# Effect of Cancer Diagnosis and Suggestions for Diagnostic Communication in Patient **Vision**

https://doi.org/10.32635/2176-9745.RBC.2018v64n4.197

Efeito do Diagnóstico de Câncer e Sugestões para Comunicação Diagnóstica na Visão dos Pacientes Efecto del Diagnóstico de Cáncer y Sugerencias para Comunicación Diagnóstica en la Visión de los Pacientes

Alessandra da Cunha Neumayer¹; Márcia Cristina Maciel de Aguiar²; Eldsamira da Silva Mascarenhas Schettini Sobrinho³; Alinne Santiago Ramos Gonçalves<sup>4</sup>

#### Abstract

Introduction: Cancer is classified as a chronic disease and has been growing in the world; therefore, the doctor needs, more and more, to prepare to attend cancer patients. Most of the bad news protocols are not performed through the patient's lens. **Objective:** To know the effect of the diagnosis of cancer for the patient, and his suggestion about the way of communicating the diagnosis. Method: Qualitative study of narratives of oral histories, recorded and later transcribed, using the method of content analysis proposed by Laurence Bardin. The sample consisted of 30 cancer patients aged 34 to 88 years in a private clinic in Salvador, Bahia. Results and Discussion: The categories were: acceptance (53%), shock/fright (33%), suffering (20%), fear (2%), rationalism (2%), patient was able to present one or more types of reactions. Selected categories on diagnostic communication: diagnosis by non-oncologist (53.3%), diagnosis by non-physician (30%), diagnosis by oncologist (16.6%), and subcategories were: adequate and inadequate. Pessimistic speech was considered an inadequate medical communication; while an appropriate physician-friendly posture. Conclusion: Acceptance of the disease and shock/fright were the most prevalent effects at diagnosis. Patients with mild to moderate symptoms were considered to be diagnosed. What it indicates in this study is that, perhaps, oncologists are more prepared to report bad news than other professionals. Taking into account the characteristics of the subject and giving information in a gentle manner, giving hope were the main suggestions of diagnostic communication by the patients. Key words: Neoplasms; Truth Disclosure; Personal Narratives; Qualitative Research; Psycho-Oncology.

Introdução: O câncer é classificado como uma doença crônica e vem crescendo no mundo; logo, o médico precisa, cada vez mais, se preparar para atender aos pacientes oncológicos. Na maioria das vezes, os protocolos de más notícias não são realizados por meio da óptica do paciente. Objetivo: Conhecer o efeito do diagnóstico de câncer para o paciente e a sua sugestão sobre o modo de comunicação do diagnóstico. Método: Estudo qualitativo de narrativas de histórias orais, gravadas e, posteriormente, transcritas, sendo utilizado o método de análise de conteúdo proposto por Laurence Bardin. A amostra foi constituída por 30 pacientes oncológicos de 34 a 88 anos em uma clínica particular de Salvador, BA. Resultados e Discussão: Sobre o efeito do diagnóstico, as categorias extraídas foram: aceitação (53%), choque/ susto (33%), sofrimento (20%), medo (2%), racionalismo (2%), sendo que o mesmo paciente pode apresentar um ou mais tipos de reações. Categorias selecionadas sobre comunicação diagnóstica: diagnóstico por médico não oncologista (53,3%), diagnóstico por não médico (30%), diagnóstico por médico oncologista (16,6%); as subcategorias foram: adequada e inadequada. Fala pessimista foi considerada uma comunicação médica inadequada; enquanto uma postura amiga do médico, adequada. Sobre sugestões de comunicação diagnóstica, as categorias foram: levando em consideração as características do paciente, modo suave e dando esperança, e junto a um familiar. Conclusão: A aceitação da doença e o choque/susto foram os efeitos mais prevalentes ao diagnóstico. O que indica neste estudo é que, talvez, os oncologistas são mais preparados a informarem más notícias do que os outros profissionais. Levar em consideração as características do sujeito e dar informação de modo suave, dando esperança, foram as principais sugestões de comunicação diagnóstica pelos pacientes.

Palavras-chave: Neoplasias; Revelação da Verdade; Narrativas Pessoais; Pesquisa Qualitativa; Psico-Oncologia.

