

# Health professionals and the delivery bad news: patient perspectives

## *Profissionais de saúde e a comunicação de más notícias sob a ótica do paciente*

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### ABSTRACT

**Introduction:** “Bad news” includes those that alter drastically and negatively patients’ view of their future. Delivery of bad news is relevant in the context of healthcare and can have irreparable impact, posing a threat to life, to personal, family, and social welfare. Studies addressing this issue from the perspective of patients and on the use of specific protocols are scarce. **Objective:** to assess the quality of bad news delivery through the eyes of patients. **Methods:** A cross-sectional study based on the SPIKES protocol with 500 participants. **Results:** in 10% of cases, news was delivered by non-medical professionals, 5% by phone and 17% in a non-private space. About 1/3 of the sample considered that the professional was unprepared for breaking bad news, and 60% of respondents considered themselves unprepared to receive such news. Transmission was considered to be friendly (34%), calm (43%) or indifferent (15%). Calm and sincerity were cited as important when receiving bad news. **Conclusions:** delivery of bad news must be based on a good doctor-patient relationship. After bad news are broken, while most patients are expected to report feelings of grief, despair, and sadness, such feelings can be exacerbated when news are transmitted tactlessly or indifferently. Among important areas for improvement, finding a private place to convey the news is one of the least complex to implement. The main aspects patients mentioned as requirements for professionals to deliver bad news more humanely are behavioral aspects.

**Key words:** Communication; Physician-Patient Relations; Education Medical; Psychology, Medical.

### RESUMO

**Introdução:** “más notícias” são aquelas que alteram de forma drástica e negativa a visão do paciente sobre seu futuro. Sua comunicação é relevante no âmbito da saúde, podendo proporcionar impactos irreparáveis. Incluem situações que constituem uma ameaça à vida, ao bem-estar pessoal, familiar e social, pelas repercussões que acarretam. São incomuns os estudos que abordam esse assunto sob a perspectiva do paciente e as informações sobre uso de protocolos específicos. **Objetivo:** avaliar a qualidade da comunicação da má notícia segundo a visão do paciente. **Métodos:** realizou-se estudo transversal baseado no Protocolo SPIKES, em 500 participantes. **Resultados:** em 10% a notícia foi dada por profissional não médico, 5% por telefone e 17% em local não reservado; cerca de 1/3 da amostra considerou o profissional não preparado para a comunicação da má notícia; 60% dos ouvintes se consideravam despreparados para receberem a notícia; forma de transmissão: amigável (34%), tranquila (43%), indiferente (15%); sinceridade e tranquilidade foram os critérios citados como importantes no recebimento da má notícia. **Conclusões:** a comunicação da má notícia deve ser baseada numa boa relação médico-paciente; é esperado que a maioria das pessoas, após recebê-la, apre-

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*sente sentimentos como angústia, desespero e tristeza, porém tais sentimentos podem ser exacerbados quando a notícia é transmitida de forma grosseira e indiferente; dos aspectos passíveis de melhora, a escolha de um local reservado é um dos menos complexos de se obter; os principais aspectos mencionados como necessários para um profissional comunicar uma má notícia de forma humanizada são comportamentais.*

*Palavras-chave: Comunicação; Relações Médico-Paciente; Educação Médica; Psicologia Médica.*

## INTRODUCTION

Communication between health professionals and patients or their family members is a crucial process and the foundation of a good doctor-patient relationship. It usually takes place in two ways: as a working tool for physicians, who must obtain information relevant to the patient; and as a way to make themselves understood by the patient. Thus, it is necessary to understand this process and its importance, and to develop skills to deliver health information, thereby adding great quality to services.<sup>1-3</sup>

Bad news is defined as that which drastically and negatively changes how patients view their future. "These include situations that constitute a threat to life, to personal, social and family well-being due to the physical, social and emotional repercussions they entail. They are associated, in most cases, with serious illness or loss within a family, unique experiences that can be influenced by a number of factors related to the disease itself, the individual, family, and socio-cultural context in which patients live".<sup>2</sup>

