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Internal medicine residents, notspecialized in palliative care, disclosing bad news about a terminal illness[1]

Wendy García-Reyes, MD;* Argelia Lara-Solares, MD;** Uriah Guevara-López, MD;** Armando Flores-Rebollar, MD;*** Aurora Loaeza-Del Castillo, MD***

* Resident of Pain Clinic and palliative care.
** Pain Clinic and Palliative Care Department. Instituto Nacional de Ciencias Médicas y Nutrición "Salvador Zubirán".
*** Department of Internal Medicine Instituto Nacional de Ciencias Médicas y Nutrición "Salvador Zubirán".

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Wendy García Reyes MD
Instituto Nacional de Ciencias Médicas y Nutrición "Salvador Zubirán"
Vasco de Quiroga Núm. 15, Tlalpan 14000, México, D.F.
Phone: (+52) 55 5487 0900 Ext.: 5008
E-mail: wafcalatrava04@yahoo.com.mx

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SUMMARY

Introduction: Breaking bad news is a stressful and difficult situation for medical doctors. **Method:** A cross sectional survey was conducted with internal medicine residents at the INCMNSZ. The survey used a 21 items questionnaire, which allowed evaluating and categorizing following aspects related to the delivery of bad news: previous information, first experience, emotional impact, accordance with basic concepts, and communication with the patient, self-critique of the interviewee, previous experience and willingness to be trained about this topic. **Results:** Fifty-six percent of respondents have never received information or training to deliver bad news and they regarded that their ability ranged from poor to regular. 96% considered that the patient has the right to know the diagnosis; 38% asked to patients to what extent they wanted to learn about the prognosis; 8% answered that they would only inform to the responsible relative; 100% answered that if they were the patients suffering the terminal illness, they would like to be informed. 58% had experienced receiving bad news and this had a positive influence in their professional development. Eighty percent acknowledged the need to be trained about this topic. **Conclusions:** The survey shows that the ability to disclosure bad news needs improvement among specialists.

Key words: Communication, bad news, residents, physician-patient relationship.

RESUMEN

Antecedentes: *Decir la verdad cuando se trata de informar «malas noticias» es una situación estresante y difícil para los médicos.* ***Material y métodos:*** *Se realizó un estudio observacional, prospectivo, transversal, en residentes de Medicina Interna del INCMNSZ. El cuestionario quedó conformado con 21 preguntas, que permitieron evaluar y categorizar la forma de dar malas noticias: Identificar la primera experiencia, impacto emocional, conceptos básicos, comunicación con el paciente, autocrítica del encuestado y deseo de capacitación.* ***Resultados:*** *El 56.0% de los encuestados jamás recibió capacitación para dar malas noticias, y creen que su capacidad para dar malas noticias es de mala a regular. El 96.0% considera que el enfermo debe conocer su diagnóstico; sólo el 38.0% de los residentes pregunta al paciente hasta dónde desea conocer el pronóstico de su enfermedad. El 8.0% considera informar únicamente al familiar responsable. El 100% respondió que si ellos fueran el paciente desearían ser informados en caso de presentar una enfermedad*

terminal. Sólo el 58.0% ha tenido experiencia de recibir malas noticias, ésta influyó positivamente en su desarrollo profesional. El 80.0% reconoce necesitar capacitación en este tópico. ***Conclusiones:*** *Al igual que en otros países, esta encuesta refleja que la capacitación para dar malas noticias es escasa entre los médicos especialistas.*

Palabras clave: *Comunicación, malas noticias, médicos residentes, comunicación médico-paciente, información de malas noticias.*

INTRODUCTION

Death is a significant event for any person, and dying or being a witness to someone's death is always a traumatic experience. Throughout such an event, emotions are intense and mixed. The patient, his/her relatives and even health care professionals experience the emergence of apparently forgotten fears[1].

Communication is an essential tool that enables a medical doctor to notify patients and their family and significant persons about events that are within his area of competence. Good communication can be helpful in improving the quality of life of a patient. Furthermore, effective alleviation of symptoms is impossible if the patient does not have an adequate understanding of his/her clinical conditions[2]. Communicating the truth, mainly when it is about sharing "bad news", is a stressful and difficult situation for all medical doctors, regardless of their specialty[3].