Introducción: El cáncer se clasifica como una enfermedad crónica y viene creciendo en el mundo; el médico necesita, cada vez más, prepararse para atender a los pacientes oncológicos. La mayoría de los protocolos de malas noticias no se realiza a través de la óptica del paciente. Objetivo: Conocer el efecto del diagnóstico de cáncer para el paciente, y su sugerencia sobre el modo de comunicación del diagnóstico. Método: Estudio cualitativo de narrativas de historias orales, grabadas y posteriormente transcritas, siendo utilizado el método de análisis de contenido propuesto por Laurence Bardin. La muestra fue constituida por 30 pacientes oncológicos de 34 a 88 años en una clínica particular de Salvador, BA. Resultados y Discusíon: En el caso del diagnóstico, las categorías extraídas fueron: aceptación (53%), shock/ susto (33%), sufrimiento (20%), miedo (2%), racionalismo (2%), siendo que el mismo, el paciente pudo presentar uno o más tipos de reacciones. En la mayoría de los casos, se observó un aumento de la mortalidad por rotavirus en los últimos años. Habla pesimista fue considerada una comunicación médica inadecuada; mientras que una postura amiga del médico, adecuada. En las sugerencias de comunicación diagnóstica, las categorías fueron: tomando en consideración las características del paciente, modo suave y dando esperanza y junto a un familiar Conclusión: La aceptación de la enfermedad y el shock/ susto fueron los efectos más prevalentes al diagnóstico. Lo que indica en este estudio es que, quizás, los oncólogos están más preparados para informar malas noticias que los demás profesionales. Tomar en consideración las características del sujeto y dar información de modo suave, dando esperanza fueron las principales sugerencias de comunicación diagnóstica por los pacientes. Palabras clave: Neoplasias; Revelación de la Verdad; Narrativas Personales;

Investigación Cualitativa; Psicooncología.

Address for correspondence: Alessandra da Cunha Neumayer. Rua do Mangalô, 233 - Salvador (BA), Brazil. CEP 41680-048. E-mail: alessandraneumayer@gmail.com



<sup>&</sup>lt;sup>1</sup> Faculdade de Tecnologia e Ciências (FTC). Salvador (BA), Brazil. Orcid iD: https://orcid.org/0000-0002-7790-3561

<sup>&</sup>lt;sup>2</sup> Escola Bahiana de Medicina e Saúde Pública. Salvador (BA), Brazil. Orcid iD: https://orcid.org/0000-0001-7797-4530

<sup>&</sup>lt;sup>3</sup> Instituto do Câncer Arnaldo Vieira de Carvalho. São Paulo (SP), Brazil. Orcid iD: https://orcid.org/0000-0001-6107-5098

<sup>&</sup>lt;sup>4</sup> FTC. Salvador (BA), Brazil. Orcid iD: https://orcid.org/0000-0002-3596-8711

#### INTRODUCTION

Cancer, as other diseases, as diabetes, cardiovascular and kidneys diseases is classified as a chronic disease; but unlike the others, when people hear the word, it alluded to scenarios as hair fall, chemotherapy, nausea, vomit, sadness and hospitalization because of the negative perception society has about cancer 1,2.

According to the World Health Organization (WHO), in 2017, cancer incidence in the world was higher than 14 million and the mortality rate was 8.8 millions<sup>3</sup>.Its incidence is growing, in 2030 it is estimated that it will reach more than 21 million of new cases<sup>3</sup>.

Cancer has an invasive and aggressive potential, but it has been noticed a steady evolution of the diagnosis and therapies (chemotherapies, radiotherapy, immunotherapy, surgical techniques) and a higher possibility of cure<sup>4</sup>. In addition, even for diagnosis of advanced stages, it is possible to devise actual plans of good perspectives of life to the patients, with extended survival and improvement of life quality<sup>4</sup>.

In the light of this perspective, the doctor needs, even more, to get prepared to provide care to oncologic patients and for this, to be aware of the atmosphere, which involves the patient during the disclosure of the diagnosis. It is essential to help the patients through the treatments and oncologic routines. Currently, and in addition to this, though there are many protocols for breaking bad news, - the most famous is Spikes - most of them are grounded in the doctors opinions and not in their patients' 5-8.

As cancer is a high morbidity and mortality disease and generator of physical and emotional suffering, it is relevant to analyze the existential issues of the patients at the moment of disclosing the news of the cancer. This study may help the doctors with how to disclose a so sensitive diagnosis, whereas the paucity of the studies under the perspective of the patient. This paper has the objective of knowing the effect of the cancer diagnosis for the patient and its suggestion about how to disclose the diagnosis.

#### **METHOD**

Qualitative, narrative approach study, based in the completion of a socio-demographic questionnaire and semi-structured interview. The script of the interviews contained questions about what type of cancer, who disclosed the diagnosis, how this news was received, the opinion of how the communication was made, in addition to suggestions for a better communication. The narratives were recorded and transcribed as faithfully as possible and will be kept for 5 years by the investigators. The interviews lasted from 2 minutes and 57 seconds to 30 minutes and 57 seconds, 10.19 minutes in average. Earlier, it was done a pilot of 5 minutes and 30 seconds.

