

THE IMPACT OF BAD NEWS IN PATIENTS WITH NEUROLOGICAL DISEASES: THE CHALLENGE OF DOCTOR-PATIENT COMMUNICATION

Trujillo-de Los Santos Zoila ¹  | Paz-Rodríguez Francisco ²  | Sánchez-Guzmán María Alejandra ³ 

1. Geriatric Physician. Palliative Care Program. National Institute of Neurology and Neurosurgery. "Manuel Velasco Suarez.". Ciudad de México. México. Insurgentes Sur No 3877, Col La Fama, México D. F. CP 14269.

2. Laboratory of Clinical Neuropsychology. National Institute of Neurology and Neurosurgery. "Manuel Velasco Suarez.".

3. Graduate Studies Division of the School of Medicine. National Autonomous University of Mexico. Postgraduate Studiez

Correspondence

Dr. Paz Rodríguez Francisco
Departamento de Neuropsicología y Grupos de Apoyo. Instituto Nacional de Neurología y Neurocirugía Manuel Velasco Suarez. Ciudad de México. México. Insurgentes Sur 3877, Col La Fama, CP 14269, México.
fpaz@innn.edu.mx

Abstract

Objective: In the context of neurological diseases, bad news is frequently communicated. We describe how bad news is given/received in the doctor-patient relationship.

Material and Method: Descriptive cross-sectional study by means of a survey. Participation of 50 neurologists and 145 patients with neurological disease. An ad hoc questionnaire was elaborated to assess the communication/reception of bad news.

Results: Only 11% of doctors always report bad news; regarding training, 56% learned by watching other specialists. For patients, notification of diagnosis is the most frequent "bad news" (53.4%). Both neurologists and patients report that the mode of communication was verbal 85.5% and 36.0%, respectively. Regarding emotional expression, 52% of the physicians noted that they allow the patient to express himself/herself; only 4.8% of patients said they were able to express their emotion.

Conclusion: Doctors do not receive training on the subject. These results suggest that adjustments should be made in the training of neurologists to include tools that favor dialogic communication.

Keywords: *Neurological diseases, bad news, communication, doctor-patient relationship, medical education*

Background

Bad news is "news that will drastically and negatively affect a person's vision of the future", and even the present, by affecting their emotional, work, family, social and economic life^{1,2}. The context of clinical care is a space in which health care personnel must continually communicate bad news, which not only implies giving a diagnosis with a poor prognosis, but also not having an accurate diagnosis. Even if there is clear information about a catastrophic event in daily life, the evolution of a condition may not be known³. In general, in the practice of medicine there is rarely certainty, as Sir William Osler would say: "medicine is a science of probability, and the art of handling uncertainty"⁴. In some specialties the lack of certainty is more evident, particularly in neurology, a field in which it is not easy to establish a prognosis, since an initial event may mask a more serious problem. In addition, even if one can be sure of the evolution, bad news usually represent a biographical rupture in patients because of its impact on daily life activities. For example, stage III and IV glioblastoma

multiforme, considered the most malignant tumors with poor survival⁵, or amyotrophic lateral sclerosis^{6,7}, whose prognosis is poor and short-lived, since it will progressively affect swallowing and respiratory function; in some cases, there is also cognitive impairment. Likewise, in demyelinating diseases, which mostly affect young productive people with more or less long survival, if disease-modifying treatment is not provided, severe disability can occur, which impacts the patient and his or her family emotionally and physically, as well as causing economic dependence^{8,9}. Other neurodegenerative diseases, such as dementias, may have long survival, but at severe functional, social and economic cost and burden of patient care. On the other hand, the Internet has become the most widely used source for consulting on health care issues, generating a web of complex social and cultural relationships⁹. At this stage, patients and families are increasingly demanding dialogic communication, which makes paternalistic relationships obsolete and leads to the gradual empowerment and autonomy of patients¹⁰⁻¹².



