

# The doctor-patient relationship in oncology: a study from the patient's perspective

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## Abstract

The peculiarities of cancer diagnosis require the doctor to adopt a different approach and make the study of the psychosocial aspects of the patient and communication techniques necessary to avoid iatrogenesis. This paper aims to study the relationship between the doctor and the cancer patient in a public oncology reference center. A qualitative and descriptive exploratory study was performed involving 17 patients diagnosed with cancer at Fundação Centro de Controle de Oncologia do Estado do Amazonas (Amazonas State Oncology Control Center Foundation), Brazil. The patients interviewed expressed a wide variation of feelings; they wanted greater sincerity and clarity from doctors during diagnosis; they questioned the difficulty of access to health care; they complained about the effects of treatment and the emotional and physical limitations experienced during the process; and finally they emphasized the importance of the doctor-patient relationship. In conclusion, it was noted that patients recognized important aspects of the diagnostic process and the treatment of cancer, which, when duly contextualized, serve as a basis for rethinking medical practice and the doctor-patient relationship.

**Keywords:** Physician-patient relations. Neoplasms. Medical oncology.

## Resumo

### Relação médico-paciente na oncologia: estudo a partir da perspectiva do paciente

As peculiaridades do diagnóstico de câncer impõem ao médico abordagem diferenciada, tornando necessário o estudo dos aspectos psicossociais do doente e de técnicas comunicacionais, de modo a não gerar iatrogenias. O objetivo do trabalho foi estudar a relação médico-paciente com câncer em um centro de referência em oncologia do serviço público. Trata-se de estudo exploratório qualitativo e descritivo, envolvendo 17 pacientes diagnosticados com câncer na Fundação Centro de Controle de Oncologia do Estado do Amazonas. Os entrevistados demonstraram diversos sentimentos: desejaram mais sinceridade e clareza dos médicos no diagnóstico; questionaram a dificuldade do acesso ao sistema de saúde; queixaram-se dos efeitos do tratamento e das limitações emocionais e físicas vivenciadas; e, por fim, destacaram a importância da relação médico-paciente. Portanto, foram reconhecidos aspectos importantes do diagnóstico e tratamento de câncer, devidamente contextualizados, de modo a se repensar a prática médica e a relação médico-paciente.

**Palavras-chave:** Relações médico-paciente. Neoplasias. Oncologia.

## Resumen

### Relación médico-paciente en oncología: un estudio desde la perspectiva del paciente

Las peculiaridades del diagnóstico de cáncer imponen al médico abordajes diferenciados, tornando necesario el estudio de los aspectos psicossociales del enfermo y de las técnicas de comunicación, con el fin de no generar iatrogenias. El objetivo del trabajo fue estudiar la relación médico-paciente con cáncer en un centro de referencia en Oncología del servicio público. Se trata de un estudio exploratorio cualitativo y descriptivo, con 17 pacientes con diagnóstico de cáncer en la Fundación Centro de Control de Oncología del Estado de Amazonas, Brasil. Los entrevistados mostraron diversos sentimientos: desearon mayor sinceridad y claridad de parte de los médicos en el diagnóstico; cuestionaron la dificultad en el acceso al sistema de salud; se quejaron de los efectos del tratamiento y de las limitaciones emocionales y físicas experimentadas; y, finalmente, destacaron la importancia de la relación médico-paciente. Por lo tanto, se reconocieron aspectos importantes del diagnóstico y del tratamiento del cáncer, debidamente contextualizados, de modo tal de poder repensar la práctica médica y la relación médico-paciente.

**Palabras clave:** Relaciones médico-paciente. Neoplasias. Oncología médica.

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Declararam não haver conflito de interesse.

Research into the doctor-patient relationship has revealed the importance of studying the subject, not only for the possible use of the narrative of the patient as a therapeutic instrument<sup>1,2</sup>, but also to improve communication techniques to improve the quality of this relationship<sup>3</sup>. In the holistic and integrated conception of health, there is a growing interest among professionals and institutions in improving the quality of medical care provided, something that is directly associated with the interpersonal relationship that occurs between clients and those who attend to them – be they doctors, nurses, nutritionists, speech therapists, or other medical professionals<sup>4</sup>.

From studies on the subject in the 1970s and 1980s, it is known that the quality of these services, as perceived by patients, depends from 30 to 40% on the diagnostic and therapeutic skills of the physician, and 40 to 50% on the relationship between professionals and users<sup>5,6</sup>. It is therefore no longer possible to organize medical care considering only effectiveness in curing disease, but also the *respect for the patient's subjective values, the promotion of autonomy, and the protection of cultural diversities* (authors' translation) must also be considered<sup>7</sup>. Medical psychology has developed based on new perspectives in the care given to sick individuals seeking health care. For the techniques of caring for the patient to be used in the most appropriate way, it is necessary to understand aspects relating to the feelings and tensions that govern the doctor-patient relationship, which is a dual in nature.

