

## Development of a new instrument to assess the quality of physicians' delivery of bad news

*Desenvolvimento de um novo instrumento para avaliar a qualidade da comunicação de más notícias pelos médicos.*

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### ABSTRACT

**Introduction:** Most instruments to assess physicians' delivery of bad news have been developed for patients with cancer and then adapted to other contexts. In clinical practice, some news may not be considered bad by the physicians but may have an important negative impact on the patients' life. Yet, instruments to assess this communication across diverse clinical settings are needed.

**Objective:** To develop, from the patients' perspective, an instrument to assess how physicians deliver bad news in clinical practice.

**Method:** This study was conducted using an exploratory qualitative approach by means of semi-structured, in-depth interviews with 109 patients from two referral hospitals in Brazil. Content analysis was used to generate categories, from which the initial instrument items were developed. The clarity and relevance of the items were evaluated by a committee of 11 medical professionals and 10 patients.

**Results:** The instrument included items about the physicians' attitudes, such as attention, respect, and sincerity, as well as items about sharing information using language that patients could understand. The initial instrument had 19 items, answered in a 5-point Likert scale with labeled endpoints. After evaluation by the committee of judges, 2 items were modified, and 3 were excluded. The final instrument thus had 16 items.

**Conclusion:** A new 16-item instrument was developed from the patients' perspective to assess physicians' delivery of bad news. After additional validation, this instrument may be useful in real and diverse bad news settings in clinical practice.

**Keywords:** Health Communication; Physician-Patient Relations; Questionnaire; Quality; Physician.

### RESUMO

**Introdução:** A maioria dos instrumentos para avaliar a comunicação de más notícias pelos médicos foi desenvolvida para pacientes com câncer e adaptada a outros contextos. Na prática clínica, muitas notícias podem não ser consideradas tão ruins pelos médicos, mas possuem um impacto importante negativo na vida dos pacientes. Assim, ainda há a necessidade de instrumentos para avaliar essa comunicação nos diversos cenários clínicos.

**Objetivo:** desenvolver, a partir da perspectiva dos pacientes, um instrumento para avaliar como os médicos comunicam más notícias na prática clínica.

**Método:** o estudo foi realizado usando uma abordagem qualitativa exploratória, através de entrevistas semiestruturadas em profundidade com 109 pacientes em dois hospitais de referência no Brasil. A análise de conteúdo foi utilizada para gerar categorias, a partir das quais os itens iniciais do instrumento foram desenvolvidos. A clareza e a relevância dos itens foram avaliadas por um comitê de 11 profissionais médicos e 10 pacientes.

**Resultados:** O instrumento incluiu itens sobre as atitudes dos médicos como atenção, respeito e sinceridade e sobre o compartilhamento de informações compreensíveis na linguagem do paciente. O instrumento inicial foi composto por 19 itens, respondidos em uma escala-Likert de 5 pontos. Após avaliação do comitê de juizes, 2 itens foram modificados e 3 foram excluídos; ficando o instrumento final com 16 itens.

**Conclusão:** um novo instrumento com 16 itens foi desenvolvido a partir da perspectiva dos pacientes para avaliar a comunicação de más notícias pelos médicos. Após validação adicional, este instrumento poderá ser útil em cenários reais e diversos de más notícias da prática clínica.

**Palavras-chave:** Comunicação em saúde; Relação médico-paciente; Instrumento; Qualidade; Médico.

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## INTRODUCTION

Teaching physicians how to deliver bad news (BN) has become an essential part of medical formation, in view of its frequency in clinical practice and importance for the patient and physician<sup>1</sup>. BN is defined as any news that negatively affects a person's view of their future<sup>2</sup>. Consequently, the one who determines whether the news is bad is the person who receives it and not the physician. Although receiving a diagnosis of cancer has a negative impact on a person's view of their future, a variety of other news, such as a diagnosis of diabetes mellitus, neurodegenerative diseases, the need to undergo surgery, or performance limitation due to injuries may also be perceived as BN, depending on patients' previous experience and expectations<sup>3</sup>. Recently, the SARS-CoV-2 (Covid-19) pandemic, with the necessary isolation, has challenged physicians regarding how to deliver BN to patients and families<sup>4</sup>.