According to Sobrino López², in several countries a high percentage of patients, between 50% and 75%, wish to be fully informed, as is the case in Spain. This implies that health professionals need to have good communication with the patient and the family, which requires a clear, precise, empathetic and not only technical language¹³⁻¹⁵. This type of communicative relationship can benefit care; patients could handle their doubts and anxieties with much more knowledge and understanding, and, in turn, have an impact on the acceptance of different treatment offers.

Against this backdrop¹⁻³, various strategies have been developed for the communication of bad news, such as guides, protocols, seminars. Among the best known are: the A, B,C,D,E¹⁴ which focuses on the following steps: A. Advance preparation; B. Building therapeutic environment and relationships; C. Good communication with patient and family; D. Addressing family reactions and coping with emotional reactions of patients and family; E. Framing and validation of emotions. Another widely disseminated protocol is known as S-P-I-K-E-S², developed by Buckman R. and Baile W. who, through a real-time survey applied to medical oncologists, showed that despite frequently informing cancer patients of their diagnosis, verbal communication was not enough; it was essential to take into account their emotional reactions, their expectations regarding their prognosis, as well as the inclusion of the family, faced with the dilemma of maintaining hope in spite of the somber situation, which confirmed the complexity of giving bad news. In this context, they developed a method that has served as teaching and training. It is based on 6 steps or stages to follow: 1) setting the stage (favoring privacy, involving their close affections if desired by the patient, avoiding barriers between patient and doctor, maintaining an attitude of frankness by looking the patient in the eye, avoiding interruptions); 2) assessing the patient's perception (they implemented an axiom that should always apply "before speaking, ask"); 3) invitation to the patient to give him/her information that he/she is likely to reject initially, wait until the patient is sure of what he/she wants to hear; as it is a valid psychological mechanism, 4) acknowledge feelings and knowledge, give clear information; 5) address the patient's emotions with empathic responses; responding to the patient's emotions represents the most difficult challenge of giving bad news. Emotional reactions can range from silence to disbelief, crying, denial or anger, often an expression of shock, isolation and grief. The physician can offer support and solidarity by providing an empathetic response; 6) gathering and strategizing. Before discussing treatments or a plan, ask the patient if he or she is ready for this discussion, presenting realistic options.

Sharing decision-making responsibility with the patient is important because it helps to decrease the sense of failure when treatment is unsuccessful, and helps to restore the perception that the patient's wishes matter.¹⁴

In the review of the communication provided by doctors about bad news, two main topics were observed: 1. Lack of curricular preparation and 2. Anxiety and stress. Regarding the first topic, a study surveyed doctors (men and women) with several years of experience. What was remarkable was that 98.7% frequently give bad news, however, 80% did not receive any training to carry out this task¹⁴. Regarding the second topic: a study conducted on ALS patients treated by doctors with more than 20 years of professional practice and over 50 years of age, reported greater stress and anxiety when reporting the diagnosis and prognosis of a neurological condition with short survival and great impairment of functionality^{7,8}.

In both cases, the shortcomings of doctor-patient communication were not considered, such as the expectations of the patient and those of the doctor in the consultation^{5,13}. From another point of view, the approach to the subject was the lack of empathy and dissatisfaction in communication with the doctor, patients and family members. Part of this approach is the work of Stern¹⁵, which analyzes effective communication between doctors and patients with epilepsy. Neurologists in three countries (United States, Spain and Germany) tended to avoid the term epilepsy and were more explicit in the seizures, avoiding talking about the chronicity of the condition, which left patients and families dissatisfied. The neurologists unilaterally decided on the treatment and the information provided, without taking into account the patient's needs. In Multiple Sclerosis, satisfaction with communication is related to the age of the patient, the time dedicated to the consultation and the adequate emotional support provided⁶.

Taking all of the above into account, the present study describes doctor-patient experiences of giving and receiving bad news in neurological diseases.