The situation is even more delicate in oncology clinics, as cancer is fraught with social stigma and often one of the most frightening diagnoses for individuals seeking medical care. The disease represents a triple threat to the patient: physical pain, mutilative care and death<sup>8</sup>.

Studying the aspects that permeate the relationship between health professionals and cancer patients is therefore of paramount importance in order to rethink the medical practice and academic education of professionals dealing with patients envisioning the finitude of life.

## Theoretical reference

### *Medicine of the person*

According to Eksterman<sup>9</sup>, the introduction of the notion of the sick person in medical concern – and not just a subject with a disease, is attributed to psychoanalysis, with the “discovery” of the patient

considered *one of the most remarkable medical innovations of the twentieth century*. Perestrello<sup>10</sup>, when studying what he called “medicine of the person”, that is, medicine directed at the patient in his or her singularity, considers the historical dimension as an essential perspective for understanding the phenomenon of becoming ill. The disease, in the words of Abdo, is presented as a product of the historical structure of the patient, *linking successive events that are part of the biography of man, transcending the limits of the Natural Sciences and introducing it into the Social Sciences*<sup>11</sup>.

According to this author, when a physician and patient establish a therapeutic bond, they actually construct a third character, the product of the interaction of both, a “transpersonal” relationship. It is this new character that will receive care, emphasizing the historicity of the patient, subject to therapeutic influx. Since this relationship is a “living relationship,” every medical act will affect the sick person and will have therapeutic or anti-therapeutic significance<sup>10</sup>.

It is also within the historical context that certain roles and functions of the participants are determined. This relationship is subject to the occurrence of triangulations that, according to Andolfi *apud* Soar Filho<sup>12</sup>, are the minimum units of observation of interpersonal relations. In other words, interfering between doctor and patient are the illness, the family of the patient and the health institution.

When a disease significantly affects family dynamics, the physician – or his or her therapeutic intervention – can be considered a threat to the homeostasis of this family system. However, the family, in other cases, may be a valuable tool to support and collaborate with treatment<sup>12</sup>. The institution in which the patient seeks care can also impair their relationship with the professional. When seeking a reputable service, for example, greater expectations about the doctor's competence are created, or the health professional may become the recipient of frustrations and anger when the service is of inadequate quality or the health system is inefficient and inhumane<sup>12</sup>.

### *Psycho-oncology*

From the perspective of oncology, the doctor-patient relationship has its own peculiarities related to the malignant disease. The patients themselves seem to create more expectations in their relationships with the oncologist than with other health professionals<sup>13,14</sup>.

The severity of the diagnosis, fueled by uncertainties, insecurities and myths surrounding the disease, makes approaching it especially difficult. A great deal of anxiety on the part of the patient and the doctor is perceived during consultations<sup>15</sup>. The treatment itself - mutilating, lengthy and with complications - generates additional morbidity and tension<sup>16</sup>.

Understanding each patient as unique in his/her individuality is fundamental during the approach to and identification of cancer, regardless of how many similar diagnoses the health professional has already performed. The patient is not always able to discuss the probabilities and consequences of this diagnosis on a technical level. The physician should seek information about the patient's perception of the disease and how this possibility will affect their state of equilibrium<sup>14</sup>.

According to the Code of Medical Ethics, art. 34, doctors are forbidden *to fail to inform patients of the diagnosis, prognosis, risks and objectives of the treatment, except when direct communication may cause harm to his or her person, in which case he or she must notify a legal representative*. Furthermore, in art. 35, *the physician is prohibited from exaggerating the severity of the diagnosis or prognosis, complicating treatment, or exceeding the number of visits, consultations, or any other medical procedures*<sup>17</sup>.

According to Silva et al.,<sup>18</sup> the *altered emotional status of the patients and their families, the different approach to transmitting the diagnosis, bad news, and treatment that, in the short term, is more difficult than the disease itself* are factors that limit the construction of an appropriate bond, user satisfaction or adherence to treatment. This imposes particular difficulties on the doctor-patient relationship in oncology, which in turn requires an improvement of humanization and communication techniques for the cancer patient.