"Bad news" is any information that negatively affects the vision that a patient has about the future. Medical doctors should personally and continuously inform the patients about the negative aspects of their health; however, the literature reveals huge chasms on this topic[4,5].

The resistance of health professionals to disclose bad news is related to the ways in which it generates stress, intense emotions, feelings of responsibility and fear of being evaluated negatively. In 2003, in Japan, 83% of patients were informed that they had a cancer diagnosis. This was done considering that the patient has the right to know the diagnosis before his family has the information; however, due to cultural reasons, this does not happen in Latin American countries. The family receives the information first, thus taking on a special role as liaison between the patient and the medical doctor regarding the disclosure of bad news[6,8].

In a retrospective study carried out from the years 1999 to 2001 with internal medicine residents at Harvard University, 42% reported fear of the patient's emotional reaction[9,10]. Deciding factors related to physicians' behaviour include personal and professional experiences of the health professional in the face of pain and death as well as his capability to show empathy towards somebody else's feelings.

Medical students and internal medicine residents are frequently involved in giving bad news. This is a difficult task to undertake, mainly due to their lack of experience, and because they are not adequately trained[12].

The traditional concept of medicine emphasizes the healing process and alleviation of suffering as its utmost mission, while worsening health and death confront the medical doctor with the limitations of medicine[13].

In 1998, in a symposium of the American Cancer Society, it was reported that 60% of oncologists disclose bad news 5 to 20 times a month; 42% mentioned that they had difficulty in communicating bad news and 47% considered that their abilities to do so were inadequate[14,15].

Albert Jovel emphasizes that patient-medical doctor communication remains as one of the most important available technologies, and that creating reciprocal confidence is the best practice to favour such communication, which should be based upon respect, comprehension and affection. Communication is the most important ability needed to assist somebody and its proper use has an immediate beneficial impact on the patient[16].

It is important to know how to disclose bad news. This is an interaction comprised of three components: a code, a transmitter and a receiver. The code is the system of symbols that represent meanings. In this case, the concept addresses a fatal outcome. The World Health Organization issued criteria to identify a terminal illness.

- Diagnosis of an advanced, progressive and incurable disease
- Lack of response to the specific treatment
- Life expectancy prognosis no longer that six months
- Numerous, intense, multifactorial and changing symptoms
- Major emotional impact on the patient, the family and health providers[17]

In the last three decades, significant changes in the behaviour of medical doctors in disclosing news about terminal illness have been observed. In 1961, in a study conducted in the United States, 90% of 219 medical doctors revealed that they did not disclose the diagnosis to their patients. In 1998, a similar study was conducted in the same country.

The study reported that 98% of medical doctors were prone to tell the patients the diagnosis and all medical doctors would want to be notified if they had a terminal disease[19].

There is evidence that most medical doctors consider that they do give bad news, but that the message could not be received or was not completely understood by the patient. Integral care to a terminal patient requires a centred relationship that allows for providing psychological, affective and spiritual care[20].

There are three models in the literature for disclosing bad news. First model: no disclosure. This is a traditional model in which the diagnosis is given to a relative, who along with the medical doctor veiled the bad news. This model has shown to damage the patient-medical doctor relationship and to impair the patient in participating in decision-making processes[21].

Second model: Total disclosure. This implies notifying the patient as soon as the information is available. This model attempts to promote confidence and patient-medical doctor communication. In 1982, Reynolds et al reported that 91% of patients wanted to know their diagnosis, 97% wanted the information about their treatment and 88% about the prognosis[22].

Third model: Individualized disclosure. The amount of disclosed information is adapted according to the individual desire of the patient, through patient-medical doctor negotiation[23]. Therefore, disclosure is a process that takes time and allows a collaborative relationship between both parts.

If the information is to become a therapeutic tool, it should have features that will make it as valid as possible; adapted to the knowledge of the patient; circumscribed to the progression of the disease; without forecasting upcoming events; concrete; close to the questions of the patient; coherent, in terms of all sources; realistic without suppressing hope; able to transmit positive feelings; adapted to the psychological status of the patient and allowing his/her participation[25,26].