Methodology

Study design and participants

Descriptive cross-sectional study, using purposive sampling. Patients and doctors of the National Institute of Neurology and Neurosurgery (INN) were invited to answer an ad hoc questionnaire to learn about their experiences in communicating bad news. Of these, only 146 (21%) responded affirmatively to the question "Have you received any bad news at the INN during the last year that you feel has affected you?" On the

other hand, the 296 professionals (116 attending and 180 residents) working at the INN were invited to answer the survey on how they communicate bad news, the patients' perceptions and their emotional reactions. Fifty (17%) questionnaires were obtained with complete responses, which were returned to the palliative care area. **Figure 1.**

In both cases, verbal informed consent was requested in accordance with the Helsinki research ethics guidelines. A review of the literature on the subject was carried out^{2,6,9,14}, of the scales consulted, questions aligned with international guidelines were selected that assess the giving/receiving of bad news (13 for patients and 10 for physicians). The questions were grouped into two sections: demographic data and those related to receiving/giving bad news. For patients, the trigger question used was: "Has there been any bad news that you have been given in the hospital during the last year that you feel has affected you, and what was it?" From this answer, aspects related to the process of the bad news were assessed (Annex 1). For the doctors, the questionnaire contained 10 questions that evaluated the reporting of the bad news (according to protocol A,B,C,D,E and SPIKES). These were binary (Yes/No) or multiple choice questions with pre-coded responses, where they were asked to select one of the options (Annex 2). The questionnaire was tested in 30 patients and 10 doctors to determine their comprehension and response time.

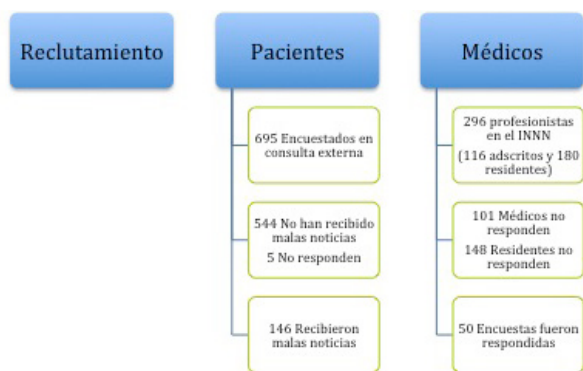


Figure 1. Recruitment of participants.

The participants shared similar demographic characteristics: they were single, Catholic and showed no differences by sex (**Table 1**). 53.5% of the patients were between 30 and 50 years of age and 65.8% had less than 5 years with the condition. 33% had secondary schooling. Most of the doctors surveyed were residents of neurology specialties, 92% reported their clinical practice in patients with neurodegenerative diseases and 50% with tumors.

Statistical analysis

A descriptive analysis (frequencies and proportions) was performed for categorical variables, mean, standard deviation, median and range, for continuous and discrete variables. To determine the differences in giving/receiving bad news among the respondents, a Chi-square analysis and Fisher's test were applied to variables that could be compared because the same question was asked to both patient and doctor.

Results

The bad news

Regarding the type of bad news given to patients: 57.5% mentioned that it was the notification of the diagnosis; 17.1% the progression of the condition; 11% were informed that their diagnosis was not known; 4.1% were informed that their disease was not curable and 7.5% that they had to have surgery. Another group of patients considered the cost of the medicine to be bad news, and this corresponded to 2.7%. Regarding who informed them: 75.3% mentioned that it was the attending doctor; 18.5% were informed by the resident; 2.7% by a family member and 3.4% did not answer.

Regarding how the patient perceives the doctor's attitude: 71.9% said it was warm; 11% indifferent; 8.2% cold; 3.4% abrupt; 2.7% rude; 2.7% did not respond.

Table 1. Demographic characteristics of the participants.

		Physicians n=50	Patients n=146	P
Sex	Female	24 (48.0)	85 (58.2)	.209
	Male	26 (52.0)	61 (41.8)	
Marital Status	Single	27 (54.0)	68 (46.9)	.118
	Married/UL	19 (38.0)	67 (46.2)	
	Widowed/divorced	8 (8.0)	10 (6.9)	
Religion	Catholic	33 (66.0)	121	.153
	Another	2 (4.0)	18 (12.3)	
	None	15 (30.0)	7 (4.8)	
Disease attended/ suffering from	Tumors	25 (50.0)	47 (32.2)	
	Epilepsy	14 (28.0)	31 (21.2)	
	Cerebral vascular	19 (38.0)	17 (11.6)	
	Mental	17 (34.0)	8 (5.5)	
	Neurodegenerative	44 (92.0)	17 (11.0)	
	Other Neurological	13 (26.0)	26 (18.6)	

Note: Physicians responded to the question "What disease do you treat?" with a multiple choice answer, which means that they can treat different conditions, therefore the percentage does not add up to 100%.