According to the Code of Medical Ethics, the health professional is responsible, among other things, for informing the patient of the diagnosis. This act or the way the information is delivered are not always tranquil or stress-free in the doctor-patient relationship.<sup>2</sup> The communication process can cause serious psychological impacts, so that the receiver of bad news will never forget the place, date and manner in which it was delivered.<sup>4</sup>

Concurrently with major technical advances in Medicine, communication between health professionals and patients is still worse than expected, especially when it involves information about a diagnosis or undesired news, such as death or a serious or incurable disease. In addition to this frequent difficulty, the act of delivering information should also be based on other four fundamental principles established in bioethics (beneficence, autonomy, justice and non-maleficence).<sup>2</sup>

For these reasons Robert Buckman created the SPIKES Protocol in 1992, to guide health professionals in communicating bad news by addressing basic guidelines such as: the professional's posture (setup), the patient's perception, exchange of information (invitation), knowledge, exploring and emphasizing emotions, strategies and summary.<sup>5,6</sup>

Thus, the most suitable way to analyze information quality would be to know how satisfied the receiver involved in this situation was.<sup>7</sup> It is also of crucial importance to realize if the receivers of news (patients and relatives) were submitted to an organized process of information delivery by means of a technical system, such as a protocol.

The objective of this work was to assess the quality of communication of bad news from the patient's or legal guardian's point of view based on the principles outlined in the SPIKES Protocol.

## CASUISTRY AND METHODS

This is a transversal, applied, original, exploratory, field and quantitative study using a questionnaire with 19 multiple choice questions based entirely on the SPIKES Protocol and two enclosed copies of the Informed Consent. Before filling out the questionnaire, people were informed that their anonymity was secure since this questionnaire was answered individually and was not identified.

The research was developed between September 2011 and May 2012.

The sample consisted of 501 participants invited to answer the questionnaire on a voluntary basis, with no costs to them, comprising 0.1% of the population of Juiz de Fora, with a sampling error of 5% (plus or minus).<sup>8</sup> This spectrum of population sample strictly meets the criteria and the statistic needs.

Interviews were made with inhabitants of the municipality comprising the city's five demographic areas (north, south, east, west and center), including all socio-economic levels. The subjects of the research were approached on the streets on the various neighborhoods.

We used the softwares Microsoft Access to build the database and Microsoft Excel to analyze the data collected. The quantitative statistical analysis was carried out in the Epi-Info software, with possible justifications being raised for the data collected.

The inclusion criteria were: being 18 years old or more, residing in the municipality of Juiz de Fora, MG,

and having received bad news in the past 10 years. Bad news was considered to be “all information delivered by health professionals that changes drastically and negatively how they or their relatives see their future”. The exclusion criteria were: interviews interrupted for any reason and failure to sign the consent form.

Participation in the research involved minimal risk to participants, i.e. there was no interference from the researcher in any aspect of their physical, psychological and social well-being, and the intimacy of participants will be respected in compliance with the parameters in Resolution 196/96 of the National Council of Health/Ministry of Health, which sets the rules for research involving humans.

The research was duly submitted to and approved by the Research and Ethics Committee (CEP) of Universidade Federal de Juiz de Fora (UFJF) according to sentence 122/2010 and protocol 0079.0.180.000 -10.

## RESULTS

The sample comprised 501 participants, 45.90% (n= 230) male and 54.10% (n= 271) female. One hundred people were interviewed (19.96%) in each of the following regions, north, south, west and center; and 101 (20,16 %) in the east region. The characterization of the sample is shown in Table 1.

**Table 1** - Sample characteristics including age, skin color, education level, and household income

Characteristic	Relative and absolute frequency
<i>Age</i>	
Up to 40 years old	40.60% (n=203)
Above 40	59.4% (n=297)
<i>Skin color</i>	
White	69.55% (n=338)
Non-white	30.45% (n=148)
<i>Education level</i>	
Up to Basic Education	45.80% (n=229)
At least Secondary Education	54.02% (n=271)
<i>Household income</i>	
R\$ 2.000,00 or less	66.8% (n=332)
More than R\$ 2.000,00	33.2% (n=165)

Concerning the period in which the bad news was delivered, it was noticed that 29.60% (n= 148) had taken place within the previous year, 22.00% (n= 110) within

one to three years, 16.60% (n= 83) within three to five years and 31.80% (n= 159) in five to 10 years previously.