## Objectives and method

The present study aims to examine the doctor-patient relationship and the illness of patients with cancer in a reference center in a public oncology service, in order to better understand the process of illness from the perspective of the patients themselves. A qualitative, quantitative and descriptive exploratory study was carried out, based on the discourses of cancer patients, at the Fundação Centro de Controle de Oncologia do Estado do Amazonas (the Foundation for the Control

of Oncology of the State of Amazonas) (FCEcon/AM), in the city of Manaus.

A total of 74 individuals were approached at random – without applying a randomizing device and/or reliable random method – in the vicinity of the outpatient clinic, reception and social service of the institution in February 2013. Of these 74 individuals, 56 were patients diagnosed with cancer and undergoing treatment and/or medical follow-up care at the institution. Of these 56 individuals, 21 agreed to participate in interviews, 17 of which were considered adequate for discourse analysis. Patients who refused to participate did so mainly because they did not want to reveal or expose their illness and the situation they were going through. All participants were cancer patients, who were treated at the hospital, could communicate verbally and were over 18 years of age.

## Data collection and treatment

The semi-structured interviews were applied and audio recorded and were then transcribed in full according to the guidelines of Preti and Rodrigues<sup>19</sup>. Content analysis was performed using the Bardin method<sup>20</sup> by categorizing the responses, and comprised three phases: pre-analysis; exploration of material and treatment of results; and inference and interpretation.

In the pre-analysis, a skim reading was performed as a first contact with the texts. Next, the index referencing and the elaboration of the indicators was performed - categorization from units of meaning, which are excerpts from the discourses provided in answer to the interviewer's question, and the preparation of the material related to the organization of the categories. The material was subsequently explored based on the application of the systematic decisions taken in the pre-analysis and, finally, the results were quantified. The Microsoft Office Excel 2010 program was used for quantitative analysis.

## Results

### Quantitative analysis

Of the 17 patients interviewed, 11 were female (64.7%) and six (35.3%) were male. The subjects were aged between 30 and 66 years, with an average age of 49.9 years and a median age of 50 years. Of the interviewees, ten declared themselves to be married, four were single and three were separated.

In terms of housing, three (17.7%) lived alone and 14 (82.3%) lived with another person.

In relation to schooling, three said they had completed higher education while two had an incomplete higher-level education; one had finished high school; three had completed elementary school and seven had an incomplete elementary level education. One patient said he only knew how to read and write his own name.

With respect to the reasons that led them to seek a doctor, 12 (70.6%) reported having had symptoms and five (29.4%) discovered the problem in routine exams, as they had no symptoms. The diagnosis was made between five months to 15 years prior to the interviews, with an average period of 3.3 years and a median of three years. All 17 respondents claimed to be religious in some way.

### Qualitative analysis

All the discourses of the subjects were identified by the patient's initials, gender (f = female, m = male) and age in years, and are summarized in Table 1 of the annex. Some of the manifestations of the patients follow.

### Reaction to diagnosis

When asked "What was your reaction when you received the diagnosis of cancer?", the emotional states reported were calm (eight, 47%); fear (seven, 41.1%); sadness (five, 29.4%); disbelief (two, 11.7%); resignation (two, 11.7%); questioning (one, 5.9%) and contentment (one, 5.9%). It should be noted that the sum of the frequency of reactions does not correspond to the total number of people (17) in the research, due to the patients reporting more than one feeling, which demonstrates the complexity and ambiguity of the reactions during the medical consultation, and alternations in the elaboration of their perception of the diagnosis of cancer.

- *Calm*

*"I cried [when the doctor gave me the diagnosis]. And he said don't cry. Don't cry because I'm going to transfer you to Cecon where I'm from, I work here and I work there I will treat you and you'll be fine. You'll go home. And then I felt happy again"* (PAT.1, f, 45 a).

- *Fear*

*"Because you know you're going to be diagnosed with cancer today and you see yourself as practically dead. I was devastated"* (PAT.2, f, 50 a).

- *Sadness*

*"I was very sad. It hit me very hard"* (PAT.3, f, 38 a);

*"My God, I was, well, hum! I felt up and down at the same time. And I cried"* (PAT.1, f, 45 a).

### Communicating the diagnosis of cancer

When asked if the communication of the diagnosis of cancer was adequate, six individuals (35.3%) included in their discourses the request that the doctor be clear and sincere in their words. Of those interviewed, three (17.6%) expressed a desire for the doctor to be empathetic and two (11.8%) said they would like the doctor to provide details in his or her explanations during diagnosis. Six (35.3%) had no opinion.