In the case of doctors, 20% mentioned being empathetic (putting themselves in the patient's place).

Differences were observed between the way doctors and patients give/receive information, $\chi^2 (2, N=1)=41.588, p=0.001$. Receiving the bad news by the patient (verbally and nonverbally 14.4%) was significantly lower. **Figure 2**

On the other hand, patients mentioned that once they had received the bad news, 23.3% were offered support through the care of another professional: 38.2% psychological, 32.4% psychiatric, 11.8% social work and 5.9% thanatology, and 11.8% were sent for clinical analysis.

The doctor refers to providing instrumental support (use of images or studies when giving the bad news) to the patient in 28.9%, to a family member 7.9%, and 63.2% to both. He/she provide information in 5.1% to the patient, 5.1% to a family member and 89.7% to both. He/she gives 10.0% emotional support to the patient, 10.0% to a family member and 80% to both, in the case of spiritual support: 24.1% to the patient, 3.4% to a family member and 72.4% to both, respectively.

Regarding the place where information is given/received: Differences were observed between what doctors and patients report, $\chi^2 (2, N=1)=50.207, p=0.001$. If the information was given in a private and comfortable place; the physician reports 62% vs. 11% reported by the patient. Differences were also observed when asking if the information given/received, was done in the office, $\chi^2 (2, N=1)=9.492, p=0.002$; the doctor reports 54% vs. 78% reported by the patient. In addition, there are differences with respect to giving/receiving information in the hallway or elsewhere, $\chi^2 (2, N=1)=4.126, p=0.042$; the doctor reports 10% vs. 2% by the patient.

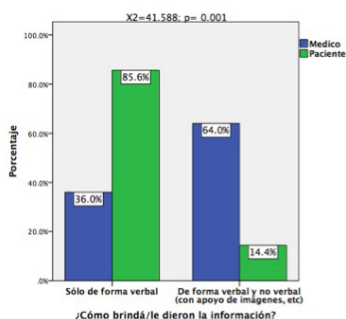


Figure 2. How bad news is given/received in the hospital outpatient clinic.

Another significant difference was when information was reported to be given/received at the patient's bedside, $\chi^2 (2, N=1)=14.183, p=0.001$; the doctor reported 12% vs. 4% by the patient. **Table 2.**

On the other hand, significant differences were observed in communication, $\chi^2 (2, N=1)=55.665, p=0.001$. Regarding allowing emotions to be expressed; the doctor allowed it in 52% of the occasions vs. 8% reported by the patient. Finally, when establishing a trust relationship, $\chi^2 (2, N=1)=44.647, p=0.001$, the doctor reports establishing such a relationship on 42% of occasions vs. 3.4% reported by the patient. **Figure 3.**

(11%) of the doctors mentioned that they always report the bad news, while (78%) do so sometimes. 42% report it completely and only once. 52% do it in a gradual way and with the support of information. 2% mentioned not communicating the bad news, and 4% did not answer the question. Regarding how they learned to give bad news: 56% refer to seeing other specialists; 40% by trial and error; 36% by searching for information on the subject.

Discussion

The present study describes how doctors deliver bad news and how patients receive this type of information. A significant percentage of the doctors (29%) are emotionally distant, which corresponds to the perception of the patients in confirming this distant attitude (indifferent, cold, abrupt and even rude) and coincides with the doctors' own statement that they are empathetic only 20% of the time. It is likely that this doctor-patient communication attitude or the lack of strategies is due to deficient curricular training or workshops that focus on the communication of bad news, with a global and inclusive

Table 2. Place where the bad news is received/given.

