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Facing death in the clinical practice: a view from nurses in Mexico

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Abstract

Objective. To explore the views of nurses on death in their practice, and their perception about physicians' actions dealing with terminally ill patients. **Materials and methods.** Two hundred ninety-five nurses with experience caring for terminally ill patients responded to a questionnaire developed for this study. **Results.** The majority of participants considered that terminally ill patients should know about their prognosis. Although nearly all nurses said that when a patient brings up the subject and they talk with the patient about death, several of the nurses find it difficult to establish a relationship with these patients. Concerning nurses' perception about physicians' actions, they considered that physicians avoid the subject of death with their patients more than the physicians acknowledge. **Conclusions.** More education and training of physicians and nurses on end-of-life issues is needed to improve communication with dying patients and to provide them with better care.

Keywords: nurses; death; nurse-patient relationship; physician-patient relationship

Marván ML, Oñate-Ocaña LF, Santillán-Doherty P, Álvarez-del Río A. Enfrentando la muerte en la práctica clínica: una visión desde la enfermería en México. Salud Publica Mex 2017;59:675-681.
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Resumen

Objetivo. Explorar las opiniones de enfermeras y enfermeros sobre el tema de la muerte en su práctica clínica, así como su percepción sobre las acciones de los médicos que tratan pacientes en fase terminal. **Material y métodos.** Doscientas noventa y cinco enfermeras y enfermeros con experiencia en enfermos terminales respondieron un cuestionario que fue desarrollado para este estudio. **Resultados.** La mayoría de los participantes consideraron que los enfermos terminales deben conocer su pronóstico. Aunque casi todos dijeron que cuando los pacientes abordan el tema de la muerte hablan con ellos al respecto, varios encuentran difícil establecer una relación con ellos. En cuanto a su percepción sobre los médicos, el personal de enfermería considera que éstos evitan el tema de la muerte con sus pacientes más de lo que reconocen. **Conclusiones.** Es necesario brindar capacitación a médicos y personal de enfermería sobre temas relacionados con el fin de la vida para mejorar su comunicación con los pacientes terminales y brindarles una mejor atención.

Palabras clave: enfermeras; muerte; relación enfermera-paciente; relación médico-paciente

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There is deep fear about the end-of-life process in Western society.[1] A cultural denial of death, together with so many medical advances, affects all members of the health care team, who find it difficult to deal with terminally ill patients and to offer them comfort and guidance.[2] Early integrated palliative care in terminally ill patients suffering from cancer improves their quality of life.[3] Additionally, nurses play a very special role in end-of-life care. Their role is broader in scope than that of physicians' because their care encompasses physical contact and emotional support for patients while helping them and their families during the life-to-death transition.[4,5] However, the majority of nurses treating terminally ill patients have not received specialized training to care for them; hence, they feel insecure and sometimes avoid communication with patients and their families, although they do know that communication is an effective therapeutic resource.[6] Moreover, nurses can feel emotional exhaustion and stress when caring for terminally ill patients, which results in a decreased ability to provide quality care.[7] There is scarce information on this topic in Mexico, but one study confirms the lack of this training in nurses.[8]

In a recent study that explored the views of Mexican physicians about death in their clinical practices, end-of-life was found to be an important topic for them.[9] Though the majority of these physicians valued the need to communicate uncertain outcomes when standard treatments begin to fail, the data obtained appeared to reflect what they thought the correct thing to do was, rather than what they actually did, which remained unknown.

Taking this finding into account, nurses comprise a unique source of information to enhance our knowledge of health care during the end-of-life period. The objectives of this study were as follows: a) to explore the views of Mexican nurses about death in their clinical practice, and b) to explore their perceptions regarding physicians' actions while treating terminally ill patients.

Materials and methods

Participants

We recruited a non-probabilistic sample of nurses who work at one of two high specialty-level public hospitals in Mexico (National Cancer Institute and National Institute of Respiratory Diseases), and care for patients with highly complex medical situations, including cancer and other fatal conditions. Inclusion criteria embodied having completed at least one year of clinical practice in caring for terminally ill patients. Surveys were completed from May to November 2014.