In order to prepare medical students and physicians for this task, the teaching has combined theory and practice<sup>5</sup>, generally based on frameworks that systematize the key steps of BN delivery<sup>6-8</sup>. Studies on the effects of interventions have included outcome measures such as the participants' subjective aspects (satisfaction, self-confidence, and comfort),<sup>9</sup> knowledge, performance in Objective Structured Clinical Examination (OSCE) rated by observers, standardized patients<sup>10-16</sup> and/or analogue patients,<sup>17</sup> as well as performance in recorded consultations with real patients in relation to the patients' distress, satisfaction with the consultation, and trust in the physician<sup>18</sup>. Nevertheless, the most effective way to teach and learn utilizing simulated patients in medical education is still unknown<sup>19</sup>. A meta-analysis including 17 articles on interventions involving medical students, residents, and/or physicians demonstrated large improvement in the participants' performance in the OSCE and moderate improvement in self-confidence<sup>15</sup>. The authors suggested further studies to evaluate the effects of interventions in clinical practice with real patients, which has also been highlighted by other authors<sup>16-20</sup>. One outcome measure should be the patients' perception on how they received BN.

Nowadays, "most of the research into the delivery of BN has focused on patients with cancer and subsequently, applied to the delivery of bad or serious news in non-oncologic settings"<sup>21</sup>. Recommendations on how to deliver BN were based on empirical evidence and expert opinions, with little patient-based evidence until 2001,<sup>22,23</sup> when studies investigating the preferences of patients with cancer for receiving BN began to increase. A systematic review on patients' preferences for receiving BN showed that patients wanted physicians to communicate BN clearly and honestly, using words that they could understand and providing written explanation as needed. They preferred to receive information on whether their

illness was cancer, details about the disease, treatment options, chance of a cure, and impacts of treatment on their activities of daily living. Also, patients wanted physicians to show empathy for them and their families, as well as to be hopeful and supportive. The authors emphasized that physicians should tailor their communication to each patient, considering their perspective<sup>23</sup>. The instruments to assess preferences included the Information Needs/Information Styles Questionnaire<sup>25</sup> and the Measure of Patients' Preferences (MPP), based on a literature review and expert opinion and validated for patients with cancer<sup>22,24</sup>. A study applying the SPIKES protocol to assess the perspective of patients with other life-changing diagnoses was carried out by Mirza et al (2018), and it showed that the protocol largely reflected the preferences of these patients. The authors also suggested additional components, such as assessing the patient's understanding<sup>25</sup>.

The recommendations for delivery of BN are divided into steps with tasks and behaviors suitable for the participants' training and assessment by trained observers or standardized patients. However, patients in real clinical scenarios may evaluate communication differently, and instruments for assessing how they received BN are necessary. Delivery of BN is difficult to evaluate, and there is little evidence of assessment of this process; therefore, instruments are needed to measure it, mainly in clinical settings<sup>26</sup>.

Aiming to create a literature-based instrument for patients' assessment of how doctors delivered BN, we developed a questionnaire consisting of 37 items based on the protocols to guide BN delivery. After the assessment of clarity, relevance, and semantics by a committee of judges, the number of items was reduced to 20. This instrument was applied to 20 patients in a pilot study. However, many of the patients could not understand or remember the instrument items, and we realized that patients assessed the delivery of BN in a more holistic way, not paying much attention to the protocol steps, which were developed to guide the physicians' practice and training. Thus, we realized that it was necessary to identify, together with the patients, using their own language, what they considered important for the process of delivering BN. Therefore, the aim of this study was to develop an instrument to assess how physicians deliver BN in clinical practice, based on the patients' perspectives.

## METHOD

We used an exploratory qualitative approach and followed the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN)<sup>27</sup>. Approval was obtained from the institutional review board (number 78418417.0.0000.0121). All subjects who agreed to participate signed the free and informed consent form.

## Population

The population consisted of patients from two public referral hospitals in the state of Santa Catarina (Southern Brazil). One was a general hospital, and the other was a hospital attending patients with infectious and respiratory diseases. Patients were invited to participate in the study during regular rounds on the wards (hospitalized patients) and in the ambulatory care unit. The inclusion criteria were: speaking Portuguese and being older than 17 years. The exclusion criteria were: having communication difficulty due to cognitive impairment, decompensated mental disorders, altered state of consciousness, respiratory distress, and uncontrolled pain. The sample was selected by convenience, with an estimated number of 150 participants or until data saturation was reached.