	Physicians	Patients	p
If you report, where do you report?			
Private and comfortable place			
Yes	31 (62.0)	16 (11.0)	.001
No	19 (38.0)	61 (89.0)	
Office			
Yes	27 (54.0)	114 (78.1)	.002
No	23 (46.0)	32 (21.9)	
In the corridor or other place than the office			
Yes	5 (10.0)	3 (2.1)	.027
No	45 (90.0)	143 (97.9)	
Sitting at the patient's bedside			
Yes	6 (12.0)	6 (4.1)	.080
No	44 (88.0)	140 (95.9)	

approach to the emotional part, and without neglecting the technical and formal aspect of the process. The lack of empathy is accentuated as specialization advances, where technological advances, productivity and bureaucracy are prioritized over personalized attention^{14,15}. The effects of this situation affect the doctor-patient relationship and the relationship with the family, which leads to an institutional complaint, despite the excellence of the specialized care received, as has been mentioned in various studies¹⁶⁻¹⁹.

As in other studies, a significant percentage of doctors did not receive training or information on how to give bad news, which reinforces the previous comments. This deficiency is due to the fact that in the university curriculum in our country, the subject of palliative care has not been included and only tangentially deals with aspects of identification and management of pain²⁰⁻²³. For example, in the Faculty of Medicine of the National Autonomous University of Mexico (UNAM) it is only in the ninth semester and in the subject of algology where some topics related to PC are taught. Currently under health policies, implemented by the General Health Council (August 2018)²¹ efforts are being made to prepare health personnel, in terms of PC as established by the General Health Law and NOM-011²².

Confidence and expression of emotions is more overrated by doctors than by patients. The same applies to the use of clear, understandable language, without raising false expectations when detailing the patient's problems.

According to Trujillo et al. (2015), good communication also depends on the ability of patients to ask questions and to be aware of their right to be informed, without forgetting that some patients and family members "hear" the bad news, but do not "listen" because of the situation they are facing at that moment¹². Acquiring these skills requires a process of empowerment and training, which involves inviting patients to express their emotions and reasonable preferences in medical care. This goes hand in hand with respect for their rights, by the institutions and their staff.

Conclusions

Neurologists require education and training to communicate bad news. Communication, to be effective, must contain elements such as listening attentively, explaining the situation, showing respect, dedicating sufficient time, and encouraging participation in joint decision-making to strengthen autonomy, giving adequate information and paying attention to the thoughts and emotions of the persons being treated, as it could substantially improve their active participation in the treatment.¹⁸

Doctor-patient communication should be dialogic, containing three dimensions: biomedical, emotional and cultural identity²¹⁻²⁷. Giving bad news is a challenge for health professionals, regardless of hierarchy, since the doctor-patient relationship is based on the trust of those who suffer from a disease, towards those who have