Instrument

The Nurses' Views on Death (NVD) questionnaire was developed for this study and was based on the Physicians' Views on Death (PVD) questionnaire.[9] It is an 18-item, 5-point Likert scale whose scores range from 1 (strongly disagree) to 5 (strongly agree) and is divided into two parts: a) twelve items explore the nurses' views about their practice of caring for terminally ill patients, and b) six items about nurses' perceptions with respect to physicians' behaviors in dealing with terminally ill patients, four of these similar to those of the PVD, in that the sole difference is that the wording of the PVD is in the first person and the wording of the NVD is in third person, because it refers to physicians. As in the case of the PVD, NVD content validity was assessed using the Lawshe formula (asking 18 judges), and the discriminative capacity of each item was calculated using the extreme groups method. The instrument was pilot-tested in 15 nurses who had had experience in caring for terminally ill patients.

In order to be able to compare the results of the NVD with those obtained in the previous study in which the PVD was employed, we followed the same procedure to analyze the questionnaire's responses for both. That is, items were analyzed individually instead of obtaining subscales, and responses in agreement were scored in one category, undetermined responses in another, and those of disagreement in yet another.[9]

Procedure

The Research Ethics Review Board of both institutions approved the study where it was conducted, as did that of the School of Medicine of the *Universidad Nacional Autónoma de México*. The questionnaire was applied from May to November 2014. A researcher visited different places at the hospital and asked nursing personnel if they would be willing to participate in a research project about their relationship with terminal ill patients. Ninety-seven percent of the nurses accepted the invitation, and they were asked to respond to a few questions to determine whether they fulfilled the eligibility criteria for participating in the study. After ascertaining that the criteria were fulfilled, the researcher gave the nurses the questionnaire and asked them to return it no later than the following day. To ensure anonymity, participants were instructed not to insert identifying marks on the questionnaire, and informed consent was deemed as given if the questionnaire was returned duly answered. The time required to complete the questionnaire was calculated at 10–20 minutes.

Statistical analyses

Data distribution was determined utilizing the Kolmogorov–Smirnov and Shapiro–Wilk tests. Frequency of response was analyzed using the chi-squared goodness-of-fit test. Spearman correlations were conducted among the questionnaire's items. Logistic regression analyses were performed to test the association of explanatory variables and the responses to the questionnaire. These responses were categorized by the median method. Odds Ratios (OR) were calculated as measure of association, along with their 95% Confidence Intervals (CI).

Results

Nurses' responses

Of the 304 nurses invited to participate, 295 agreed (97%). Ages ranged from 20 to 70 years (mean, 38 years) and they had 1 to 45 years of clinical practice. Characteristics of the population are depicted in table I. Frequencies of the responses of participants who disagreed, neither disagreed nor agreed, or who agreed are presented in table II. The majority of participants were of the view that terminally ill patients should be informed that they are going to die (item 1). Moreover, when terminally ill patients have not been informed that they are going to die, the majority of nurses refer them to their physician for being informed (item 5). However, when patients ask nurses about their prognoses, there was a similar percentage of nurses who agreed to tell the patients that they are going to die than nurses who disagreed (item 11).

When nurses were asked about their relationship with their terminally ill patients, nearly all agreed that when patients broached the subject of death, the nurses would converse with the patients about it (item 8). Only slightly more than one half of the participants stated that it was not difficult for them to establish a relationship with terminally ill patients and that they do not avoid the subject of death with them; however, the remainder of the participants either reported a difficult relationship with terminally ill patients or were undecided in their answers (items 4, 6, 7, 9, and 10).

The majority of nurses felt that they were well prepared to care for terminally ill patients, but agreed that they should be offered access to seminars or workshops that reflect on issues related with death (items 18 and 2).

Concerning items exploring nurses' perceptions about the relationship between physicians and their terminally ill patients, there were no significant differences between the number of nurses who claimed that physicians tell their patients the truth when they are going to die and do not avoid the subject of death with them, and nurses who claimed the contrary (items 12 and 14). On the other hand, approximately one half of participants concurred that when the patients' relatives asked physicians to hide from the patients that they are going to die, the physicians consented, whereas the remainder of nurses either did not perceive that physicians consented, or were undecided with regard to their response (item 13). Finally, nearly one half of participants stated that physicians do not withdraw from terminally ill patients when they know that they are going to die (item 15).

The majority of nurses agreed that terminally ill patients talk more with them than with physicians about death (item 16). There were no significant differences between the number of participants who agreed and who disagreed that physicians were used to being prepared to hear the nurses' views about terminally ill patients (item 17).