No general rules exist, although is important to take into account the stages of the process of information: choice of the external context (the place in which information is disclosed should be adequate); exploration of the level of information (what the patient knows and what information he/she wants to know); information (be delicate when informing, do not use technical language); evaluate the impact (allow time for the patient to assimilate the information); favour the expression of emotions (through the impact that information caused); confirmation (what the patient understands, without giving direction about how the patient should organize his/her life); support (show continuous interest about the needs of the patient, that includes scheduling another interview in two to three days to evaluate the impact of the information on the patient)[27,28].

In this context it is not enough to establish rules of action, and it is necessary to sustain and interiorize ethical principles. This explains the importance of training the medical doctor, by providing basic information and strategies to disclose bad news while conserving his/her human quality and bio ethical thinking. This has the aim of offering to the patient the capability of free self-determination within a relationship of reciprocal confidence.

METHODOLOGY

An observational, prospective study was conducted with Internal Medicine residents at the Instituto Nacional de Ciencias Médicas y Nutrición "Salvador Zubirán" (INCMNSZ).

The INCMNSZ is a national referral centre and a teaching hospital for the specialization of internal medicine, to which the National Autonomous University of Mexico gives recognition. The instrument for evaluating the residents was a 21-questions self-applicable questionnaire. The questionnaire was pilot-tested with nine internal medicine residents that were randomly chosen. The aim of the pilot test was to evaluate whether the questions were understandable and to allow the researchers to adapt the multiple-choice questions and the group tendencies of each answer. Overall, the questions were not difficult to understand. The researchers discussed every question with the pilot test group. Suggestions for possible questions and answers were given and adapted accordingly. This allowed for pertinent modifications that the group of researchers discussed until reaching the final version of the questionnaire.

The final questionnaire had 21 questions. All were closed questions with 3-5 possible answers to be chosen; five questions were binary and there were three dependent questions.

The questions focused on evaluating and categorizing the following issues:

A. Information received during university training about how to disclose bad news
B. First experience when disclosing bad news
C. Emotional impact of disclosing bad news
D. Adherence to the concepts and recommendations for disclosing bad news
E. Communication with the patient
F. Self-critique regarding how to disclose bad news
G. Personal experience of the interviewee receiving bad news
H. Desire of information or training about how to disclose bad news

Information from the questionnaires was analyzed by using descriptive statistics. Software SPSS (Statistical Package for the Social Sciences) version 13 (SPSS Inc, Chicago Ill) was used to run the analyses. The association between

categorical variables was analyzed by estimating odds ratios and by using Fisher test and χ^2 test.

RESULTS

There were 84 internal medicine residents distributed in the four-year course. The questionnaire was applied during the last trimester of the academic year. Two clinical sessions with high attendance of residents were chosen as times to apply the questionnaire. Participation of residents was anonymous and voluntary. Fifty residents participated. Most were in 1st and 2nd years of residence, given the larger size of the group (51/84). The average age was 26 ± 1.59 years. Most were in their first year (27/50) and were single (88%) (Table I).

Fifty-six percent of interviewees never had received information or training to give bad news; only 8% mentioned that, according to their judgment, their training was complete or satisfactory. They were trained at the School of Medicine. Among the residents with no previous training to give bad news, during their first experience, 27% imitated what other senior medical doctors or residents with more experience did, and the rest did what they believed to be correct in such a situation. Fourteen percent considered that their first experience in giving bad news was negative. Thirty two percent considered their experience as fair and 82% declared that was difficult to give bad news; of these residents, 67.4% considered that the reaction of the patient and/or the family is the difficult part.

Twelve percent preferred to delegate this responsibility to another medical doctor. A full 96% considered that the patient should know the diagnosis and prognosis. The junior residents emphasized communicating the prognosis to the patient (OR 4.72; p value 0.04). However, only 38% of residents asked the patient about to what extent he/she wants to know the prognosis of the disease. Residents' opinions about who should know or receive the bad news included both the patient and the family (86%), and only 8% considered only informing the family or responsible relative as correct.

Regarding the proper place to disclose bad news, only 52% would choose a private place. Most residents are aware of the emotional impact that the information causes, and they would allow the patient to express his/her emotions. Fifty-six percent of interviewees considered that their abilities to disclose bad news ranges from bad to regular. The 2nd year residents considered that their capability was good (OR 15.75, $p < 0.05$). Regarding their own personal experiences with bad news, 100% answered that they would want to be informed if they have a terminal disease. Over half (58%) had previous experience in receiving bad news and 81% of them considered that this had a positive influence in their professional development. Almost all (80%) declared being trained in this topic is useful and necessary.