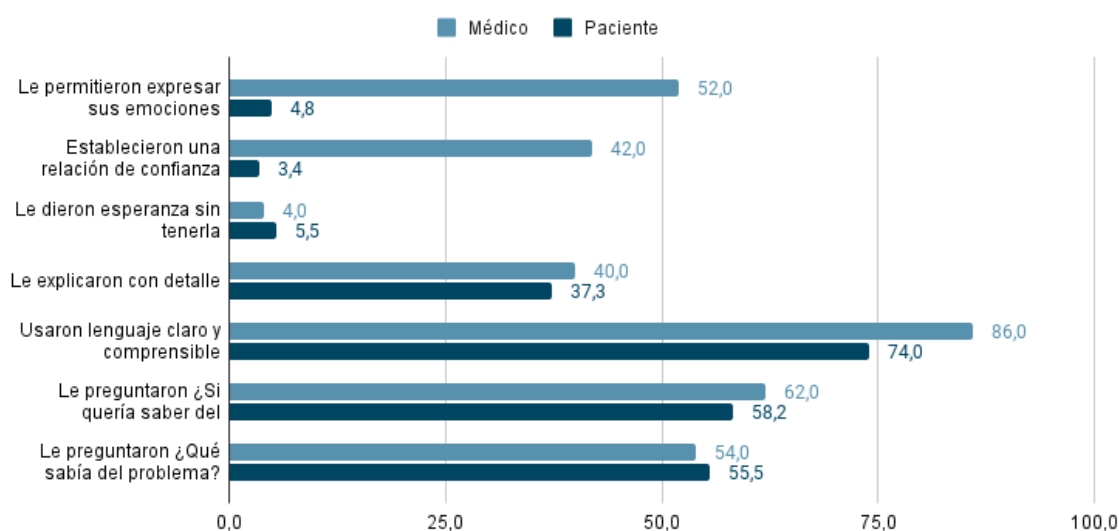


Figure 3. Doctor-patient communication relationship

the knowledge that can help or solve their problem. The apothegm of Dr. Cicely Saunders on "Always tell the truth, but season it with kindness" is applicable in all fields of medicine.

We suggest that this theoretical-methodological proposal be considered to substantially improve doctor-patient communication in general, and in particular, the transmission of bad news²³⁻²⁷.

Limitations

The sample is not representative since only patients attending the outpatient clinic participated and one third of the doctors of the National Institute of Neurology were residents of the neurology specialty who agreed to answer the survey. However, it shows a daily reality in hospital care.

References

1. VandeKieft KG. Breaking Bad News. *Am Fam Physician* 2001; 64:1975-8.
2. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the patients with cancer. *The Oncologist* 2000;5: 302-311. <http://dx.doi.org/10.1634/theoncologist.5--4-302>
3. Ascencio-Huertas L, Allende-Pérez S, Castañeda-de la Lanza C, Verástegui-Avilés E. La comunicación de "malas noticias" en cuidados paliativos. *Gac Mex Oncol* 2013; 12(4):276-279.
4. Serra VMA. Sir William Osler: el padre de la medicina moderna. Aportes a la reumatología. *Rev Cubana Reumatol* 2015; 17: 162-168.
5. Goebel S, Mehdorn HM. Breaking Bad News to Patients with Intracranial Tumors: The Patients' Perspective. *World Neurosurg* 2018;118:e254-e262. <http://dx.doi.org/10.1016/j.wneu.2018.06.168>
6. Messina MJ, Dalla Costa G, Rodegher M, Muiola L, Colombo B, Comi G, et al. The Communication of Multiple Sclerosis Diagnosis: The Patients' Perspective. *Mult Scler Int* 2015;2015:353828. <http://dx.doi.org/10.1155/2015/353828>
7. Aoun SM, Breen LJ, Edis R, Henderson RD, Oliver D, Harris R, Howling D, O'Connor M, Birks C. Breaking the news of a diagnosis of motor neurone disease: A national survey of neurologists' perspectives. *J Neurol Sci* 2016;367:368-74. <http://dx.doi.org/10.1016/j.jns.2016.06.033>
8. Aoun SM, Breen LJ, Oliver D, Henderson RD, Edis R, O'Connor M, et al. Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey. *J Neurol Sci* 2017;372:144-151. <http://dx.doi.org/10.1016/j.jns.2016.11.043>
9. Domínguez D, Álvarez, J. Redes sociales y espacios universitarios. Conocimiento e innovación abierta en el espacio iberoamericano del conocimiento. *RUSC* 2012;9(1):51-64
10. Poole R, Smith D, Simpson S. How Patients Contribute to an Online Psychoeducation Forum for Bipolar Disorder: A Virtual Participant Observation Study. *JMIR Ment Health*. 2015;2(3): e21. <http://dx.doi.org/10.2196/mental.4123>
11. Suriá MR, Beléndez VM. Grupos de apoyo virtuales dedicados a problemas de salud: estudio de su tipología y análisis de su representatividad. *Anal Psicol* 2011;217(1): 210-220. <http://dx.doi.org/10.6018/analesps>
12. Trujillo de los Santos Z, Paz-Rodríguez F, Sánchez-Guzmán MA, Nava-García G, Zamora RP, García-Pastrana C, et al. Estudio piloto en cuidadores de pacientes con enfermedades neurológicas, sobre el significado y conocimiento de cuidados paliativos. *Acta Bioeth* 2015;21(2): 191-198. <http://dx.doi.org/10.4067/S1726-569X2015000200005>
13. Sobrino López A, Comunicación de malas noticias. *Semin Fund Esp Reumatol*. 2008; 9:111-22. [https://doi.org/10.1016/S1577-3566\(08\)74928-5](https://doi.org/10.1016/S1577-3566(08)74928-5)
14. Martín del Campo A, Romero-Cabello R, Sánchez CJ, P. Ángeles Moreno AC, Romero-Feregrino R, Bustamante-Rojano JJ, et al. ¿Cómo transmite malas noticias el médico especialista? Estudio realizado con médicos especialistas del Hospital General de México. *Rev Med del Hosp Gen (Mex)* 2012;75(2):76-83.
15. Stern JM, Cendes F, Gilliam F, Kwan P, Ryvlin P, Sirven J, et al. Neurologist-patient communication about epilepsy in the United States, Spain, and Germany. *Neurol Clin Pract*. 2018;8(2):93-101. <http://dx.doi.org/10.1212/CPJ.0000000000000442>
16. Laxe S, Capdevila E. La comunicación de malas noticias en el daño cerebral adquirido: ¿mucho ciencia pero tal vez poca complacencia? *Rehabilitación (Madr)*. 2015; 49(1):1-3. <http://dx.doi.org/10.1016/j.rh.2014.07.003>
17. Verlinde E, De Laender N, De Maesschalck S, Deveugele M, Willems S. The social gradient in doctor-patient communication. *Int J Equity Health* 2012 12;11:12. <http://dx.doi.org/10.1186/1475-9276-11-12>