Data collection occurred from July 10 to 21, 2017 at "Núcleo de Oncologia da Bahia" (a private practice, which accepts health insured patients), in Salvador; the sample consisted of 30 patients that already knew their diagnosis. Prior to approaching them, the investigator verified with the staff the understanding the patients had. The interview happened in a closed place where the patient received chemotherapy or in the room where the patient waited for some procedure; it was a reserved environment to protect the secrecy and privacy of the patients. The Institutional Review Board of "Instituto Mantenedor de Ensino Superior da Bahia", of the "Faculdade de Tecnologia e Ciências (FTC)", approval number CAAE: 65633317.9.0000.5032. Patients were contacted earlier to create a *rapport*, to foster a more harmonious environment9. The objectives of the study were disclosed and an Informed Consent Form (ICF) was signed.

The patients accepted to participate of the study soon after signing the ICF, responded to the socio-demographic questionnaire and, next, the interview was done.

The sample was completed per saturation when a certain diversity, scope and richness of the narratives was

It was utilized the content analysis proposed by Bardin<sup>11</sup>, which grants the investigator the technical analysis of every detail of the narrative, which favors the extraction of the most profound ideas of the speech.

All the interviews transcribed were analyzed through "fluctuation of attention", with no previous definition of categories to attempt to grasp an overall idea of the text to be approached<sup>11</sup>. Upon this reading, it were coded the categories of analyzes that mustered all the main topics of the responses given by the interviewees. The subcategories were created after a more Cartesian reading of the text, and it were noticed certain links in the interviewees' speeches.

The participants were 34 and 88 years old, mean of 61.5 years and standard deviation of 11.22; 66.7% were female, 56.5, Caucasian, 53.3% were retired, 66.6% had completed college, 66.7% were married, 83.3% lived in Salvador and 43.3% were Catholic. The type of cancer was 26.7%, intestine, 13.3%, breast, 10%, lung and 10%, lymph tissue, 50% found cancer between 2016 and 2017.

The first or last names of the authors of the literature or philosophy were tagged in the samples as well as the type of cancer to prevent the identification of the participants.

#### RESULTS AND DISCUSSION

The backbone of the semi-structured interview were the effect of receiving the news, type of communication of the diagnosis and suggestions to improve the communication. Based in the analysis, categories and subcategories were selected to respond to the objectives of this study. Some portions of the participants' narratives are cited as an example of the categories.

#### BACKBONE OF THE NARRATIVE: EFFECT OF RECEIVING THE NEWS

Based in this topic, categories of acceptance, shock/ fright, suffering, fear and guilt came up. After receiving the news, the majority of the patients (53%) accepted the diagnosis, many were frightened (33%), some showed suffer (20%) and a few showed fear (2%) or rationalization (2%). The same patient can present one or more effects after the disclosure of the news.

## Category: Acceptance

Acceptance appeared because cancer can happen to anyone, lack of fearing death and face cancer as any other disease.

- [...] I always say I'm neither worse or different than the others. This can knock at the door of a neighbor as it knocked in mine, right? (Gertrude lymphoma).
- [...] I was never afraid of dying, but at my age, the only thing I would ask God is to have more time because of my granddaughters [...] (Gregório lymphoma).

Because Gertrude thinks she is no better than anyone else is, she binds her acceptance to the idea that every human being is vulnerable, fallible, even in health questions12.

Seneca, the philosopher, immortalized by the phrase "living is learn to die", the awareness of finitude is a tough learning process, a condition that may have helped Gregorio to accept his diagnosis<sup>12</sup>.

Souza 13 study with patients with various types of cancer encountered as main responses the shock and acceptance of the diagnosis. Studies with lung cancer patients in the United Kingdom had shock and resignation (acceptance) as the most frequent reactions to the diagnosis 14.

### Category: Fright/Shock

Surprise was the reaction of the participants to what wasn't expected.

> [...] I was frighten [...]. Actually, it was a great surprise, I was sure it would be negative [...] (Clarice, uterus).

> A shock, a surprise, because you think it's not going to happen with us, at least, I always felt very healthy (Jane, non-metastatic breast and uterus).

When responding with surprise to the diagnosis, it was understood that the patients of this study were not prepared for the possibility of having a cancer diagnosis.

A study in Sweden showed that the word most present in the diagnosis was surprise<sup>15</sup>. One Australian study with breast cancer or melanoma had as main reactions to the diagnosis the shock and fright followed by acceptance and sadness16.

### **Category: Suffering**

Suffering was metaphorically associated to pain.

[...] the news about the cancer, you can figure it out, but you can't feel, I don't want people to feel, it is a pain that hurts, it is the pain that hurts (Florbela, *liver*).