- *Sincere/Objective*

*"I always ask: look, doctor, don't lie to me. Whatever is going on you can tell me. There's no problem. And for me there really isn't a problem"* (PAT.4, m, 47 a);

*"No, I want to know as soon as possible. To find out soon. There are doctors who hesitate, aren't there? Call the children and the relatives. I said straight away: doctor I want to know the truth (...)"* (PAT.1, f, 45 a).

- *Empathetic*

*"I think he spoke in the normal way. Normal, because he didn't go around in circles, he went like this, saying: Look, it might be, it might not be. At no stage did he say: ah, you're going ... When he got the biopsy, he said: yes, it really is what I was already ... what I told you I was suspecting, right??"* (PAT.5, f, 52 a).

- *Detailed*

*"To tell you the truth, even talking to others – and I really like to talk, these new doctors, they have a better dialogue with patients. Those older doctors are more reserved. I think this is very good because every patient feels good with a doctor who is fully informed about them"* (PAT.6, m, 66 a).

### Negative aspects when seeking diagnosis

Respondents were asked about the history of their diseases. During their speeches, it was possible to recognize criticisms and negative aspects from their perspectives regarding the process of being diagnosed with cancer in the public health system in

the state of Amazonas (Table 1), with manifestations sometimes occurring in more than one aspect.

**Table 1.** Negative aspects in process of diagnosis of cancer

Negative aspects	nº	%
Health system lacking	5	29,4
Conflict in doctor-patient relationship	4	23,5
Referral for evaluation by a specialist without clear explanations about cancer	3	17,6
Incorrect initial diagnosis	2	11,7
Possible cancer diagnosis rejected	2	11,7
Lack of complete understanding of disease	2	11,7
Doctor informed family only	2	11,7

### Health system lacking

*"Ah, I was really sick. Really sick. And in Tefé, where I live, there are no resources, are there?" (PAT.7, m, 58 a);*

*"(...) since 2009 I've been fighting with the SUS for an operation. (...) It's so difficult! To get an operation (...) I told him: doctor, for God's sake. Doctor, if we carry on like this I'm going to die! I can't take it" (PAT.8, m, 44 a).*

### Conflict in doctor-patient relationship

*"He said some things that I don't even like to talk like that because it hurts me (...). And I was angry at that doctor" (PAT.9, f, 46 a).*

### Referral for evaluation by a specialist without clear explanations about cancer

*"No, he didn't say anything [about the disease]. He said I'm going to send you to one of my colleagues! And he's a specialist in this" (PAT.10, m, 59 a).*

### Incorrect initial diagnosis

*"Then the doctor told me it was ameba. Take medicine for ameba. Another: I don't know what you have" (PAT.6, M, 66 a).*

*"Then he just gave me medicine for high blood pressure, my pressure was high, but I still told him: doctor, my pressure is high due to the illness I have! Look at the lump!" (PAT.9, f, 46 a).*

### Possible cancer diagnosis rejected

*"Because when he saw the lump he said it was nothing, he said I shouldn't worry because it was an inflamed gland and I mentioned that I had four cases of cancer in my family. He said that if it was a cancer I would already be dead!" (PAT.9, f, 46 a).*

### Negative aspects during treatment

Analysis of the discourse of the interviewees revealed the problems that they encountered during treatment. The main complaints were related to the difficulty in scheduling curative surgeries, the delay in waiting to start chemotherapy and obtaining tests. The lack of specialized medication in hospitals was mentioned on eight occasions, corresponding to 30.8% of the complaints. Complications resulting from the treatment also appeared in eight (30.8%) manifestations. The psychological *affectations* resulting from the disease were reported in seven (41.2%) statements. Difficulties in the doctor-patient relationship were reported on three (17.6%) opportunities as negative aspects during treatment.

### Lacking infrastructure

- *Lacking doctors*

*"I think there isn't enough government investment, the federal government. There weren't enough materials for the chemotherapy. They were sending people home! Because there were no materials! I had no medicine" (PAT.9, f, 46 a).*

- *Long waits for treatment*

*"I think there were changes in chemotherapy. There was a time when I had to have it every twenty-one days, and there was a time when I did not, or I had to wait more than a month. Because there were no places or something" (PAT.5, f, 52 a).*

- *Logistic problems at hospitals*

*"And ... now ... there was only one time, that I thought ... so the doctor went on leave because he was sick, too. He's a human being, he gets sick too ... So, I think the hospital should have immediately provided a replacement, right? Who the patient could be referred to. But that's not what happened.*

*I'd just been operated on, hadn't I? I'd recently had an operation and I didn't have this" (PAT.11, f, 66 a).*