Table 1. Characteristics of participating internal medicine residents

Characteristic	Values
Average age, years ± SD	26.76 ± 1.59
Sex, n (%)	
Women	20 (40)
Men	30 (60)
University , n (%)	
Public	41 (82)
Private	9 (18)
Year of residence, n (%)	
1	27 (54)
2	11 (22)
3	9 (18)
4	3 (6)

The average age was 26.76 ± 1.59 years, Most of respondents were first year residents.

DISCUSSION

In the patient-medical doctor relationship, the medical doctor has more influence in the decision-making process. That depends upon what and how the bad news is disclosed. Every medical doctor has his/her own philosophy, beliefs and accrued experience; in most cases, this is maintained in a subconscious way.

Regrettably, medical schools provide little or no training at all to medical doctors about this topic[31]. We corroborated in this study that only 8% had being trained satisfactorily. The school of Medicine trained them. Concerning those residents without previous training, 27% mentioned that in their first experience they imitated the more experienced medical doctors or residents. Yet they considered this first experience as awful or regular.

Most participating residents in this study found it difficult to release bad news. Other surveys have reported similar results. In the 1998 annual meeting of The American Cancer Society, 500 oncologists were surveyed and 90% recognized that they were not trained to disclose bad news to their patients or to control the emotional reactions of the relatives[32].

In this study, the difficulty of disclosing bad news was associated with the fear of the patient's and/or the family's reactions. This situation has been reported in other studies. A survey carried out with Greek oncologists reported that 60% were sad and 30% were anxious when disclosing bad news[33].

Most of interviewed residents considered that the patient should know the diagnosis and prognosis. However, only 30% ask the patient to what extent he/she wants to know the prognosis of the disease. These results are similar to those from other surveys in which 80-90% of medical doctors declared that they say the truth about the diagnosis to the patient. This has a cultural connotation. Non-western countries have reported different results. A survey with Turkish oncologists showed that 48% hardly ever tell the diagnosis to patients and only 7% do that in a routine way[34]. This is a crucial point; veracity of information is a cornerstone in the act of disclosing bad news.

In 1962, Gilbersten and Wangesteen conducted a study in the United States. They looked into what patients preferred and found that 80% of patients wanted to know about their physical conditions and their prognosis[35]. More recently, in 1996, Meredith et al carried out a survey in Scotland in which 250 cancer patients participated. More than three-quarters (79%) of patients mentioned that they wanted to have the most up-to-date information about their disease, 96% wanted to know if the disease was cancer; 91% wanted to know the chances of being cured and 94% wanted to know about the possible adverse effects of the treatment[36].

In 1980, a study carried out in the United Kingdom reported that 75% of general practitioners and 56% of hospital medical doctors do not routinely inform their patients[37]. González-Barón y Poveda de Agustín conducted a survey in which it was reported that 62% of interviewed medical doctors found out that the reaction of the patients was better than expected after communicating with them about the disease and the prognosis[38].

Regarding personal experiences of medical doctors with bad news, 100% of residents answered that they would like to be notified if they had a terminal illness. A national survey carried out with primary care medical doctors in Spain revealed that 32.1% would like to be informed should they had cancer; however, only 58.6% of this group notifies routinely to their patients and 8.09% did not want to know[39].

The behaviour of the residents regarding to whom they give information includes both the patient and the family (86%), while a small percentage (8%) considered providing information only to the family or responsible relative as correct. Other studies support the notion of having a relative present when the diagnosis is being released to the patient. Although, the same study reports that most families do not want the patient to be informed[40]. A full 86% of residents answered that they would like to have clinical guidelines to disclose bad news. Those with more years of experience considered such a guideline to be less necessary. In our study, 80% of respondents believed that it is useful and necessary to be trained in this topic.

CONCLUSIONS

This survey shows that the abilities of internal medicine residents to disclose bad news was weak. Disclosing bad news is one of the most intense moments in the patient-medical doctor relationship. This is a relevant topic that should be included in the training of residents.

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