The suffering reported by Florbela about the diagnosis as a "pain that hurts" may be because of the possible idea of the cancer as an image of pain and death. According to Pelaez Dóro et al.<sup>17</sup>,this is consistent with a selfelaborated prophecy that, instead of the patient succeeding in accepting the process and cope with it, it tends to maximize the difficulties.

#### Category: Fear

[...] much fear, lost my ground [...]. I sat in the bench in the hospital garden to open the result and I was staring at it and wondering: "what is going to happen from now on?" [...] (Cecília, ovary).

Through her speech, Cecília shows apprehension not only for the future, but to the future with cancer; this can be attributed to the social negative construction of the cancer perceived by the patient.

A Norwegian study observed that fear is more present at the moment of the suspicion of the diagnosis until its confirmation and in the periods where the patient already treated would be routinely tested for reassessment, which created the fear of relapse<sup>18</sup>.

### Category: Rationalization

Rationalization appeared as the anticipatory agent to cancer diagnosis.

> It was received as I was expecting because I smoked for 55 years and this node appeared, I had already other complications in the lung. Then, from this moment on, the next thing was the cancer [...] (Gabriel, lung).

When Gabriel revealed he already expected the cancer diagnosis, even before the doctor disclosed the news, he

used the rationalization proposed by Descartes<sup>19</sup> in the XVI century. In that case, Gabriel used the scientific correlation of tobacco smoking to the appearance of lung cancer to ground his diagnosis.

# BACKBONE OF THE NARRATIVE: TYPE OF DIAGNOSIS COMMUNICATION

About the type of diagnosis communication, the categories that appeared were: communication by nononcologist doctor, 53.3%; communication by non-doctor, 30,0%; communication by oncologist doctor, 16,6%.

# Category: Communication by non-oncologist doctor

About this category, there are the following subcategories: adequate and inadequate. Of the patients who received the diagnosis by non-oncologist doctor, 56.25% found the disclosure adequate, while 43.75%, found it inadequate.

#### Subcategory: Adequate

The patients see as adequate a communication done clearly and calmly. It was seen as positive as well, the doctor's attempt to create empathy, care and knowledge shown.

> The doctor was quite calm and tranquil [...]. She was quite friendly controlling to see what was my reaction [...] (Virginia, intestine).

> The doctor was very thoughtful, a very special person, wanted to speak himself. He went to the lab to get the biopsy results, he wanted to disclose the result in person, already knew it wasn't a good thing. And then, his own expression, I saw [...], he was very careful, very tender (Zélia, lymphoma).

> The doctor is a very humane person and with a great spiritual potential, then, she told me honestly [...] I thought the doctor helped me a lot, the way she told me, because she was honest and very capable. She showed she knew what she was doing [...] thought it was the right way she bonded with me (Simone, multiple melanoma).

The above narratives show that the doctor was not only the discloser of the health conditions of these persons, but bonded with them. The creation of a rapport, under a cognitive view brings the idea of continuity, of order, trust and this softens the disorder the disease unconsciously provokes in the individual<sup>15</sup>.

#### Subcategory: Inadequate

To associate cancer to the reality we are all going to die someday, the lack of sensitiveness of the doctor and not giving hope, these are seen as inadequate attitudes.

[...] he said "everybody is going to die someday", it was how he told me, didn't like, I thought he was very rude. He meant I had no cure, didn't he? [...] (Lewis, lung).

I thought it was awful, this neurologist only gave me bad news. Don't remember he ever gave me good news. Every time he came into my room, he always brought bad news. When he got to the door, I saw right away "there is something coming" [...], honestly, I think he needed to be best prepared, because breaking the news as he did "hey, look, is malignant, got it?", only gave me bad news. Honestly, I would never be his patient. I thought he wasn't prepared to do this kind of thing (Baudelaire, brain).

Cold, very cold. He started to sketch and called my husband, started to sketch and [...] later, he said it was cancer [...] (Cora, intestine).

Other studies showed that the patients felt a pessimistic attitude of the doctor, neither giving hope nor pointing out the positive points of the treatment 15,18,20. The patients above talked about how the diagnosis was disclosed without pointing out the positive aspects.

Cancer diagnosis given in few words and not focusing in the person who receives the news may be seen as inhumane and humiliating 18.

Cora's narrative shows that the excess of information given by the doctor failed to be positive. This disapproval was addressed also in Salander 15study since the participants did not like when the doctor explained with many details the information about their illnesses and were seen as sadists. It appears to be a quite reasonable aspect for the doctor, while breaking the news to the patient, to focus in the information rather than in the patient because science is used as a shield, a cloak against negative emotions.