- **Long wait for tests**

*"So he was very, well, like: whatever you can afford, you should do. The same for the biopsy: if you can afford it, you go private because here at Cecon it takes a while" (PAT.5, f, 52 a).*

### Complications resulting from treatment

- **Treatment sequelae**

*"So all the clothes I wore [after the mastectomy] were ugly. It was a nightmare!" (PAT.12, f, 53 a);*

*"They opened my belly straight away, as well as the large tumor, I also had a prostate. Then they operated on me directly, prostate and everything. They took everything. That's why I want to get a report from him, about the surgery, because I wasn't right after the surgery, I wasn't normal. So for me to get back to normal, I had to wear a prosthesis, doctor said that I'm very young ... and you know, my wife worried about me" (PAT.8, m, 43 a).*

- **Suffering/pain**

*"The most painful, you mean? Chemotherapy ... it really affects you badly... yes" (PAT.11, f, 66 a);*

*"When I looked in the mirror. The removal of my breast thus wasn't as painful as my hair falling out" (PAT.9, f, 46 a).*

### Significant psychosocial consequences

- **Limitations in daily living**

*"I live ok, I suppose, but not like I was before. I eat well, but again I don't eat everything I could" (PAT.13, f, 39 a);*

*"You already feel this way, no, because of your illness you can't do it, no, because of your illness you can't do that. You feel so rejected. You feel terrible. [cries]" (MPSPG, f, 55 a).*

- **Prejudice**

*"You feel this way ... and now that you have to walk around with a mark from the ink they use [for radiation*

*therapy]. And you see, from there you will see that the human being is prejudiced" (PAT.2, f, 50 a);*

*"And my biggest dream was going back to work [crying], you know? Only you come back and it's not like it was [crying] anymore. People are prejudiced [cry]" (MPSPG, f, 55 a).*

### Difficulties in doctor-patient relationship

*"Because of my relatives [I did not do the exams that the doctor requested]! They said I was going to die! That if I came here that the doctors were going to study me and would take advantage of me, wouldn't they? of the human being that's being studied, ok, ok, that's when I stopped" (PAT.14, f, 38 a).*

### Self-evaluation of health condition

When asked "How do you see your health condition today?", the patients tended to demonstrate a positive outlook, but with some caveats, either because of the sequelae of the disease or the treatment or by the greater acceptance of their condition processed during the treatment period (Table 2).

**Table 2.** Evaluation of patients regarding their current health condition

Health condition	nº	%
excellent/wonderful/cured/100%	2	11,8
fine/good/positive/no problems	5	29,4
good but with reservations (sequelae, complications, limitations...)	6	35,1
normal/average	1	5,9
poor/not feeling well /negative	2	11,8
terrible/practically dead/moribund	0	0
can't say	1	5,9

From a generic perspective, 13 (76.3%) people considered that their health condition was, in some way, good, although with reservations, and 76.4% of respondents had an optimistic opinion.

- **"Excellent", "wonderful", "cured" or "100%"**

*"Wonderful. He said that I'd like I'm a new person. To give you an idea what I've gone through, they took out fifteen pieces. It really affected me" (PAT.5, f, 52 a);*

"My health, I think, I feel I'm cured" (PAT.1, f, 54 a).

- "Good", "I'm fine", "positive" or "no problems"

"I don't know ... the power of the mind is really strong. I think I'm fine! I haven't collapsed yet [laughs]" (PAT.3, f, 38 a);

"I see it positively. With the view that I'll feel good tomorrow. I have a lot of faith, I think" (PAT.15, f, 30 a).

- Good but with reservations (sequelae, complications, limitations...)

"Oh, it's good, right? Okay ... Okay, as far as possible, right? Of course when you, when I (...) after breast removal surgery, mastectomy, then there are sequelae. So that's what they're trying to avoid, because they know, well, the sequelae they get. But ... overall, in general ... it's okay ... okay." (PAT.11, f, 66 a).

### Perception and impact of illness on life of patients

The people interviewed were asked about changes in their lives following the diagnosis of cancer. The categorization of responses in order of frequency is as follows: personal values (four, 25.5%); perception of disease (two, 11.7%); information on the disease, (two, 11.7%); financial issues, (two, 11.7%); personal plans (one, 5.8%); marital relationship, (one, 5.8%); loss of autonomy, (one, 5.8%);

#### Personal values

"So, what has changed for me, it is so, especially, about people, we discover a lot. When you get sick like this, you find out you have lots of friends. We find that we are very loved. So there are these things. We start giving more value to life. There are some things that we did that we even avoid doing" (PAT.5, f, 52 a);

"I ... my look at life. And ... hug my relatives when I can [cries]" (IGSM, f, 38 a).