Concerning the professional responsible for breaking the bad news, it was found that 89.84% (n= 451) of the sample were made aware by the assisting physician, 2.59% (n= 13) by another doctor, 3.98% (n= 20) by a nurse, 0.80% (n= 4) by a social worker, while 0.20% (n= 1) were informed by psychologists and 2.59% (n= 13) by another professional.

As regards the kind of service provided by the health institution where the bad news was delivered, it was found that 61.91% (n= 304) were from the public sector while only 38.09% (n= 187) were from the private sector.

According to 70.82% (n= 347) of the interviewees, the professional was prepared to deliver the bad news, while 29.18% (n= 143) considered the professional unprepared. Among the participants, 59.27% (n= 294) did not consider themselves apt to receive the bad news, while 40.73% (n=202) considered themselves prepared.

The percentage of professionals considered unprepared was similar in the public and in private health systems: respectively, 29.53% (n= 88) and 27.47% (n= 50). The difference was also small as far as the quality of the information received is concerned: 39.90% of those treated in the public service (n= 125) considered the delivery of bad news very bad, bad or reasonable. In the private service, 31.10% (n= 58) were of similar opinion.

Regarding the definition of bad news, 17.73% (n= 89) of the interviewees related it to the death of a family member or a friend. In addition, 7.97% (n= 40) reported that the bad news was a cancer diagnosis, 8.57% (n= 43) said it was a cancer diagnosis in the family, and only 2.99% (n= 15) said it was failure of the curative treatment of relatives and 1.59% (n=8) failure of their own treatment. It was also noted that 19.92 % (n= 100) reported having had a diagnosis of chronic disease, of which the most reported was diabetes mellitus (DM) in 20.00% (n=20) of cases and 41.23% (n= 207) for other reasons. The necessity of surgical procedure had the most mentions, 28.50% (n= 59).

At the time they received the bad news, 45.58% (n= 227) of the interviewees were alone, 48.19% (n= 240) were accompanied by a relative and 6.23% (n= 31) by a friend. Most interviewees, 77,35% (n= 386), were in a private environment when they were told the bad news. Only 17.64% (n= 88) were not in a private place. In 5.01% (n= 25), the interviewees reported having been informed over the telephone.

It was found that 71.08% (n= 349) of the people received the bad news in a single meeting with the health professional, while 28.92% (n= 142) reported

that the health professional needed more than one meeting to tell them. Of these, 35.92% (n= 51) were given bad news in two meetings, 25.35% (n= 36) in three and 38.73% (n= 55) in more than three meetings.

Regarding the understanding of the news received, 69.56% (n= 345) of the interviewees reported having understood it fully, 20.16% (n= 100) expressed partial understanding and 10.28% (n= 51) answered they understood nothing. It was also found that the understanding of the news is related to each interviewee's educational level. Among illiterate respondents, 41.20% (n= 7) stated they understood nothing. The same result was found in 14.10% (n= 26) of those with primary education. Among those who had secondary and higher education, only 8.60 % (n= 13) and 3.90% (n= 5), respectively, made a similar statement. None of the interviewees with a post-graduate degree reported having understood nothing.

Moreover, understanding the information is related to the interviewee's judgment of the quality of the information received. Among those who understood nothing, 62.80% (n= 32) judged the information to be poor, bad or fair. Among those who understood partially, 53.00% (n= 53) made the same judgment, while only 27.50% (n= 95) of those who fully understood were of the same opinion.

The main feelings mentioned after receiving the bad news were: sadness 35.72% (n= 210), indifference 15.48% (n= 91), anguish 12.24% (n= 72), despair 9.35% (n= 55) and others 15.48% (n= 91).

When asked about how long it took to overcome such feelings, it can be noticed that 19.79% (n= 93) of the interviewees needed hours, 19.36% (n= 91) one to three weeks, 20.00% (n=94) 1 to 11 months, 12.13% (n=57) a year or more, and 28.72% (n= 135) said they had yet to overcome them.

