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COMMUNICATION OF A NEW MESSAGE: THE DIAGNOSIS OF CANCER IN THE PERSPECTIVE OF PATIENTS AND PROFESSIONALS

COMUNICAÇÃO DE UMA MÁ NOTÍCIA: O DIAGNÓSTICO DE CÂNCER NA PERSPECTIVA DE PACIENTES E PROFISSIONAIS

COMUNICACIÓN DE UNA MALA MOTICIA: EL DIAGNÓSTICO DE CÁNCER EN LA PERSPECTIVA DE PACIENTES Y PROFESIONALES

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ABSTRACT

Objective: to understand the perception of patients and health professionals about the diagnosis of cancer and its relation to death. **Method:** this is a descriptive and exploratory study with a qualitative approach with four health professionals and four patients, who answered a semi-structured interview script, evaluated through the technique of content analysis. **Results:** the general corpus was divided into two blocks of analysis. In the first block, the patient interviews counted 273 Elementary Context Units (UCEs), distributed in six categories, which show that patients diagnosed with cancer, thought of death as a prognosis. In the second block, the interviews with the professionals counted 452 UCEs, distributed in six categories and four subcategories, showed that the professionals recognize the cancer-death association. **Conclusion:** the care in the notification and clarification on the diagnosis is important in the process of acceptance of the disease and treatment of cancer. **Descriptors:** Diagnosis; Communication; Cancer.

RESUMO

Objetivo: compreender a percepção dos pacientes e profissionais da saúde sobre o diagnóstico de câncer e sua relação com a morte. **Método:** estudo descritivo e exploratório, de cunho qualitativo, com quatro profissionais da saúde e quatro pacientes, que responderam a um roteiro de entrevista semiestruturado, avaliado por meio da técnica de Análise de conteúdo. **Resultados:** o corpus geral foi dividido em dois blocos de análises. No primeiro, as entrevistas dos pacientes contabilizaram 273 Unidades de Contexto Elementar (UCEs), distribuídas em seis categorias, que evidenciam que os pacientes no momento em que foram diagnosticados com câncer pensaram na morte como prognóstico. O segundo, as entrevistas com os profissionais, contabilizou 452 UCEs, distribuídas em seis categorias e quatro subcategorias, mostrando que os profissionais reconhecem a associação câncer-morte. **Conclusão:** o cuidado na notificação e esclarecimento sobre o diagnóstico é importante no processo de aceitação da doença e tratamento do câncer. **Descritores:** Diagnóstico; Comunicação; Câncer.

RESUMEN

Objetivo: comprender la percepción de los pacientes y profesionales de la salud sobre el diagnóstico de cáncer y su relación con la muerte. **Método:** estudio descriptivo y exploratorio, de enfoque cualitativo, con cuatro profesionales de la salud y cuatro pacientes, que respondieron una guía de entrevista semi-estructurada, evaluada por medio de la técnica de Análisis de contenido. **Resultados:** el corpus general fue dividido en dos bloques de análisis. En el primero, las entrevistas de los pacientes contabilizaron 273 Unidades de Contexto Elementar (UCEs), distribuidas en seis categorías, que mostraron que los pacientes en el momento en que fueron diagnosticados con cáncer, pensaron en la muerte como pronóstico. En el segundo, las entrevistas con los profesionales contabilizaron 452 UCEs, distribuidas en seis categorías y cuatro subcategorías, mostró que los profesionales reconocen la asociación cáncer-muerte. **Conclusión:** el cuidado en la notificación y aclaración sobre el diagnóstico es importante en el proceso de aceptación de la enfermedad y tratamiento del cáncer. **Descriptores:** Diagnóstico; Comunicación; Cáncer.