Eleven professionals with expertise in teaching BN delivery and/or dealing with patients who had received a difficult diagnosis or who were in palliative care (4 family physicians, 2 oncologists, 3 palliative care physicians, and 2 internists) and 10 patients participated in the committee of judges.

## Data collection

Data were collected between July 2018 and October 2018 through semi-structured, in-person interviews carried out by three interviewers who received previous training and assessment by the research team. The guiding question was: "In your opinion, how should doctors deliver BN to patients?" The answers would often lead to further questioning by the interviewers, such as: "Tell me more", "Explain it in more detail", "What else?", "What do you mean by...?". The interviews were transcribed, and they lasted about 30 minutes. Data collection continued until saturation was reached. An additional 10% was added as an extra margin to see if any new concept really appeared. Gender, age, level of schooling, and reason for medical care were also collected.

## Data analysis

The demographic variables were analyzed using descriptive statistics, and the qualitative data were analyzed using content analysis, carried out independently by 3 researchers, after an initial reading to become acquainted with the reports. They were then coded by meaning units, and the codes were subsequently grouped into categories. Next, the researchers met and discussed the categories. The differences were discussed until a consensus was reached regarding the final categories<sup>28,29</sup>. [Ramani, 2016, Introducing medical educators to qualitative study design: Twelve tips from inception to completion] The items were built from the results of the categorization.

The clarity of the items was assessed using a 4-point Likert scale (1 – very unclear; 2 – unclear; 3 – clear; 4 – very clear) by the committee of judges. As the patients showed difficulty

in rating the Likert scale, they were asked to rate the clarity on a numerical scale ranging from 0 to 10 (0 = not at all clear to 10 = totally clear). When clarity was assessed by at least one expert as "unclear", the item was reviewed, and, if considered "very unclear", it was excluded. When clarity was rated by the patients as 7 or 8, the item was reviewed; if the score was below 7, the item was excluded.

The relevance of the items was evaluated by the experts on a 4-point Likert scale (1 – irrelevant; 2 – low relevance; 3 – moderate relevance; 4 – high relevance). The answers were calculated to measure the relevance of the items using the content validity ratio (CVR). The minimum CVR for the total of 11 experts considered is 0.59<sup>30</sup>.

For the patients' assessment of the relevance of the items, a card with 35 round golden stickers was given to them, and they were instructed to place as many "gold coins" as they wished on the items they considered more important; it was not necessary to put coins on all of them, only on those they considered important.

The IBM® SPSS Statistics 22.0 program for Windows (SPSS, Chicago, IL, USA) was used in the analyses.

## RESULTS

### Demographic data

One hundred and nine patients were interviewed, 66 of them from the general university hospital (60.5%; 95%CI = 49.3 – 71.7) and 43 from the hospital attending patients with respiratory and infectious diseases (39.5%; 95%CI = 32.3 – 46.7). The participants' median age was 49 years ( $P_{25-75} = 35.0 – 61.0$ ); 50 of them were male (45.9%; 95%CI = 33.5 – 54.3), and 59 were female (54.1%; 95%CI = 44.2 – 64.0). Regarding the level of schooling, 42 participants had incomplete elementary school (38.5%); 14 had complete elementary school (12.8%); 8 had incomplete high school (7.3%); 35 had complete high school education (32.1%), and 10 had higher education (9.3%). The most frequent reasons for medical care reported by the participants were cancer, AIDS, the need to undergo abdominal surgical procedures, and respiratory illnesses.

### Development of items

Table 1 displays the categories and subcategories with some illustrative quotations. Eighteen items were developed based on the content analysis. One item "[...] asked what I already knew about my health problem" was added because of its importance according to the experts and its frequency in the BN delivery protocols, resulting in a total of 19 items, as displayed in Table 2.

**Table 1.** Categories, subcategories and illustrative quotations from the content analysis on patients' preferences to receive bad news (n = 109).