As for indication of treatment by a healthcare professional, 83.93% (n= 350) of the people were guided to seek some kind of therapy and 16.07% (n= 67) did not receive any guidance. Among the interviewees who were given treatment options, 78.00% (n= 308) joined and 22.00% (n= 87) did not join.

As regards the relationship between the patient and the health professional, it was found that, after the bad news was delivered, 36.64% (n= 181) of the interviewees felt a strengthening of their relationship of trust with the health professional, 17.41% (n= 86) felt their relationship remained indifferent, 11.54% (n= 57) felt their relationship weakened and 34.41% (n= 170) never saw the professional who delivered the news anymore.

Regarding the conduct of professionals in delivering bad news, 33.33% (n= 171) of the interviewees considered their behavior friendly; 42.11% (n=216) calm; 6.04% (n= 31)

rude; 15.2% (n=78) considered their behavior indifferent to the situation; and 3.32% (n= 17) mentioned other forms of behavior. Based on this, the interviewees rated the manner in which they were informed as: very bad (10.20 %; n= 51), bad (9.80 %; n= 49), fair (16.60 %; n= 83), good (38.80 %; n= 194), very good (10.80 %; n= 54) and excellent (13.80 %; n= 69). Most of those who rated the delivery of bad news as "good", "very good" or "excellent" reported a "quiet and/ or friendly" posture on the doctor's part (94.30 %; n= 298).

As for the aspects regarded as the most relevant upon receiving bad news, 11.24% (n= 91) considered the place to be the main aspect; 12.59% (n= 102) stated that information quality is most important; 31.11% (n= 252) believe that sincerity on the doctor's part is essential; while 14.32% (n= 116) believe it is choosing the appropriate time. It was also noted that 25.43% (n= 206) of the people value tranquility on the doctor's part and 5.31% (n= 43) value other aspects, among which 13.95% (n= 6) mentioned the need for humanization.

Analyzing the many exposure variables and the outcome variable "quality of the information given", we note that they were statistically significant (Table 2). The exposure variables income, ethnicity, gender, and not being accompanied upon receiving bad news were not statistically significant.

Regarding the service provided by the professional when delivering the bad news, it was possible to infer with statistical significance that the professional's best performance is related to an understanding on the part of the individual and greater adherence to the proposed treatment (p-value < 0.001).

## DISCUSSION

The representations of bad news among health professionals and citizens are almost always associated with severe diseases, with no possibility of cure, cancer, and death. The concept is sometimes also related to admissions, accidents, deterioration of health status and loss of physical capacity.<sup>2,9-11</sup>

Our study showed the same perception since the bad news was related to considerably prevalent in diseases Brazil, such as SAH (18.00 %) and DM (20.00 %). Other associations were: cancer diagnosis (7.97%), failure of curative treatment (1.59%), death of a family member/ friend (17.73%), diagnosis of cancer in the family (8.57%), failure of the curative treatment of a family member (2.99 %), diagnosis of incurable disease (18.92%) and 41.23% for other factors (28.50% related to surgery).

**Table 2** - Exposition variables associated with classification of healthcare – outcome variable

Exposition variable	Outcome variables Classification of healthcare on delivery of bad news							
	Good		Bad		Total	p-value	OR	RR
	n.	%	n.	%	n.			
Above 40 years old	205	69.3	91	30.7	296	0.0013	0.37 - 0.79	0.68 - 0.92
Up to Basic Education	156	68.4	72	31.6	228	0.0372	1.10 - 2.14	1.09 - 1.31
Private healthcare	129	69.4	57	30.6	186	0.0370	1.02 - 2.21	1.01 - 1.31
Only one meeting with health professional	138	61.1	88	38.9	226	<0.0001	1.82 - 4.59	1.22 - 1.56
Full understanding of information	250	72.7	94	27.3	344	<0.0001	0.19 - 0.43	0.49 - 0.72
A private place to break news	277	67.7	132	32.3	409	<0.0001	0.23 - 0.60	0.51 - 0.83
Feeling prepared to receive the news	159	78.7	43	21.3	292	<0.0001	0.20 - 0.46	0.59 - 0.77

Symbols: n= Absolute frequency, %=Percentage, OR=Odds ratio, RR=Relative risk.