Table I
SOCIODEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE (*N*=295)

	N	%
Sex		
Feminine	253	85.8
Masculine	42	14.2
Age (years)		
21-35	138	46.8
36 or more	157	53.2
Religion		
None	4	1.4
Catholic	262	91
Other	22	7.5
Clinical practice (years) caring for terminally ill patients		
1-10	135	45.8
11 or more	160	54.2
Academic training		
Registered nurse	183	63.4
Specialist	91	31.5
Nurse's aide	11	3.8
Master degree	4	1.4
Academic training related with death		
None	101	34.7
Thanatology	150	51.5
Palliative care specialist	9	3.1
Thanatology and palliative care	3	1
Other	28	9.6

Table II
Summary of responses to the Nurses' Views About Death (NVD) questionnaire by item

		Disagree (n) (%)	*Neither agree nor disagree (n) (%)*	*Agree (n) (%)*	*p*
Nurses' views:					
1.	When it is known that patients are going to die, they should be informed	13 (4.4)	26 (8.8)	256 (86.8)	0.0001
2.	Nurses should have access to special places to reflect on issues related with death (seminars, workshops, etc.)	1 (.3)	1 (.3)	293 (99.3)	0.0001
3.	The attending physician is the only staff member responsible for informing terminally ill patients that they will die	69 (23.4)	48 (16.3)	178 (60.3)	0.0001
4.	I attempt to talk with my terminally ill patients about death	25 (8.5)	89 (30.2)	181 (61.4)	0.0001
5.	When patients are going to die and have not been informed, I refer them to their physician for them to be informed	18 (6.1)	20 (6.8)	257 (87.1)	0.0001
6.	It bothers me to have terminally ill patients	181 (61.4)	72 (24.4)	42 (14.2)	0.0001
7.	I avoid the subject of death with my terminally ill patients	148 (50.2)	79 (26.8)	68 (23.1)	0.0001
8.	When my terminally ill patients bring up the subject of death, we talk about it	5 (1.7)	20 (6.8)	270 (91.5)	0.0001
9.	I find it hard to establish a close relationship with a terminally ill patient	155 (52.5)	64 (21.7)	76 (25.8)	0.0001
10.	When a patient asks me, "Am I dying?", I try to change the subject	164 (55.6)	75 (25.4)	56 (19)	0.0001
18.	I feel well prepared to care for terminally ill patients	43 (14.6)	50 (16.9)	202 (68.5)	0.0001
11.	When patients who are going to die have not been informed of this and they ask me about it, I tell them	94 (31.9)	85 (28.8)	116 (28.8)	n.s.
Nurses' perceptions about physicians' actions:					
12.	Physicians tell their patients the truth when they are going to die	89 (30.2)	89 (30.2)	117 (39.7)	n.s.
13.	If the patient' relatives ask physicians to hide from patients that they are going to die, the physicians consent to this	82 (27.8)	72 (24.4)	141 (47.8)	0.0001
14.	Physicians avoid the subject of death with their terminally ill patients	116 (39.3)	83 (28.1)	96 (32.5)	n.s.
15.	When physicians know that one of their patients is going to die, they withdraw from the case	140 (47.5)	87 (29.5)	68 (23.1)	0.0001
16.	Terminally ill patients talk more with nurses than with physicians about death	15 (5.1)	30 (10.2)	250 (84.7)	0.0001
17.	Physicians used to be prepared to hear nurses' views about their terminally ill patients	106 (35.9)	80 (27.1)	109 (36.9)	n.s.

Note: All probability values <0.05 were considered significant (x^2 test for goodness-of-fit)

Correlations between item 1 ("When it is known that patients are going to die, they should be informed") and the remainder of questionnaire items were calculated. There were significant positive correlations, albeit weak, between agreement with the idea that patients should be informed that they are going to die and the following: 1) the idea that nurses should have access to special places to reflect about death (r=0.22; p <0.0001); 2) the fact that nurses attempt to talk to terminally ill patients about death (r=0.24; p <0.0001), and 3) the fact that nurses notify sick patients about their situation when they have not been informed and ask them about this (r=0.19 p <0.001). Contrariwise, item 1 correlated negatively, also weakly, with the following: 1) the idea that the attending physician is the only staff member responsible for informing terminally ill patients that they will die (r=-0.12; p <0.05); 2) the perception that when the patients' relatives ask physicians to hide that they are going to die from the patients, the physicians consent (r=-0.13; p <0.03), and 3) the perception that physicians use to be prepared to hear nurses' views regarding terminally ill patients (r=-0.12; p <0.04).