#### Category: Communication by non-doctor

Thirty five percent of the patients knew the diagnosis through a non-doctor. Of the patients who knew the diagnosis in that manner, there were those who knew by their own, 77.77%, reading the complementary exam and those who were informed by their family, 22.22%.

#### Category: Diagnosis by reading the own exam

The majority of the patients in this category (57.14%) concluded this is inadequate, while 42.85% considered adequate.

#### Subcategory: Inadequate

Dorothy believed the absence of the doctor was negative.

[...] as I did the test in another state, I could not pick up the result. Had to ask them to send me over [...].And it wasn't easy, because when you listen to your doctor, she will guide you nicely [...] it wasn't good the result in this way, was not cool (Dorothy, breast).

#### Subcategory: Adequate

The old medical patronizing posture is being replaced by a medicine who respects the patient autonomy and many doctors are increasingly concerned in placing the patient as an active part of its health<sup>21</sup>.

> [...] I liked being alone in that moment. I prefer to read and ask later [...] in my case, I would rather have it bluntly and then, share (Clarice, uterus).

> Great, because I am very independent, things that are mine, I like to have a saying. Wasn't afraid when I went, wasn't fearful, picked it up and opened it [...]. Left, called the mastologist who had advised me one year before and then he said "where are you?", I said "I'm here at the lab". He said "come to my office" [...] (Hilda, breast).

#### Category: Diagnosis by a family member

Two participants received the news from family members or friends, one thought it adequate and the other, inadequate.

#### Subcategory: Adequate

Having a representative, family member or friend as an intermediate for breaking the news worked as a sieve, only pertinent information were passed to the patient, Balzac thought it was adequate.

> I knew through someone, I wasn't deep into it, because it was embarrassing for me and be stuck in yourself because you are ill, it is more problem yet (Balzac, liver).

According to Pereira<sup>21</sup>, it is relatively usual, in the Brazilian context to have the family ask the doctor for the patient not to be informed about the diagnosis. The ideal, however, is the doctor to talk with the family, weighing the benefits of disclosing the diagnosis and the unpleasantness of the omission<sup>21</sup>. Balzac's family decided not to hide the diagnosis from him, but expected the right moment to do so.

#### Subcategory: Inadequate

Another patient thought inadequate that the doctor had first informed the diagnosis to a friend, he felt that information were held from him:

Initially, the doctor hasn't told me, instead he told a friend of us who was with us and then, it reached me. I think it doesn't need to hide anything from me, in my opinion, doesn't have to hide anything from anyone (Gregório, lymphoma).

A study in Japan found that the patients that were not informed about the cancer diagnosis experimented severe suffering more than those who were informed 22.

### Category: Communication by doctor oncologist

A total of 16.6% of the patients received the diagnosis by a doctor oncologist. All of them considered adequate how the news were disclosed.

A dialogue in steps is considered adequate, when the doctor assess the patient's reaction to move on with the information.

> I liked because the doctor didn't give it like that, you know? Because if she gave it this way, I think, ,laughs. She was giving, explaining, talking, chatting, then I could absorb better, see? If she was blunt, I don't know how it was going to be (Rachel, intestine).

A Brazilian study with oncologic patients and their family revealed that 87.9% of non-specialized doctors omitted the cancer news from the patient, while only 6.4% of the oncologists omitted the diagnosis<sup>23</sup>. This appears to suggest that the oncology specialty prepares better the doctors to approach the bad news than other medical specialties.

This deserves to be emphasized, because, in despite of the preparation of the oncologist, in many cases, it is not him who gives the initial cancer diagnosis to the patient. The generalist doctor, mainly in the National Health System (SUS), may be the first to contact the patient and the first to refer it to the oncologist. The familiarity with the protocols, themes and discussions about breaking bad news should be mandatory for all medical specialties.

# BACKBONE OF THE NARRATIVE: SUGGESTIONS TO IMPROVE THE DISCLOSURE OF THE DIAGNOSIS

Based in the suggestions given by the participants of this study, it were selected categories: disclosure tailored to the patient, gentle disclosure of the diagnosis, giving hope and disclosure of the diagnosis with a family member.

Of the patients who gave suggestions about how to better disclose the cancer diagnosis, 50% said that the doctor must consider the emotional characteristics of the patient, 35.7% that the doctor must disclose the news gently, giving hope and 14.2%, that the diagnosis must be disclosed with a family member. The same patient may give one or more suggestions.

Regardless of many protocols for breaking bad news in place, overall, the documents are grounded in the doctor opinion, rather than the patient's 5,9,15,16,22,24,25.

The guidelines should be patient-based rather than in doctor's opinions<sup>16,20,22</sup>.