18. Padilla, EM, Sarmiento-Medina P, Ramirez-Jaramillo A. Percepciones de pacientes y familiares sobre la comunicación con los profesionales de la salud. *Rev Salud Pública (Bogotá)* 2014;16(4):585-596. <https://doi.org/10.15446/rsap.v16n4.40556>
19. Martins RG, Carvalho IP. Breaking bad news: patients' preferences and health locus of control. *Patient Educ Couns* 2013; 92(1):67-73. <http://dx.doi.org/10.1016/j.pec.2013.03.001>
20. García-Reyes W, Lara-Solares A, Guevara-López U, Flores-Rebollar A, Loaeza-Del Castillo A. Cómo se dan las malas noticias de enfermedad terminal por un grupo médico no especializado en cuidados paliativos. *Rev Mex Anest* 2008;31(1):9-14
21. Pastrana T, De Lima L, Sánchez-Cárdenas M, Van Steijin D, Garralda E, Pons JJ. *Atlas de Cuidados Paliativos en Latinoamérica 2020*. Houston: IAHPC Press.
22. Consejo General de Salubridad. DOF 26 diciembre 2014. Manejo integral de Cuidados Paliativos (Informe 2017)
23. Guía de Manejo Integral de Cuidados Paliativos. Ed. Consejo de Salubridad. Early Institute e Instituto Nacional de Cancerología 1a. edición julio 2018.
24. Hamui A, Grijalva M, Paulo-Maya A, Dorantes- Barrios P, García-Tellez S, Duran- Pérez V, et al. Las tres dimensiones de la comunicación paciente: biomédica , emocional e identidad cultural. *Revista CONAMED*, 2015;201(1): 17-26.
25. Borrel CF. el Modelo Bopsicosocial en evolución. *Med Clin (Barc)* 2002;119(5):175-9
26. Villegas S CE. Comunicación en el currículo médico *Medicina* 2017 U.PB;36(1):59-70
27. Toivonen AK, Lindblom-Yläne S, Louhiala P, Pyörälä E. Medical students' reflections on emotions concerning breaking bad news. *Patient Educ Couns* 2017;100(10):1903-1909. <http://dx.doi.org/10.1016/j.pec.2017.05.036>