Nurses' ages and years of professional experience were associated with item 1 only by bivariate analysis. Age presented an OR of 1.046 (95%CI, 1.02-1.07; p=0.026) and nurses' years of clinical practice presented an OR of 1.05 (95%CI, 1.01-1.07; p=0.024), with both OR interpreted by each year of age or years of clinical practice. No other significant explanatory variables were found either by bivariate or by multivariate analysis (data omitted for parsimony).

Comparisons between questionnaire responses provided by nurses and by physicians

Table III illustrates the six NVD items that were also utilized in the PVD questionnaire applied to physicians in the previous study (seven). The same table depicts the frequencies of both nurses and physicians who agreed or disagreed with each of these items.

Concerning the relationship between physicians and their terminally ill patients, fewer nurses than doctors considered that physicians tell their patients the truth when they are going to die. There were more nurses than doctors who considered that physicians avoid the subject of death with their terminally ill patients, or that they withdraw from the case when they know that one of their patients is going to die. In contrast, there were fewer nurses than physicians who claimed that when the patients' relatives ask doctors to hide that they are going to die from their patients, the physicians consent to this.

Finally, there was a similar frequency of nurses and physicians who thought that a patient who is going to die should be informed. There were more nurses than physicians who thought that they (the nurses) should have access to special places to reflect on issues related with death.

Discussion

This study explored, on the one hand, the views about death of nurses working with terminally ill patients, which has scarcely been explored in Mexico. On the other hand, we investigated nurses' perceptions with respect to physicians' actions dealing with terminally ill patients, which allowed us to compare nurses' responses with those provided by physicians in a previous study.[9]

Of the nurses invited to respond to the questionnaire, only 3% declined to participate. This high response frequency indicates an interest that may be explained by the fact that the subject of death is a concern in the nurses' daily work. It appears possible that nurses were willing to participate due to the fact that they are frequently not considered to address these matters in their practice.

The majority of nurses considered that terminally ill patients should be informed that they are going to die, and agreed that the attending physician is the staff

Table III
COMPARISON BETWEEN RESPONSES PROVIDED BY NURSES (CURRENT DATA: *N*=295) AND BY PHYSICIANS (PREVIOUS DATA: *N*=413)

		Agree n (%)	*Neither agree or disagree*	*Disagree n (%)*	*p*
Nurses' perceptions vs. physicians' statements about the physicians' actions:					
NVD	Physicians tell their patients the truth when they are going to die	117 (40)	89 (30)	89 (30)	
PVD	In my clinical practice, I tell my patients the truth when they are going to die	324 (79)	69 (17)	15 (4)	0.0001
NVD	Physicians avoid the subject of death with their terminally ill patients	96 (33)	83 (28)	116 (39)	
PVD	I avoid the subject of death with my terminally ill patients	56 (14)	77 (19)	276 (68)	0.0001
NVD	When physicians know that one of their patients is going to die, they withdraw from the case	68 (23)	83 (29)	140 (48)	
PVD	When I know that one of my patients is going to die, I withdraw from the case	21 (5)	30 (7)	356 (88)	0.0001
NVD	If the patient' relatives ask physicians to hide from patients that they are going to die, the physicians consent	82 (28)	70 (24)	140 (48)	0.0001
PVD	If the patients' relatives ask me to hide from the patients that they are going to die, I consent to this	209 (51)	113 (28)	86 (21)	
Views of nurses vs. views of physicians:					
NVD	When it is known that patients are going to die, they should be informed	252 (87)	26 (9)	13 (5)	
PVD	When it is known that patients are going to die, they should be informed	350 (85)	45 (11)	18 (4)	n.s.
NVD	Nurses should have access to special places to reflect on issues related with death (seminars, workshops, etc.)	291 (99)	1 (0.3)	1 (0.3)	
PVD	Physicians should have access to special places to reflect on issues related with death (seminars, workshops, etc.)	319 (77)	60 (15)	34 (8)	0.0001

Notes:
1. Only six items were compared because they were those that were included in both Nurses' Views About Death (NVD) and Physicians' Views About Death (PVD) questionnaires.
2. Data from the PVD are those who were published in Álvarez del Río and colleagues, 2013

member responsible for providing their patients with this information, as has been established in several countries.[10]