The Protocol Spikes was created by Robert Buckman in 1992. It is a mnemonic in English meaning setting up the *interview* – configuring or setting up the interview – when the doctor reviews in his mind the information that will be given to the patient and prepares a proper environment; "P" (perception), moment to find out the level of knowledge the patient has about his current condition; "I" (invitation), time to know whether your patient would like to be aware of its diagnosis; "K" (knowledge), this is the moment of the news, firstly the speech can be initiated with "unfortunately we don't have good news", transmitted in understandable terms, gradually, avoiding to use very harsh words; "E" (emotions), the caregiver must attempt to read the patient emotions and show concern; "S" (strategy and summary), time to devise a plan with goals together with the patient, always bringing in the will of the patient and sharing the responsibilities<sup>5,7,8</sup>.

While reviewing protocol *Spikes*, pursuant to studies involving the perception of the patients about the moment "S", complaints about the place and privacy were not brought up, maybe these aspects have been ensured by the doctors; it is also very appropriate to invite a companion to be present at this moment<sup>15,16, 22,26</sup>.

Stages "P" and "I" are very relevant, as the majority of the participants of this study and of other researches advocate that the diagnosis should be tailored to the participants' conditions<sup>13-16,22,24</sup>.

About phase "K", the oncologic patients of one study revealed that they did not very much like when the doctor initiated the phrase pessimistically, with "unfortunately" or "I'm sorry" 15. In addition, patients emphasize the importance of the doctor transmitting the news in a gentle manner<sup>13,14,22</sup>. Studies also show that the doctor should give the diagnosis clearly, understandable to the patient<sup>14,22,24,27</sup>.

In relation to stage "E", the patients report that the doctor should ever leave the room and let them alone after the reaction to the diagnosis<sup>27</sup>. In some cases, the doctors bring other caregivers to help; but the patients feel unnecessary the presence of other non-health care professionals at the moment of breaking the news<sup>15,16,21,26</sup>.

The last stage "S" is perhaps the most difficult for the doctors because they may fear to pass false expectations to the patient. However, the patients, in the studies, report about the importance of the caregiver to pass hope at the moment of the diagnosis 13-15,18,22. The patients reiterate that hope could be focused to treatment-related questions instead of in the disease as caregivers usually do, instead<sup>14,18,22,24</sup>. Convey the diagnosis step-by-step, in a gentle manner, was also suggested by the studies, which have incorporated the patients opinion<sup>14,22,24</sup>.

# Category: Communication considering the characteristics of the patient

The participants considered that the diagnosis have to be conveyed by the doctor according to the emotional aspects.

> I think it depends a lot of the patient, more of the patient than the doctor. There are patients who are very emotional and others, very realistic and some that are very religious (Gabriel, lung).

> [...] I would talk with the patient to know whether he is able to listen to this news, because, sometimes, the patient isn't prepared and has no idea of what is happening [...] (Agatha, intestine).

When the doctors convey the diagnosis of cancer, they need to see the patient in a particular manner, acknowledging the mechanisms of personal coping 14.

# Category: Communication of the diagnosis gently, giving hope

Hope was brought as a tool to overcome the disease, the success of the treatment.

> Has to tell gently and giving hope: "Look, you can win this". It is the best way (Marguerite, intestine).

> I think the best way to tell this maybe is connected to the possibility of affirming the perspective of success of the treatment [...] it is important to pass energy to this patient [...] (Manuel, thymus).

According to Salander<sup>15</sup>, the patients in his study felt the necessity of the doctor, while announcing the cancer diagnosis, to focus in the possibilities of the treatment, which brings a sense of hope for the patient. In the present study, Manuel has also mentioned hope associated to the treatment.

In Marguerite's view, the doctor, while announcing the news about the cancer, has to give hope to the patient. It is known, nevertheless, that, in many cases, the prognosis of the disease may be dismal; so, the caregiver tends to fear transmitting encouraging feelings to his patients<sup>7</sup>. But even when the patient has not an actual chance of cure, the doctor should not deny it because there is a plan to be designed, as for instance, pain control strategy<sup>7,8</sup>.

#### Category: Communication of diagnosis with a family member

The presence of the family at the announcement of the cancer was suggested as emotional support.

What I think is more important is to always have someone, that you are never alone, because I, in this moment, when I heard the result, if it wasn't my husband support [...], don't know what I would be able to do [...] (Dorothy, breast).

The family member, at the diagnosis, appears to have a buffering effect because it shares the emotions lived by the patient <sup>28-30</sup>. This fact was reported by Dorothy.