#### Perception of illness

"Before entering Cecon, I was terrified of the place, you know. Just to walk by it, I was terrified. Then I went in to take care of a brother, to accompany a

brother here. Then, right? I came ... from the disease. And I saw that Cecon is not the bogeyman, no. It does not scare you or haunt you. On the contrary, people here find a lot of support, good treatment" (PAT.11, f, 66 a);

"Before I got sick, for me, cancer was a terrifying prospect, but then we mature with life, and this business of getting sick, this and that" (PAT.6, m, 66 a).

#### Information about the disease

"But it was good that more people receive guidance, with this scare, practically my whole family, my sisters, my relatives ... then everyone has this concern to seek this guidance. To apply preventive measures more often" (IGSM, f, 38 a).

### Essential Qualities for a Medical Professional

The people interviewed also described characteristics they considered positive, the essential qualities of a good doctor or the most important abilities for practicing the profession. Dialogue, empathy and politeness were highlighted in 23 (85.2%) of the manifestations.

#### Dialogue

"It's important that he explains it clearly to us. For me. In my opinion" (PAT.7, m, 58 a);

"The doctor is like a priest! He has to know how to guide the faithful!" (PAT.10, m, 59 a).

#### Empathy

"But then, so, the doctor, he shows interest, love for the patient, it helps the patient a lot to cope. Because it's not easy, for a person to say that you they cancer. It frightens, it frightens us ... when we come in here, right? It comes already with fear, even by the disease itself, is already debilitated, comes sensitive, right??" (PAT.11, f, 66 a);

"A kind person who treats people well. Because the person is already fragile, then she finds a doctor who is harsh, it isn't good" (PAT.12, f, 53 a).

### Politeness

*"Treat the patient well, give them attention. Don't be an arrogant or ignorant doctor, because there are some, aren't there?"* (PAT.4. f, 66 a);

*"It's ... graciousness. Knowing how to measure words. Don't be harsh. There are some situations when you need to be, but not all"* (IGSM, f, 38 a).

### Discussion

Some authors<sup>21</sup> argue that neither the age nor the education of the patients or the integrity of family care received seem to influence the knowledge of the doctors about the complaints of patients. Kaplan et al.<sup>22</sup> corroborated the influence of the physician-patient relationship on the outcome - from physiological, behavioral or more subjective indicators - of patients with chronic diseases, regardless of their sociodemographic characteristics.

Likewise, the failure to adhere to medical treatment among children with acute lymphoblastic leukemia was not related to the schooling of the parent or guardian, the number of family members or the per capita income in a study by Oliveira et al.<sup>23</sup>. Pinto<sup>24</sup> states that the desire of cancer patients to receive information about the disease is not related to sociodemographic data.

Other researchers<sup>25</sup>, while studying the effect of spirituality on terminally ill patients with cancer, found negative correlations between spiritual well-being and hopelessness and suicidal ideation, identifying this well-being as a possible protective factor against the despair of death.

### Reaction to diagnosis

With regard to the psychosocial aspects of each patient, it is understood that each individual will react to the diagnosis of cancer in his or her own way. The physician should then be attentive to the patient's fears and anxieties, which does not occur most of the time (91.4%)<sup>3</sup>. Knowing a little about the patient's personality is important as it facilitates how they will react to bad news.

Other studies on the reactions of patients to diagnosis define the situation as a dramatic, unexpected and shocking experience<sup>26</sup> in which the patient experiences uncertainties, anguish, reactions of

disbelief, questioning, and a delay in accepting reality<sup>27</sup>. These works appear, in this context, to diverge from the present study in the assertion of patients that they remain calm at the time of diagnosis.

According to Soar Filho<sup>12</sup>, when faced with the unknown, stressful situations and emotional tension, there is a normal tendency to react with some degree of regression, in the psychoanalytic sense of the term. The degree of regression of the sick person may vary based on at least three factors of interaction factors: a) characteristics of the personality of the individual; b) quality of information about the nature of the problem and the procedures performed; and c) how the institution and the doctor receive and respond to their demands.

The author also points out other internal mechanisms for the protection of the sick person, such as transference, production of fantasies, denial and secondary gain, which must be respected as necessary ways of adapting to stress, at least until adequate protection is provided by the health team<sup>12</sup>. The most important task is to make the patient overcome the denial phase, which is undoubtedly the most complex stage, when suicidal ideation and depressive symptomatology occur most of the time. Gomes, Silva and Mota<sup>28</sup> in their research on the omission of the diagnosis of cancer state that, of patients who were not informed, 83% already suspected that they had a malignant disease, which coincides with the discourse of some of our interviewees.