Categories / Subcategories / sub subcategories*	Illustrative quotations
<b>What to do before the encounter</b>	
<i>Summon other people</i>	"summon family members;" "prepare individual before delivering news together with a team"
<i>Choose a suitable setting/location</i>	"have patient come to the doctor's office;" "invite patient/family member to a reserved space"
<i>Assess whether the moment is appropriate</i>	"do not deliver the news when the person feels ill"
<i>Be certain of the diagnosis</i>	"be certain of the diagnosis before delivering the news;" "wait for confirmation [...] and, if uncertain, don't say it"
<b>Different perspectives on who to tell</b>	
<i>Family member/companion</i>	"Summon family members first. Deliver the news explaining things well. Reassure them and inform them well [...] so they can tell the patient;" "inform companion if it is serious"
<i>Most stable person</i>	"deliver the news to the right person, the most "stable" person, the person who seems to have it "together"
<i>Patient</i>	"the first person to know must be the patient, and not the person sitting next to them [...] don't tell others"
<b>Who should deliver the news</b>	
<i>The physician</i>	"hear it from the doctor's mouth, and not from others;" "the patient's doctor should be the one to deliver the news"
<b>How to address the patient</b>	
<i>Address the patient by name</i>	
<i>Invite the patient to sit down</i>	
<i>Look the patient in the eyes</i>	"look person in the eye;" "look at the patient"
<i>Listen to the patient</i>	"be open to listen"
<b>What to consider before delivering the news</b>	
<i>Spirituality</i>	"we are Christians, and this really helps us to cope with situations like these [...] only He can give us strength"
<i>Conversation with the family members</i>	"clarify things so that the family doesn't feel guilty;" "the companion should know more than the patient"
<b>Different perspectives on when to deliver the news</b>	
<i>After learning whether patient wishes to hear the news</i>	"if I don't want to know, don't tell me;" "[...] unless the person doesn't want to know"
<i>After assessing patient's health condition</i>	"check everything first, such as blood pressure;"
<i>After observing patient's psychological condition</i>	"carefully observe the person before deciding how to say it [...] or how much should be said"
<i>After preparing the patient</i>	"together with a (medical) team"
<i>"in a conversation [...] don't show up out of the blue so as not to scare" / "so as not to shock"</i>	the person;" "don't jump right into it, but be subtle"
<i>Without preparing the patient</i>	"you should be direct;" "not beat around the bush;" "go straight to the point;" "don't be evasive... speaking in circles only makes a person more anxious;" "just spit it out"
<i>Depends on the:</i>	
<i>- person and culture</i>	"learn what the person is like [...] get to know the person [...] anxious or nervous..."; "it depends on the culture"
<i>- news</i>	"it depends on the illness;" "it depends on the news, for example, a cancer"

Continues...

**Table 1.** (Continuation) Categories, subcategories and illustrative quotations from the content analysis on patients' preferences to receive bad news (n = 109).

Categories / Subcategories / sub subcategories*	Illustrative quotations
<b>How to prepare the patient</b>	
<i>Include other persons such as family members in the conversation</i>	
<i>Sit down and talk</i>	"sit down, put the person at ease... let's talk"
<i>Keep a conversation going</i>	"prepare the patient psychologically;" "have a conversation first, and finally, when the time is right, deliver the news;" "[...] the diagnosis should be put together through words that guide the listener to the delivery of a critical piece of news;" "at first, take your time discussing and going over the diagnosis, little by little... have a conversation to help the person understand what is happening [...]" "it's necessary to contextualize things;" "... if it's cancer, report everything that has been discovered before delivering the diagnosis;" "explain what the patient had... which resulted in the current condition... explain sequentially, ask about the patient's life"
<i>Have a structured conversation</i>	"1) have a conversation and appease the shock, 2) the exam results indicate that you have a health condition 3) this is not definitive, your condition is treatable 4) you need to be strong now"
<i>Give clues</i>	"say words to prepare the patient;" "begin by giving clues so the person slowly gets what is happening to them;" "hint at the fact that the person may have something serious"
<b>Different perspectives on how much should be said</b>	
<i>Everything</i>	"I want to know everything... you can say it;" "explain details [...]" "whether there's a solution or not"
<i>Only parts</i>	"never deliver the full news"
<b>Characteristics of communication</b>	
<i>Verbal language:</i>	
- clear	"as natural and clear as possible"
- using appropriate words/ being gentle with the words	"use appropriate words;" "be careful with the choice of words"
- without using scientific language/technical jargon	"without using scientific language;" "not using technical jargon"
- that the patient can understand	"ease into your speech;" "explain things correctly [...]" "not leaving the person clueless"
- with little information at a time	
- in a succinct/objective manner	
<i>Provide written material</i>	"furnish a written report of the problem"
<i>Non-verbal language:</i>	
- speak calmly, slowly, paying attention to the tone of voice	"things must be said gently;" "pay attention to your voice" / "your tone of voice;" "speak calmly [...], slowly;" "explain things slowly"
- look the person in the eye	
<b>Attitudes during delivery</b>	
<i>Presence/attention</i>	"the news should be delivered as if that patient were special;" "do not leave someone 'hanging' saying you'll be back later to talk"
<i>Active Listening</i>	"listen, be considerate [...]"
<i>Caring</i>	"put the person at ease;" "don't scare the person;" "calm the patient, when the patient cries, embrace them"
<i>Compassion</i>	"their compassionate gaze said everything [...]" "their expression helped me to realize it was serious [...]" "the look in their eyes said it all..."