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INTRODUCTION

At the beginning of the Middle Ages, the death was part of the daily life of the people, and the wakes were at home with family and friends. Just like birth, death was open to the people. The children participated in the wakes, the conversations and they were not excluded, learning from an early age to see death as natural. At that time, the so-called "traditional death" was caused by epidemics and their lack of treatment, with high mortality rates and low life expectancy.¹

Over time, the view on death and its causes have changed. Medical science has progressed, reducing mortality rates and prolonging life expectancy. Death became a socially interdicted issue, silenced and sometimes denied. It also reduces the number of deaths from illnesses caused by lack of health care or health attention, increasing the number of people who die from "modern diseases" such as chronic diseases and cancer.²

Cancer is now one of those diseases that science has dedicated more efforts, creating technologies such as equipment, medicines and medical techniques that can treat and even cure patients. On the other hand, invasive procedures and the still significant number of cancer deaths make it a dreaded disease, and it is still seen as a synonym for death by its patients.³⁻⁴ For this reason, communicating the diagnosis of cancer represents a very suffered moment for the patient, his family and the professional. For patients and families, the occurrence of the disease and its painful treatment are marked by small daily losses (the lost health, falling hair, mutilated body, separation from family life and deferred or lost life plans) and fearing the possibility of death.⁵⁻⁶

Careful care of the interdisciplinary health team is required on the subjective aspects of the patient and the team-patient-family relationship. Therefore, an effective professional-patient communication carried out is recognized as the diagnosis and throughout the treatment and loss process, allows the recognition of the doubts and feelings associated with the disease, and represents the opportunity to offer information and support to the patients and their relatives.⁷

For the health professional, communication with the patient is still difficult and flawed, especially when referring to the communication of something unwanted, such as the diagnosis of cancer. Therefore, the communication of "bad news" is one of the

most difficult and distressing tasks in the practice of health professionals, especially for physicians, because of the deficiency in the training of the necessary skills in academic formation. Also, fear of death and the view of death as synonymous with failure also provoke the emotional distancing of health professionals towards patients with negative prognosis.⁷

Besides to planning these moments, it is necessary that professionals also work out their own fears and be prepared to accept the natural hostilities of the patient and the family. Therefore, it is recognized that a careful diagnosis marks the beginning of a good relationship between patient and team, facilitating adherence to treatment.⁸

In view of the foregoing, the purpose of this study was to understand the oncological patient's and health professionals' views on the diagnosis of cancer and its relationship with death.

METHOD

This is a descriptive and exploratory study with a qualitative approach. The study had two groups of participants: four health professionals and four patients, following the saturation criterion. The inclusion criteria were health professionals, who work with cancer patients; and for patients, men or women diagnosed with cancer, over 18 years old. They responded to a semi-structured interview script containing questions about understanding the significance of the cancer diagnosis and its relation to death.

After approval of the project by the Research Ethics Committee of the University of Fortaleza (UNIFOR) with an opinion Number 1,228,028, dated September 15, 2015. Previously known participants were contacted, and they indicated new participants, through the snowball technique. They were asked to read and sign the Free and Informed Consent Form, which model was elaborated in accordance with Resolution Number 466/12 on research involving human beings, informing the participant that it is a scientific study and that all information will be kept confidentially, as well as the anonymity of their participation. Then, individual interviews were conducted, in a reserved environment, with the help of the tape recorder.

The interviews were understood through the Content Analysis Technique, dealing with the analysis of the messages and the empirical orientation, exploratory as characteristic, linked to real phenomena and predictive purpose. For the development of the

technique, the structure of recommended steps were used: 1) organization of the analysis; 2) message encoding; 3) categorization; and 4) inference.⁹

RESULTS AND DISCUSSION

The general corpus was composed of eight interviews, constituting the Initial Context Units (UCI), divided into two blocks of analysis. The first block had four interviews with the patients that counted 273 Elementary Context Units (UCEs), distributed in six categories: 1- First suspicions about the disease; 2 - Posture of the professional in the diagnosis communication; 3- Reaction to the diagnosis; 4- Fears about the disease; 5- The treatment; 6- Self-perception and perception about cancer.