Receiving bad news can have an emotional impact on the listener that leaves a lasting impression of the place, the date, and the manner of communication. It was found that 159 people (31.80%) had received the bad news more than five years previously and could still report how they were approached in detail. This fact is referred to in another study, which showed that time does not mitigate the perception of patients regarding the quality of delivery of bad news.<sup>2</sup> It was found many times during the interviews that the interviewees could recall details such as the exact time, day of the week, or the exact words used.

Delivery of bad news is preferably a role of assisting physician as they usually have all the available information on the case. It was found that 92.43% of our sample had received this information from the doctors themselves, in coincidence in another study, which found 88.70%.<sup>12</sup>

There are references in the literature to guidelines and protocols containing recommendations on how health professionals should proceed to deliver bad news, offering practical guidance which can reduce the professional's stress when delivering bad news and which is applicable to most situations.<sup>13-15</sup> One of best-known protocols is called SPIKES, an acronym with the initials of each step to be performed by healthcare professionals.<sup>16</sup>

In the first stage (setting), the professional should create an action plan. It concerns the aspects including the search for an appropriate environment, with comfort and privacy, the attention to the presence of any acquaintances or next-of-kin and the attempt to anticipate the patient's emotional reactions.<sup>13</sup> This item already refers to the need to train the professional to understand clearly what are the most relevant psychological

aspects involved in each case, thereby minimizing suffering and offering encouragement. However, since the past decade the literature has been showing a low percentage of doctors (14.00%) with any specific training in delivery of bad news in undergraduate courses.<sup>17</sup> Still, while recognizing the importance of this task, most of them were skeptical about the value of learning it and preferred to learn in their daily practice.

In our study, 70.82% (n= 347) of the interviewees reported that the professional was prepared, which is important, but we found that it was not always so since 29.18% (n= 143) considered the professional unprepared. There were similar results between those who considered the professional unprepared in the public (29.53 %) and private (27,47 %) health systems.<sup>18,19</sup> The same occurred in the evaluation of the quality of the information received. 39.90% of the patients treated in the public service and 31.10% treated in the private service considered the delivery of bad news very bad, bad or fair.

With regard to the first step of the protocol, which concerns the presence of someone the patient trusts when the bad news will be delivered, it was noticed that most of the patients were accompanied by a person of their acquaintance, 54,42% (n= 271) family members or friends. The professional who worries about this need shows attention to the individual's mental health and emotions.<sup>16</sup>

Choosing the place where bad news will be delivered is also important, suggesting zeal and respect and providing more comfort. 77.35% (n= 386) of our sample were in a private environment when they were informed.

The second phase of the SPIKES protocol (*perception*) highlights the need to understand how much pa-

tients know about their health status.<sup>16</sup> Thus, doctors should be closer to their patients in order to build a relationship based on respect, trust, and professionalism. It is important that professionals do the necessary consultations to judge the right time to deliver news. Concurrently, they may choose to break down the bad news in parts. In doing so, it is possible that the receiver will minimize false expectations, understand in a more realistic manner and absorb the information better when it is fully delivered.

The third step of the protocol, *invitation*, is intrinsically associated with the previous step and refers to the need for professionals to understand how much patients know and can be told about their health conditions so they are invited to deliver the news.<sup>17</sup> There are patients who show, even if covertly, that they will not bear receiving this information. This situation implies that doctors must carefully prepare this stage and, if possible, wait for the most appropriate occasion.

The fourth stage of the protocol, *knowledge*, directly concerns the quality of the information given to patients. Based on this stage, it is possible to understand that all professionals, mainly the ones who deliver bad news, must try to gauge the patients' vocabulary and avoid using technical language, conveying the information so as to allow perfect assimilation of the news. It can be seen in the analyzed sample that this aspect has not been included.