### **CONCLUSION**

The main effects of the diagnosis of cancer experienced by the patients of this study were acceptance of the disease and shock/fright with the new reality. In relation to the type of communication of the diagnosis, of the patients who received the diagnosis from non-oncologist doctors, the majority considered adequate, the doctor showed a friendly attitude, attempted to create a bond, with humanity. It was considered assertive. A pessimistic disclosure, cold and rich in medical information was seen as inadequate. The non-medical diagnosis disclosure included reading the test and know the result by family members or friends. Of the patients who knew the diagnosis after reading their own test results, the majority found this type of communication inadequate, while for those who received the news from family members or friends, one patient found adequate and another, inadequate. All the patients of this study who received the diagnosis of cancer by the oncologist were satisfied with how this news was disclosed, which can be the result of a better preparation and experience while breaking bad news. The access to protocols of breaking bad news should be a requirement for other medical specialties, because in many cases, the patients are referred to oncology with a diagnosis made by non-oncologist doctors.

Firstly, under the perspective of the oncologic patients of this study, based in their narratives about how to improve the disclosure of the diagnosis, the majority advocated that the doctor have to disclose the diagnosis of cancer tailored to the patient needs. This brings up the maxim of "primum non nocere"; secondly, the patients reiterated that the doctor have to disclose the diagnosis gently and giving hope and thirdly, they suggested that the diagnosis must be given in the presence of a family member.

#### CONTRIBUTIONS

Alessandra da Cunha Neumayer, Márcia Cristina Maciel de Aguiar and Eldsamira da Silva Mascarenhas Schettini Sobrinho collaborated to the study design, acquiring and/or interpretation of data, wording and

critical revision. Alinne Santiago Ramos Gonçalves collaborated in the wording and critical revision. All the authors approved the final version of the manuscript.

#### **DECLARATION OF CONFLICT OF INTERESTS**

There are no conflict of interests to declare.

#### **FUNDING SOURCES**

There are no funding sources.

#### REFERENCES

- Barbosa LNF, Francisco AL. A subjetividade do câncer na cultura: implicações na clínica contemporânea. Rev SBPH. 2007 Jun;10(1): 9-24.
- Neves MMAMC. A representação social do cancro: conhecer para (re)pensar a intervenção educativa [dissertação]. [Portugal]:Instituto de Ciências Biomédicas de Abel Salazar, Universidade do Porto: 2002. 220 p.
- 3. Nações Unidas. OMS: câncer mata 8,8 milhões de pessoas anualmente no mundo [Internet]. [Brasília]: ONUBR; 2017 Fev 03 [acesso 2018 Junho 17]. Disponível em: https://nacoesunidas.org/oms-cancermata-88-milhoes-de-pessoas-anualmente-no-mundo/.
- Medicina personalizada, terapia alvo, quimioterapia - o que tudo isso significa em oncologia de precisão? [Internet]. São Paulo: Instituto Oncoguia; 2015 Fev 27 [acesso 2018 Abr 1]. Disponível em: http://www.oncoguia.org.br/conteudo/medicinapersonalizada/7207/840/.
- Neto Chehuen JA, Sirimarco MT, Cândido TC, Bicalho TC, Matos BO, Berbert GH, et al. Profissionais de saúde e a comunicação de más notícias sob a ótica do paciente. Rev Med Minas Gerais. 2013;23(4):518-25. doi: https://dx.doi.org/10.5935/2238-3182.20130079.
- Lino CA, Augusto KL, Oliveira RAS, Feitosa LB, Caprara A. Uso do protocolo Spikes no ensino de habilidades em transmissão de más notícias. Rev Bras Educ Med. 2011 Jan/Mar;35(1):52-57. doi: http:// dx.doi.org/10.1590/S0100-55022011000100008.
- Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES – Um protocolo em seis etapas para transmitir más notícias: aplicação ao paciente com câncer. The Oncologist [Internet]. 2000 [acesso 2018 Janeiro 26];5:302-311. Disponível em: https://edisciplinas. usp.br/pluginfile.php/4356704/mod\_folder/content/0/ SPIKES%20%E2%80%93%20Um%20Protocolo%20 em%20Seis%20Etapas%20para%20Transmitir%20 M % C 3 % A 1 s % 2 0 N o t % C 3 % A D cias % 2 0 Aplica%C3%A7%C3%A3o%20ao%20Paciente%20co.pdf?forcedownload=1 Traduzido por Rita Byington.

