatever kind is necessary	3.85	1.09
12	To be able to leave when it is time to go, and not to have life prolonged pointlessly	3.61	1.30
2	To be able to retain control of what happens	3.57	1.08
5	To have choice and control over where death occurs (at home or elsewhere)	3.56	1.26
1	To know when death is coming, and to understand what can be expected	3.19	1.22

Nurses' opinions about 'principles of good death' are given in Table 3. Scores for the 'Attitudes toward Principles about Dying with Dignity Scale' were found to be higher in female than in male nurses ($p < .001$).

Nurses having undergraduate and graduate degrees had higher scores than those graduating from vocational schools ($p = .001$). Marital and parental statuses, as well as the clinic they worked in, were found to have no significant effect on the scores ($p > .05$) (Table 4).

A total of 36.4% (n = 312) stated that they had previously thought about good death, while 25.2% (n = 216) stated that the principles of good death were applied in their hospital. It was also determined that nurses who had previously thought about good death (48.52 ± 9.60) had higher good death scores than those who did not (45.37 ± 9.15) ($t = 4.29$, $p < .001$).

Table 4. Comparison of Nurses' Demographic Characteristics and Their Attitudes Toward Principles About Dying with Dignity Scale Scores (N = 856)

Variables		n	Scale Scores M ± SD	Test value	p
Gender	Female	790	46.66 ± 9.27	t = 3.94	p <.001
	Male	66	41.80 ± 13.22		
Marital status	Married	528	46.26 ± 9.76	t = 0.09	.926
	Single	328	46.33 ± 9.63		
Children	Have	399	45.97 ± 10.11	t = 0.90	.367
	Does not have	457	46.57 ± 9.34		
Clinics	Intensive care	586	46.55 ± 9.44	F = 0.80	.448
	Oncology intensive care	139	45.97 ± 10.72		
	Oncology unit	131	45.43 ± 9.78		
Graduation*	Health Vocational School	218	44.63 ± 10.19	F = 6.91	.001
	SHMYO (formal and open education)	87	44.67 ± 9.93		
	Undergraduate and graduate	551	47.20 ± 9.36		

*12 MSc and 2 PhD graduates were included in the undergraduate category for statistical analyses.

DISCUSSION

The findings of this study revealed that nurses defined the care as futile because of the imbalance between provided care and patient prognosis is, in fact, coherent with literature (12, 13). Interestingly, one-third nurses characterised the care as futile because 'care was given to patients with brain death'. The use of this phrase reflects the inadequate knowledge/education of ICU teams about ICU processes. Legally, a patient is officially declared dead at the time when he/she is diagnosed with brain death and not at the time of cardiac arrest. Hence, patients diagnosed with brain death should be declared dead, and their relatives should be informed of their condition. However, a brain-dead person (now termed as a potential donor and not a patient) is cared for until their relatives are informed and permission for organ donation is sought. If the possibility of organ donation is not feasible, medical support should be promptly discontinued. In such a scenario, nurses/doctors should be well-informed about the subject to facilitate decision-making on the futility of therapy.

Reportedly, about 90% (9 of 10) of nurses confirmed that despite considering the care to be futile, they continued caring because of hospital policies and doctors' decisions. Notably, this finding is coherent with previous studies (6, 12, 14). Hence, while finalising end-of-life issues, it is suggested that medical staff, patients and relatives should anticipate not only the medical conditions but also the environmental factors and legal concerns. In contrast, there is no law in Turkey that explicitly regulates the decisions made in end-of-life situations. This puts medical staff, especially physicians who are in charge of decision-making into a challenging situation (15). Another important reason, especially in situations wherein ethically problematic consequences have a high probability of occurrence, is the difficulty for both health care personnel and relatives to effectively communicate as a team and reach common conclusions. The perceptions of

physicians and nurses were compared in a study in Portugal. In this study, the major causes of ineffective and futile decisions were as follows: 'non-acceptance of treatment failure', 'insufficient training on ethical issues', 'difficulty in accepting death', 'incorrect evaluation of clinical conditions' and 'difficulties in communication'. A statistically significant difference was found between the opinions of physicians and those of nurses about the involvement of the medical team members in the decision making process (16). Nurses have also been generally found to be less satisfied with end-of-life decision making than physicians and are often the first team members to feel that life support should be withdrawn, which can lead to conflict with physicians (14).