The second block is composed of four interviews with professionals. A total of 452 UCEs were distributed, divided into six categories and three subcategories: 1- The diagnosis; 2- The communication of the diagnosis and its repercussions; 3- The reactions on the diagnosis; 4- Treatment; 5- Psychological support for professionals and; 6- Image about the disease and its prognosis.

♦ Analysis of the categories addressed in the interviews with patients

♦ **Category 1** - "First suspicions about the disease", composed of 29 UCEs, showing that two of the patients suspected the disease after nodule detection and sought to investigate with a specialized professional. Other two were surprised, one through routine examination and the other after a hernia surgery.

Because, in fact, I suspected, I found the scar. (Participant 4)

I discovered it through a routine examination when I tapped the ultrasound that the doctor suspected. (Participant 1)

It corroborates the literature¹⁰ showing how the discovery of this pathology is often delayed since it involves extremely significant steps that precede its diagnosis. This course is obscure in the eyes of many professionals, who start the treatment process from only the proof of the disease by laboratory tests and other methods.

♦ **Category 2** - "Posture of the professional in diagnosis communication", composed of 59 UCEs, showing that three of the patients suffered from the doctor's failure to communicate the diagnosis, while only one patient reported being well-advised at the time of communication.

The doctor who operated on me, he gave me the news coldly when I was in a situation, in

a very intense nervous frame, the pressure was very high and he said he had removed a tumor from inside me that was probably cancer. (Participant 2)

As the literature⁵ shows, communication is one of the main instruments of health care, especially when it is addressed to patients facing a frightening diagnosis such as cancer. In this situation, communication and interaction are important moments that can provoke reactions in the patient and professional that can influence the future relationship between the two, establishing trust and adherence to treatment.

I like him very much, so the doctor was a person of God [...] he was trying to calm us, we did not worry. (Participant 3)

It corroborates the literature¹¹, which shows that besides to the technical-diagnostic support, professionals need sensitivity to know the patient's reality, listen to their complaints and find, along with him, strategies that facilitate their adaptation to the lifestyle influenced by the disease. It is observed that the communication models are related to the therapeutic space, aspects of the patient (symptom, expectation, fears, and anxieties, etc.) and also aspects of the physician (communicational ability, professional experience, stress, anxiety, etc.) constituting a relationship.

♦ **Category 3** - "Reactions about diagnosis", composed of 71 UCEs, showing how much the diagnosis causes negative reactions and thoughts of the eminence of death.

At that moment, I missed my legs. I entered, thus, in panic, but a silent panic that I was at work. Then, I thought about my boys, because what really worries me is the two of them. (Participant 4)

It corroborates the literature¹⁰, which shows how the receipt of the diagnosis of cancer constitutes the moment considered as one of the worst in the patient's life, because they are faced with an avalanche of feelings putting them in a dilemma before accepting the disease, which changes all family context, needing to elaborate new concepts and adapt to the new reality.

♦ **Category 4** - "Fears about the disease" is composed of 34 UCEs. It addresses the fears patients have about the disease, mostly appearing the fear of death.

When you get the news, it's a very heavy word. Cancer, you just think it is death, the moment I got it I say, my God, my children who still need me, just whom I remembered at the time, so I still have two children who need me. But when you calm down, things go, you absorb the idea more, things change. And then, it's all time my God I

cannot think I'm going to die, I cannot go into depression, I was too afraid of depression. (Participant 1)

It corroborates the literature¹² that shows that, often, the experience of cancer can lead to death, but it can also be the time to reformulate life. The person experiences uncertainty and uncertainty about what will happen, still under the impact of the diagnosis. The attitudes and behaviors will depend on the significance he attributes to cancer, on his relationships and social interactions, and on the roles she plays.

♦ **Category 5** - "Treatment" consists of 47 UCEs. It addresses the treatments to which the patients were submitted and their experiences regarding it.