The nature of nursing care implies constant and close proximity with patients, permitting nurses to provide them with emotional support.[4] This support could be hindered when the nursing personnel cannot talk openly about ominous prognostic information that, in fact, patients suspect, as has been already reported.[11] This phenomenon has been also described since the 1960s as "mutual pretense", and it relates to the patient becoming emotionally isolated from the participants in the health care team as well as from their close relatives.[12] It is well known that facing death can be a more painful experience when it cannot be shared, as masterfully described in the Tolstoy's classic "The Death of Ivan Ilyich".[13]

It has been demonstrated that it is beneficial for patients when nursing personnel become interested in the patients' psychosocial aspects.[14] Nurses in the current study considered themselves to be well prepared to care for terminally ill patients, and stated that they were willingly to talk with their patients about their end-of-life condition, especially when these patients broach the subject. However, some of the nurses acknowledged that they avoided the subject of death with their patients with whom they find it hard to establish a close relationship, and even noted that it bothers nurses to care for these patients. This is consistent with a recent study in which nurses expressed feelings of frustration because they felt a lack of confidence in themselves and thought that they had insufficient skills and knowledge to care for terminally ill patients.[15] This is understandable because caring for dying patients implies a high level of emotional involvement.[16] It is crucial for nurses to have specific training on end-of-life issues; otherwise, they could cause emotional damage to their patients and even to themselves. In fact, all of the participants in the current study considered they should have access to seminars or workshops in order to reflect upon and discuss issues related with death. Quoting a nurse from a recent study, "we need counseling or debriefing sessions, just to talk with someone".[17]

We also found that older nurses, as well as those with more years of clinical practice, were less likely to consider that patients should be informed when they are going to die. This could be explained because younger persons are more idealistic and, according to their values, tend to respect the patients' right to know what is happening to them. To the contrary, older persons tend to be more pragmatic and know that it is not always possible to fit certain actions into the ideal situation. What nurses with more professional experience do indeed possess is better communication with dying patients.[18]

Analyzing the responses provided by nurses and those given by physicians in the previous study,[9] there were significant differences between what physicians reported that they do and what nurses said that physicians do. According to nurses, physicians do not tell their patients the truth to the extent that they say they do. Nurses also said that doctors avoid the subject of death with their terminally ill patients, and that they withdraw from them more frequently than they admit. These results could support our supposition that the physicians' responses referred to a greater degree to what they thought was the correct thing to do than to what they actually do. But we cannot know whether nurses would, in fact, inform patients about their terminal condition if they were allowed to do so. Another possible explanation, not exclusive, for the previously cited differences is that there is inadequate communication between nurses and physicians, which may be related to the fact that in Mexico, nurses' work is not recognized as it is in other countries, where nurses and physicians work in mutual collaboration. In The Netherlands, Oncologist Joep Douma says, "I cannot do it alone as a doctor. I depend on the team a great deal. So a lot is also expected from the nurses".[19] Our results highlight the importance of addressing and correcting inadequate communication between nurses and physicians because in the end, it exerts a negative impact on the patients.[20]

Our results demonstrate the importance of more education and training of physicians and nurses on end-of-life issues. In fact, it has been demonstrated that education has positive effects on communication with dying patients, providing better care for them.[18] This training must be integrated by practical experiences that complement theoretical information, enhancing coping skills for professionals who deal with the end-of-life of their patients. Another recommendation deriving from this study is to define the clinical processes involved, considering improvements in the multidisciplinary team approach.[21] In recent years there has been an increase in awareness of the importance of improving communication skills between physicians and patients with severe diseases, enabling them to discuss the concerns and desires that arise at the approach of death, avoiding unjustified aggressive treatments and focusing on a better quality of life.[2] This is expected to extend to other members of the health care team, such as nurses.

There are some limitations to this study and some suggestions should be taken into consideration. First, study participants were comprised of nurses working only at two institutions in Mexico, which makes it difficult to generalize the results. However, these institutions concentrate nurses with the highest levels of specialty, those who predominantly care for terminally ill patients

on a daily basis. Second, we cannot be sure whether participants responded according to what they really do or what they claim to do. Finally, further research should include interviews or focus groups to explore the issue in depth, as well as other variables, such as the emotional impact on nurses caring for terminally ill patients, burnout syndrome, and nurses' communication skills.

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