Three of every four nurses stated that good death principles were not applied in their hospital. In the study of Özdemir, 42% of intensive care nurses stated that care provided for terminally ill patients was inadequate, and the ICU did not provide a suitable environment for a peaceful death (17). The majority of deaths in many developed countries take place in hospitals against people's wishes. It is projected that if recent trends continue, the number of home deaths could be reduced by 42%, and fewer than 1 in 10 will die at home in 2030 (18). As population demographics change and new technologies, pharmaceuticals and interventions prolong lives, more elderly patients will have to be treated in ICUs (19-21). Ozşaker et al. determined that elderly patients in ICUs had a partially negative experience. Most of the negative experiences were about feeling unsafe, and the duration of stay and type of ICU affected their experiences (20). All these factors led health professionals and institutions to develop strategies towards good death. Nalbant et al. investigated the features of patients hospitalised in the ICU of the Internal Medicine Department. They found that nearly half of the patients were >65 years old, and the rate of oncology-related patient mortality was high (59.7%). They concluded that this situation reduces the morale and motivation of persons who work at those units and recommended that both elderly and terminally ill patients be hospitalised in an intermediate care unit (22). Another suggestion is that efforts to limit futile care should focus on public and professional education on the role and use of ICUs and available alternatives, such as palliative care (13).

In conclusion, nearly half of the participating nurses defined the care as futile considering the imbalance between the provided care and patient prognosis. On the other hand, 88% of nurses stated that they continued the care despite considering it to be futile because of hospital policies and doctors' decisions. Futile care, by nature, brings about many ethical dilemmas, such as conflicts of opinion on the starting, ending, or continuing life support attempts; extending life while ignoring the quality; determining who will participate in the decision-making; standards of application; and the idiosyncratic character of each case. Perhaps, the establishment of hospitals/clinics ethics committees for decision-making in end-of-life issues would help in uplifting the stress on medical staff. The presence of organisational factors, such as professional autonomy, fixed workload and high systematic teamwork in ICUs, could also lead to decreased perception of futile care (13). Therefore, practising futile care should be decided by the consensus of the health care team. At this point, the only principle that should not be broken is that consent from the patient or his/her relative must be mandatory. However, withdrawing/withholding therapy and Do Not Resuscitate (DNR) orders are not legally acceptable in Turkey. Therefore, consent from relatives/patients offers little hope in the ICUs. Nevertheless, in common practices, if a doctor/medical team considers a therapy to be futile, it can be withheld. Perhaps, legalisation of the concept could be another milestone for limiting futile care for terminally ill patients.

Three-fourth nurses stated that good death principles were not applied in the hospitals they worked in. Nurses with previous knowledge about good death held a more positive attitude towards good death principles than those who without the knowledge, and as more nurses became educated about the concept, the rate of adopting good death principles also increased. Presumably, for

a dignified death, the most reliable and appropriate way to support a patient is through the clarification of good death principles by health care personnel (23). Therefore, institutions should revise their policies to prioritise patient's rights and include the concepts of 'futile medical care' and 'good death' in their training programmes. Improved interventions and evidence will lead to a dignified death concurrent with human rights, increase the quality of care in clinics and improve the morale and motivation of health professionals who have to deal with death.

This study highlights that futile care and the inability to provide good death remain an ethical dilemma for health care professionals. The application of the principles of 'beneficence, nonmaleficence, autonomy and justice' that establish medical ethics in ICUs seems to be demanding.

Although these basic principles contradict each other at times, if a problem is expressed regarding concrete elements, it can be considered as knowledge management, hope management and responsibility. In this context, here are the proposed solutions:

- Information during the treatment process should be shared with stakeholders (e.g., patient, relatives and health care team), the options should be discussed and health care professionals should act according to the consensus of the stakeholders.
- Unrealistic hopes/expectations should be avoided,
- Medical care units should be prepared with a standardised approach to terminally ill patients,
- Detailed algorithms that enable medical and social criteria should be prepared and implemented,
- Unit-based efforts should be continued and integrated into an upper platform like expertise associations,
- Common standards should be announced as a manifesto and suggested to policy-makers.

Limitations of the Study

The results cannot be generalised for all Turkish nurses. This study did not consider the psychological status of the participants (e.g., depression and burnout.) that may affect the results. Admittedly, future research is required to determine the opinions of other team members and to clarify conflicts among nurses, physicians, patients and their relatives.

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