### Communicating the diagnosis of cancer

As in this study, other studies corroborate patients' desire to be informed in a sincere way, in clear but not impolite language<sup>29,30</sup>. Silva and Zago, in their article on communicating the diagnosis of cancer, describe several studies that suggest it should be performed in an honest, clear and comprehensive, yet gentle and respectful manner, avoiding euphemisms and jargon<sup>31</sup>.

In consultations, it is common for professionals to use ambiguous terms and euphemisms in an attempt to soften the impact of the diagnosis of cancer<sup>32,33</sup> and also to not appear to perceive that they are conveying the wrong meaning, especially when their nonverbal communication is not congruent with the intention of the message<sup>34</sup>. Training in medical communication is therefore important to achieve greater effectiveness in the doctor-patient relationship.



A few decades ago, the theory that the patient should not know about their diagnosis predominated among professionals and family members, a fact perhaps explained in part by the prejudice in relation to cancer patients and in the belief that they would not want to know their own diagnosis<sup>35-37</sup>. Although most cancer patients wish to be informed about their diagnosis<sup>24,26,38-41</sup>, many health professionals feel uneasy and relatively unprepared at this time<sup>42</sup>. Today, the patient is in control of their own destiny. They are the ones who define what is "well-being" and authorizes what is to be done to them. This is the synthesis of "autonomy" in the new doctor-patient relationship<sup>43</sup>.

It seems common, with the worsening of the disease and the imminence of death, that there will arise communicational problems between doctor and patient, known as a "conspiracy of silence"<sup>44</sup>, with the doctor assuming a falsely paternalistic attitude, which leads them to hide the truth from the patient<sup>45</sup>. Even today, the rate of omission of the diagnosis of cancer is a problem of medical ethics.

In the study by Gomes, Silva and Mota<sup>28</sup>, non-specialists failed to inform 87.9% of their patients, while specialists omitted diagnosis in 6.4% of cases. Although the omission rate is higher among non-specialist physicians, it is intriguing that it is not zero among specialists. However, it is important to note that despite the majority of patients wishing to be informed about their illness, they do not seek medical information on their own<sup>26</sup>.

Faced with so many conflicting feelings, what should one expect from the doctor? The health professional, although neither the owner of the truth or the destiny of others, cannot be a mere spectator to the spectacle of others. He or she plays an important role: sharing through solidarity in the journey of human care and treatment<sup>43</sup>.

### **Negative aspects during the search for diagnosis**

The view that difficulties in accessing health services, especially in cases of cancer patients, are so important that they influence the conflicts that patients experience with medical professionals when finally obtaining treatment prevailed in the discourses of the subjects.

### **Negative aspects during cancer treatment**

Regarding the importance of adequately explaining to patients about the treatment to be performed, Fallowfield et al.<sup>46</sup> found that 52% of

breast cancer patients reported being misinformed, resulting in a double chance of being diagnosed with depression or anxiety, or both, within a 12-month period. According to Dixon, Sweeney, and Gray<sup>47</sup>, it is important for the physician to develop the ability to induce positive attitudes in the patient regarding their disease and to help them cope with their illnesses, which can change the patient's life and disease course. This procedure was able to improve the clinical status of several diseases, including cancers and cardiovascular problems.

Doctors who use the participatory model of patient care, as opposed to the traditional authoritarian model, in which the physician is the patriarchal figure and who makes all the decisions of the treatment, have twice the chance of retaining patients, that is, that their patients do not change doctors<sup>48</sup>. Accurate recognition of patient problems is also associated with greater compliance<sup>49,50</sup> and better treatment outcomes<sup>21,51</sup>.

### **Self-assessment of one's health condition**

Patients experience varying feelings during and after the end of cancer treatment, which affects perceptions about their health and well-being. Values change with the perspective of illness and bring new insights into life and the self<sup>52</sup>. In the study by Greenberg and Meadows<sup>53</sup>, 40% of children who survived cancer reported a positive health status. In our sample, seven of the 17 patients (41.1%) reported having a health condition without problems or sequelae, data similar to those found in the literature.

### **Perception and impact of disease on patients' lives**

According to McDaniel, Hepworth and Doherty<sup>54</sup>, due to the instability and uncertainties of the condition itself, chronic disease causes changes in the social representations of the patient and the family and a long period of adaptation to the constant losses experienced. Araujo and Arraes<sup>55</sup> point out that most studies focus on the negative aspects of survival, and that the literature unsatisfactorily answers whether ex-cancer patients are more or less depressed and anxious.