- Cruz CO, Riera R. Comunicando más notícias: o protocolo Spikes. Diagn Trat.2016;21(3):106-108.
- Oliveira MF. Entrevista psicológica o caminho para aceder o outro [monografia]. Porto: Universidade Lusíada do Porto; 2005. 37 p.
- 10. Minayo MCS. Amostragem e saturação em pesquisa qualitativa: consensos e controvérsias. RPQ. 2017 Abr;5(7):01-12.
- 11. Bardin L. Análise de Conteúdo. São Paulo: Edições 70; 2016.
- 12. Schramm FR. Morte e finitude em nossa sociedade: implicações no ensino dos cuidados paliativos. Rev Bras Cancerol. 2002 Jan-Mar;48(1):17-20.
- 13. Souza LH. Percepções de pacientes com câncer quanto ao conhecimento e revelação deste diagnóstico [Monografia]. Florianópolis: Universidade Federal de Santa Catarina; 2004. 29 p.
- 14. Yardley SJ, Davis CL, HM, Sheldon SF. Receiving a diagnosis of lung cancer: patients' interpretations, perceptions and perspectives. Palliat Med. 2001;15(5):379-386. doi: https://doi. org/10.1191/026921601680419429.
- 15. Salander P. Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients. Soc Sci Med. 2002 Set;55(5):721-732.
- 16. Butow PN, Kazemi JN, Beeney LJ, Griffin AM, Dunn SM, Tattersall MHN. When the diagnosis is cancer: patient communication experiences and preferences. Cancer. 1996 June;77(12):2630-2637. doi: https://doi.org/10.1002/ (SICI)1097-0142(19960615)77:12<2630::AID-CNCR29>3.0.CO;2-S.
- 17. Pelaez Dóro M, Pasquin R, Medeiros CR, Bitencounrt MA, Moura GL. O câncer e sua representação simbólica. Psicol Cienc Prof. 2004;24(2)120-133. doi: http:// dx.doi.org/10.1590/S1414-98932004000200013.
- 18. Saegrov S, Halding AG. What is it like living with the diagnosis of cancer? Eur J Cancer Care. 2004 May;13(2):145-153. doi: https://doi.org/10.1111/ j.1365-2354.2004.00442.x.
- 19. Descartes R. Discurso do Método: meditações. 2 ed. São Paulo: Martin Claret; 2016.
- 20. Dhage AS, Wilkinson AR. Breaking bad news of cancer diagnosis - the patient's perspective. IJRMS. 2017 April;5(4):1617-21. doi: http://dx.doi. org/10.18203/2320-6012.ijrms20171275.
- 21. Pereira CR. Comunicando Más Notícias: protocolo PACIENTE. [Tese]. Botucatu: Universidade Estadual Paulista; 2010. 100 p.
- 22. Fujimori M, Akechi T, Akizuki N, Okamura M, Oba A, Sakano Y, et al. Good communication with patients receiving bad news about cancer in Japan. Psycho-Oncology. 2005 Dec;14(12):1043-1051. doi: https:// doi.org/10.1002/pon.917.

- 23. Gomes CHR, Silva PV, Mota FF. Comunicação do diagnóstico de câncer: análise do comportamento médico. Rev Bras Cancerol. 2009;55(2):139-143.
- 24. Schofield PE, Butow PN, Thompson JF, Tattersall MHN, Beeney LJ, Dunn SM. De. Psychological responses of patients receiving a diagnosis of cancer. Ann Oncol. 2003;14(1): 48-56. doi: https://doi. org/10.1093/annonc/mdg010.
- 25. Figg WD, Smith EK, Price DK, English BC, Thurman PW, Steinberg SM, et al. Disclosing a diagnosis of cancer: where and how does it occur? J clin oncol. 2010 Aug; 28(22): 3630-35. doi: https://doi.org/10.1200/ ICO.2009.24.6389.
- 26. Gonçalves F, Marques A, Rocha S, Leitão P, Mesquita T, Moutinho S. Breaking bad news: experiences and preferences of advanced cancer patients at a Portuguese oncology centre. Palliat Med. 2005 Oct;19(7):526-31. doi: https://doi.org/10.1191/0269216305pm1070oa.
- 27. Graner KM, Rolim GS, Moraes ABA, Padovani CR, Lopes MA, Santos-Silva AR, et al. Feelings, perceptions, and expectations of patients during the process of oral cancer diagnosis. Support Care Cancer. 2016 Nov; 24(5):2323-32. doi: https://doi.org/10.1007/s00520-015-3030-0.
- 28. Ferreira NML, Dupas G, Costa DB, Sanches KOL. Câncer e família: compreendendo os significados simbólicos. Cienc Cuid Saude. 2010 Abr-Jun; 9(2):269-277. doi: https://doi.org/10.4025/cienccuidsaude. v9i2.8749
- 29. Souza MGG, Santo FHE. O olhar que olha o outro...: um estudo com familiares de pessoas em quimioterapia antineoplásica. Rev Bras Cancerol. 2008;54(1):31-41.
- 30. Carvalho CSU. A necessária atenção à família do paciente oncológico. Rev Bras Cancerol. 2008;54(1):97-102.

Recebido em 24/9/2018 Aprovado em 4/12/2018