Continues...

**Table 1.** (Continuation) Categories, subcategories and illustrative quotations from the content analysis on patients' preferences to receive bad news (n = 109).

Categories / Subcategories / sub subcategories*	Illustrative quotations
<b>What the physician should say</b>	
<i>That they do their best to try to solve the disease</i>	"tell them: we are going to try to solve this in the best way possible"; "say that things are difficult, but that we are going to try"
<i>That they understand the patient's perspective</i>	"say that they understand the patient's point of view"
<i>That there is treatment</i>	"say that treatment exists;"
<i>That there are resources</i>	"point out the positive side, that there are available resources"
<i>Positive things</i>	say positive things, because one's self-esteem drops to the floor;"not discourage;"just keep going so you don't get depressed"
<b>What to address in the conversation</b>	
<i>Explain the disease/illness</i>	"explain the illness... what we've got... what is happening"
<i>Explain what is going to happen</i>	"explain what is going to happen;"show what is coming ahead... all this will bring about;"explain things so the patient may rebuild their life"
<i>Present treatment options and the pros and cons</i>	"present treatment options"; "present possible treatments;" "explain the pros and cons"
<i>Explain prognosis</i>	"present clear expectations;" "present the chances"
<i>Present a plan</i>	"explain what the patient should do next;" "say what the next steps are;" "present a plan"
<i>Provide referrals, including psychological support</i>	"provide necessary referrals;" "refer (patient/family) to a psychologist"
<b>Attitudes during encounter</b>	
<i>Respect</i>	"take the patient seriously;" "no jokes at this time;" "treat (the patient) like a human being, with respect"
<i>Be calm, patient</i>	"be cool [...] and calm;" "don't get annoyed or worked up if the person cries;" "to be patient and impart serenity"
Categories / Subcategories / sub subcategories*	Illustrative quotations
<i>Be considerate</i>	"be considerate;" "engage with the patient"
<i>Be loving</i>	"Treat (patients) with love and care;" "treat (them) in a special way [...] being loving"
<i>Sincerity, honesty</i>	"be sincere and truthful;" "do not hide anything;" "be frank;" "place all the cards on the table and say what the patient needs to hear;" [...] it's preferable to deal with the truth than lies;" "be realistic [...] sometimes we cry, but then we get up again;" "don't raise false expectations"
<i>Humbleness, transparency</i>	"being humble is the most important;" "be transparent;" "be a human being, not imposing oneself as a doctor"
<i>Compassion, have concern for patient</i>	"showing compassion"; "show concern for the patient; "show willingness to help"
<i>Sensitivity</i>	"treat (others) like human beings, be sensitive"
<i>Empathy</i>	"be empathetic, remember that they are human beings;" "you have to believe what the patient is feeling"
<i>Be committed to the patient</i>	"don't abandon/discontinue patient treatment"
<i>Be supportive, available</i>	"be accessible;" "be supportive, help (patient) to move forward"
<i>Be understanding</i>	
<i>Be non-judgmental</i>	
<i>Be hopeful</i>	"be hopeful [...] you can't be apathetic when it comes to hope"

Continues...