Other studies show that, for the subjects involved, overcoming an oncological experience can generate positive and adaptive changes, such as greater emotional control, maturation and motivation<sup>56,57</sup>. However, Oppenheim<sup>58</sup>, when analyzing the psychotherapeutic interviews of ex-cancer patients

(some almost two decades after completing treatment), found that the violence of the subjective experience undergone does not diminish with time, revealing that surviving patients have more difficulty in adjusting psychologically, especially in terms of an excessive concern for health<sup>59</sup>.

In this context of understanding the experience of cancer, the best way of acting after curing the disease remains uncertain. There are no clear norms of how to act, feel or be treated by others<sup>60</sup>, as the experience considered as alienating and characterized by ambivalences and uncertainties, which suggests the application of the concept of anomie to such a state of recovery<sup>61</sup>. In this sense, maintaining a good doctor-patient relationship is critical for patients to overcome persistent anxiety and depression symptoms and to return to normal activities over time.

### Final considerations

In spite of the methodological restrictions, important aspects of the process of diagnosis and

treatment of cancer, duly contextualized, were recognized, which can allow the rethinking of medical practice not only in the institution where the research was carried out, but also in terms of the public health system and its social limitations and aggravating factors.

The teaching of the social sciences - including communicational processes - for medical students continues to be a challenge for educators<sup>62</sup>, despite the fact that their importance has been emphatically demonstrated<sup>18</sup>. We therefore believe that the teaching of medical communication and the restoration of the doctor-patient relationship as a form of dual empathy – in other words, where the physician attempts to understand the physical and psychological pain of patients – must be encouraged in medical schools and cannot be dismissed. One should try to understand human suffering, respecting the individuality and personality of patients, because after all, being a good doctor is, first and foremost, to learn, to listen, to hear and be humble in relation to one's own knowledge.

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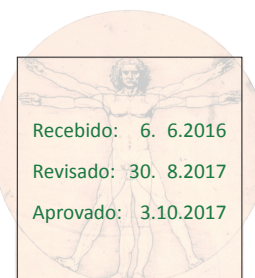
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#### Participation of the authors

Luiz Otávio was responsible for the planning of the research, data collection, inputting and analysis, and the preliminary draft of the text. Elizabeth Nogueira de Andrade and Edson de Oliveira Andrade participated in the planning of the research, data analysis and the writing of the final version of the text.



## Annex

**Table 1.** Reaction of the interviewees to the possibility of diagnosis of cancer and confirmation of the diagnosis and the justification of their reaction to the definitive diagnosis

Family support	Probable diagnosis	Definitive diagnosis	Reason for reaction
PAT.11	Denial	Calm	Calm personality
PAT.6		Calm	Presentiment / suspicion of malignant disease
			Religiosity/Spirituality
		Questioning	Desire to understand the seriousness of the disease
PAT.4	Demands sincerity/objectivity from doctor	Calm	Adaptive style most suitable for situation
PAT.7		Contentment	Anguish when faced with unknown
PAT.5		Calm	Good doctor-patient relationship
			Family support
PAT.16		Calm	Religiosity/Spirituality
			Lack of total concern regarding disease
PAT.3	Fear	Sadness	
		Calm	Sought information on his own
PAT.8	Concern	Fear	Word "Cecon"
		Calm	Religiosity/Spirituality
PAT.15		Fear	
		Calm	Good doctor-patient relationship
PAT.10		Resignation	Faced naturally
PAT.2		Sadness	Fear of death
		Fear	Stigma of disease
PAT.14		Incredulidade	
PAT.9		Fear	
		Sadness	Depression
		Incredulity	Divine punishment
PAT.17		Fear	Fear of death
PAT.1	Demands sincerity/objectivity from doctor	Sadness	
		Calm	Good doctor-patient relationship
PAT.13		Fear	

## Interview Script

This script merely guides the conversations with patients, and should not be seen as limiting in terms of its content. All manifestations, even if not directly related to what was asked of the patient, should be recorded

### Identification:

- Age;
- Gender;
- Housing;
- Schooling;
- Religion.

### Clinical profile:

- What led patient to seek medical care;
- Time for diagnosis of cancer;
- Reaction when discovering diagnosis;
- How was the diagnosis communicated by the doctor; Aspects of the course of care until confirmation of diagnosis;
- Aspects during treatment;
- Complications of treatment;
- Psychosocial complications;
- How patient self-assesses their health now;
- Perception of the impact of the disease on life;
- Desirable values and qualities in a doctor who cares for cancer patients.