Establishing a satisfactory doctor-patient relationship is imperative to the communication process. This study indicated that 49% of the individuals had a neutral perception of the process, 20% evaluated it positively, 20% had negative memories, and 6% had very negative memories. These bad memories were attributed to the abrupt, impatient and unfriendly manner of health professionals. As for the understanding of the information received, 69.56% of the interviewees considered they "understood it completely," 20.16% "understood it partially" and 10.28% said "understood nothing of it". However, as complementary data, several people, when inquired on what they had actually understood of the bad news, did not even manage to report it clearly. Besides, it was found that several of them belonged to the group that reported having fully understood what had been explained to them.<sup>13</sup>

We also found that how well the interviewees understood the information influenced their judgment of the quality of the information received. Among those who understood nothing, 62.80% (n=32) judged the information to be very bad, bad or

fair. Among those with partial understanding, 53.00% (n= 53) had the same judgment; only 27.50% (n= 95) of those who fully understood found the information very bad, bad or reasonable, which shows that perception of the quality of the information delivered is directly linked to the professionals' ability to make themselves understood by their listeners.

Prepared professionals generally behave in a calm, welcoming manner when they need to report on a bad prognosis. We can see that this conduct provides a favorable assessment by listeners. It was found that 42.11% of the interviewees reported "calm delivery", 33.33% "friendly manner", 15.2% "indifferent" and 6.04% "rude" about doctors delivering bad news. Yet, the majority of those who rated the communication of bad news as "good", "very good" or "excellent" assessed the attitude of their doctors as "calm and/or friendly" (94.30%).

The focus of the fifth step, exploring emotions, relates to the patients' emotions. Doctors should know how to react to these feelings by being ready to provide comfort, support and understanding.<sup>16</sup> It becomes relevant to decode the signs of emotions that might be hidden (perplexity, silence, tears) by expressing words and gestures calmly and spontaneously.

In relation to their feelings after receiving bad news, the majority mentioned sadness (35.72%), indifference (15.48%) and anxiety (12.24%). Barnet used a questionnaire with 106 patients after receiving bad news and revealed significant psychological stress in 22.00% of the sample. The quality of care and the way communication is carried out relate to the feelings or perception of patients or families after receiving the bad news. Doctors who behave due caution and who lack sensitivity when delivering bad news can cause psychological stress.<sup>13</sup> In our sample, one of the interviewees emphasized that he received the news of his grandmother's death, with whom he had lived for 14 years, by phone with the simple message: "We are calling to inform you of the death of Mrs ..."

The last step of the protocol, strategy and summary, refers to the moments doctors indicate treatment options, when these are available, with their expectations of prognosis and the patient's readjustment to life.<sup>16</sup> It would be appropriate to invite the individual to share responsibilities in a realistic way, which can help ensure treatment adherence. It is essential that, before discussing a treatment plan, doctors investigate if patients feel able to start it and if that is the best time.

Interpersonal relationships play an important role in medical practice since the quality of these relation-

ships is one of the determinants of therapeutic efficacy. Hence, it is crucial that the patient can trust the data provided during communication of bad news. A relationship of trust between the professional and the patient occurs on the basis of solidarity, careful assistance, individualized attention and the planning of moments for listening or touching, when the aim is to relieve immediate pain and suffering.<sup>20</sup>

Finally, professionals must be sensitive enough to choose the moment to deliver the news and even to know whether to call a family member. The interviewees named “sincerity” and “tranquility” on the part of doctors as the most important aspects for this moment. “Sincerity” was chosen by more than two-thirds of the family members of patients in ICU as the main characteristic expected at the moment of delivering bad news.<sup>21</sup> This result may reflect the patients’ need for more understanding, transparent professionals who seek to practice more humanized Medicine, something that has been on the decline in recent years.

## CONCLUSIONS

Delivery of bad news should be based on a good doctor-patient relationship since this communication affects the receiver’s trust in the health professional. Although this is one of the most difficult and delicate tasks in clinical practice, there are still evident shortcomings on the part of our health professionals when performing this task. The results reveal the need to improve medical education in this subject since there are professionals who were considered unprepared to break bad news. Of the aspects that can be improved, choosing a private place is perhaps the least complex. The quality of information as perceived by the interviewees in our setting was considered good by 63.40% of the sample.

It is expected that most people, after receiving bad news, display feelings of anguish, despair, and sadness. However, such feelings can be exacerbated when the news is delivered with rudeness and indifference by health professionals.

The main aspects raised by the interviewees as necessary in a professional who breaks bad news are behavioral: sincerity and tranquility. This realization minimizes other traditional aspects of medical routine, such as the technical and professional sides.

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