**Table 1.** (Continuation) Categories, subcategories and illustrative quotations from the content analysis on patients' preferences to receive bad news (n = 109).

<b>Categories / Subcategories / sub subcategories*</b>	Illustrative quotations
<b>Attitudes during encounter</b>	
<i>Courage</i>	"Have the courage to speak"
<i>Categories / Subcategories / sub subcategories*</i>	Illustrative quotations
<i>Professionalism</i>	"be professional about it, you must love what you do;" "someone who really embodies the role"
<i>Demonstrate confidence</i>	

\*Categories appear in bold style, subcategories in italic and sub subcategories in normal style.

**Table 2.** Assessment of the relevance of the items according to the patients' judgement.

	<b>Items<sup>1</sup> of the instrument following the statement: "When delivering the news, the doctor ..."</b>	<b>N<sup>2</sup></b>
1.	... talked to me in a suitable setting.	12
2.	... asked if I would like someone to be with me. <sup>3</sup>	10
3.	... asked what I already knew about my health problem. <sup>4</sup>	9
4.	... was well informed about my health problem.	12
5.	... talked before about the possibility of bad news. <sup>5</sup>	-
6.	... gradually explained my health problem.	9
7.	... went straight to the point. <sup>6</sup>	
8.	... told the truth about my health problem.	18
9.	... took away my hope. <sup>7</sup>	1
10.	... was careful with the words.	14
11.	... used words that I could understand.	19
12.	... showed that they cared for what I was feeling.	12
13.	... talked about treatment options.	19
14.	... explained what the next steps would be.	-
15.	... demonstrated that they would not abandon me.	18
16.	... looked into my eyes.	7
17.	... was respectful to me.	11
18.	... was kind to me.	9
19.	... treated me as a human being. <sup>5</sup>	-

<sup>1</sup> developed based on content analysis from 109 interviews.

<sup>2</sup> N = sum of the number of coins applied to the item by the 10 patients from the committee of judges.

<sup>3</sup> modified item (initial version: ...asked if I would like a family member to be present).

<sup>4</sup> item added by researchers.

<sup>5</sup> item initially excluded by the experts; it was not assessed by the patients from the committee of judges.

<sup>6</sup> item initially excluded by the researchers; it was not assessed by the patients from the committee of judges.

<sup>7</sup> modified item (initial version: ...gave me no hope).

### Evaluation by the Committee of Judges

Only two items (5 and 19) were not considered relevant by the professional experts and were removed from the instrument: "[...] talked before about the possibility of bad news" (CVR = 0.45) and "[...] treated me as a human being" (CVR = 0.27). The CVR of the remaining items ranged from 0.82 to 1. Among the items initially considered relevant, only two were rated as 'unclear' by one of the 11 experts: the item

"[...] gave me no hope", which was modified, and the item "[...] went straight to the point". The latter item was removed from the instrument, because the experts considered the item controversial and ambiguous as to whether it was a positive or negative aspect of BN delivery quality. The item "[...] asked if I would like a family member to be present" was considered only "clear" by one of the experts and was also reformulated.

In regard to the patients' evaluation, all items received a mean score between 8.5 and 10 regarding their clarity. The items "[...] asked what I already knew about my health problem" and "[...] gave me no hope" received the lowest scores (8.5 and 8.9, respectively). Thus, the questionnaire was not modified. Table 2 shows the patients' assessment of the items' relevance. We chose not to remove any item from the questionnaire before conducting the subsequent steps of instrument validation.

### The instrument

A Portuguese-language version of the instrument was developed to be self-applied or administered by an interviewer, consisting of instructions, demographic data, and 16 items. A 5-point scale with labeled endpoints (1 = "strongly disagree" and 5 = "strongly agree") was chosen for assessment. The 16 items of the instrument are displayed in the Portuguese-language version in the supplementary material.

## DISCUSSION

We developed an instrument to assess how physicians deliver BN, consisting of 16 items based on the perception of real patients. One aspect frequently mentioned by the patients was honesty. In the interviews, we observed that most patients expected to be told the truth. Some patients expected the doctor to discern and determine the appropriate time and how much to say, considering each patient's individual situation. In contrast, other patients preferred physicians to communicate with the family first. These findings are consistent with those of another study, which also identified differences in patients' preferences for truth-telling<sup>31</sup> and in the MMP instrument, whose items include aspects such as honesty in the transmission of information ("doctor is honest about the severity of my condition") and considering a family member as a recipient of the news<sup>22</sup>.

The participants stressed the importance of the presence of a person trusted by the patient at the time of BN delivery. This aspect is mentioned in the ABCDE protocol ("arrange for the presence of a support person and appropriate family")<sup>7</sup> and in the MMP instrument ("having a doctor inform my family members about my diagnosis"), which mentions the presence of family at the time of delivering the news<sup>22</sup>.

Clearly understanding "what the patient knows" about their health problem before delivering the news is recommended in some protocols<sup>6,8,32</sup>. We speculate that this was not mentioned by our patients because, although it is an aspect of the interview that facilitates communication for the doctor, patients may not perceive it as essential. However, we believe that it was important to include this item in our instrument, because it helps to introduce the subject and

maintain a dialogue with the patient, and because it was strongly recommended in other protocols.

Regarding whether or not the doctor should prepare the patient before delivering the news, we found divergent opinions. Some patients prefer that the doctor go "straight to the point", while others prefer that physicians "speak slowly or give tips until they notice it". This difference might be due to cultural factors, as well as differences in educational background, gender, and age, as reported by other authors<sup>24,33,34</sup>. With respect to the delivery of the information itself, clear and simple language was mentioned, and the item "used words that I could understand" reflects the patients' preference in this regard. Makoul et al., in their Communication Assessment Tool to measure physician communication skills developed from the patients' point of view, also demonstrated the importance of clear language ("talked in terms I could understand")<sup>35</sup>. However, the item related to language initially proposed in the MMP instrument ("giving information in simple, clear, language") was eventually removed from the final version after validation<sup>22</sup>.

The physician's attitude during BN delivery appeared as an important part of the construct and was represented in some items of our instrument, such as [...] "being attentive", "being respectful", "caring about" [...]. Understanding the patients' emotions, feelings, and concerns appears in the instrument proposed by Makoul et al. ("showed care and concern")<sup>35</sup>. It was also cited in the Consultation and Relational Empathy (CARE) Measure ("showing care and compassion")<sup>36</sup> and in the Jefferson Scale of Patient's Perceptions of Physician Empathy (JSPPPE) ("understands my emotions, feelings and concerns")<sup>37</sup>. When doctors demonstrate concern for their patients' feelings, it is quite helpful and provides supportive actions.

Therefore, our study showed that physicians' performance in BN delivery is perceived by patients in a more integrated manner, in alignment with MacLeod, who had already mentioned a less fragmented patient's view of how doctors report news, reinforcing honesty and empathic communication as a basis for BN delivery<sup>38</sup>. However, we emphasize the importance of systematic teaching. The steps exist to facilitate the teaching-learning method, but the communication process was perceived by patients as a whole. Thus, the doctors' attitudes towards their patients could be seen in a more global manner within an empathic and cordial relationship. While a well-trained simulated patient can identify the steps based on a checklist, the impact of these steps is what patients perceive. If we want to assess real patients' perception of how doctors communicate BN, we need to understand that the patients' view is more global and valued according to attitudes perceived throughout the process.

One limitation of our study was that only patients from public hospitals were included. However, as Brazil has a unified

health system, patients with different levels of schooling and diseases were included.

## CONCLUSION

A new 16-item instrument was developed to assess how physicians deliver BN. After further validation with a representative sample, the instrument may be useful for patients to assess the quality of the physicians' performance in delivering BN in actual clinical practice.

## AUTHORS' CONTRIBUTION

Luciana Burg: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing. Getúlio R de Oliveira Filho: Conceptualization; Formal analysis; Methodology; Visualization. Flávia Del Castanhel: Formal analysis; Methodology; Validation. Lara De Luca M Schuler: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Validation; Visualization; Writing – original draft. Suely Grosseman: Conceptualization; Formal analysis; Methodology; Project administration; Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing.

## CONFLICTS OF INTEREST

The authors declare no conflicts of interest related to this study.

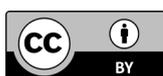
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