It is a very painful treatment, chemotherapy affects everything you imagine. And day by day, look, it gives a lack of patience, there are hours that you think will run. (Participant 1)

It is a type of nodule that I did not have to undergo chemotherapy or radiation therapy, the treatment is surgical when I received the result that was malignant, with seven days I was operated again to take the rest. It was very complicated surgery because when I went in to do it, the Doctor called my mother, he would dig my tongue well, I could not speak. (Participant 3)

It confirms the literature¹³ that shows, in addition to the label of a painful and deadly disease, how the patient usually experiences treatment, usually long, losses and adverse symptoms, resulting in impairments in functional, vocational skills and uncertainty about the future. Many fantasies and worries about death, mutilation and pain are present at this time.

♦ **Category 6** - "Self-perception and perception about cancer" are composed of 33 UCEs. It shows how the participants came to see the diagnosis and themselves after having undergone the treatment.

I think I would handle it better. I believe that because I got cured, right? And I would handle it more, I would not be as disgusted as I was the first day. But of course, there is still fear, uncertainties, right? Sure, there always is. (Participant 3)

According to the literature¹², there are now many cases of survival. Then, it is essential to understand the experience of living with cancer, because uncertainty is a constant presence in the lives of these women and is usually manifested by fear of recurrence of the disease. Fear and closeness to death lead a person to manifest various feelings, which may or may not be overcome.

I was more scared before I was patient than now, but on the other hand, I still see a lot of people 'going away' in those moments, my self-esteem goes down a bit and I see cancer again as a very devastating disease. (Participant 2)

It corroborates the literature⁶ showing that in addition to the projected idea about death, also, the impact of death that is witnessed has a great effect on the lives of these patients.

♦ **Analysis of the categories covered in interviews with professionals**

♦ **Category 1** - "The diagnosis", composed of 63 UCEs, showing how professionals perceive the meaning of diagnosis for patients.

The receipt of the cancer diagnosis, I believe it is always related to a crisis and in general by the loss because it is always associated with many changes in the life of the patient. (Participant 8)

It corroborates the literature⁷, which shows how the communication of "bad news" is always related to situations that radically and negatively modify the patient's idea of his future.

♦ **Category 2** - "Communication of diagnosis and its repercussions", composed of 69 UCEs, showing how communication is made and its importance.

The patients who received the diagnosis in a more relaxed, more conversational, more respectful way, they adhered much more easily to the treatment than patients who received the news anyway or did not have the space to ask their questions, to ask questions and that we perceived in the accomplishment of the treatment, in the adherence of it. (Participant 5)

The reality showed in the literature¹² states that patients experience uncertainty about what will happen, still under the impact of the diagnosis. Their attitudes and behaviors will depend on the significance they attribute to cancer, on their relationships and social interactions, and on the role they play. It is very important for the taking of attitudes the relationship that will develop with the health professional because the patient will be vulnerable and dependent. At that moment, he needs a relationship of trust with a view to its better acceptance, adaptation and decision making.

The performance of the psychologist at the moment of communication is also approached.

We are asked to be in that moment, for the doctor, to give support, and for the family. So, we say it support, clarification, welcome, right? (Participant 6)

Corroborating the literature⁷, showing the communication of this type of news is a difficult task for all health professionals, because these moments cause disruption, both to the person who receives it and to the person who transmits it, generating in professionals and survivors, fears, anxiety, feelings of worthlessness, discomfort, and disorientation. The psychologist's practice is carried out in all stages of the treatment, enabling the patient to confront the diagnosis and the difficulties of the treatments, helping him to develop adaptive strategies to deal with stressful situations.¹³

♦ **Category 3** - "Reactions about diagnosis", composed of 56 UCEs, refers to the ways patients deal with the diagnosis.

We're talking about children here, right? So it is usually given only to the family, the father or the mother, the caregiver in general. It is a moment of shock, some families behave crying and others do not believe, so it is that moment of catastrophe, literally, right? (Participant 6)

It confirms the literature⁷, which shows that the communication of "bad news" is always related to situations that radically and negatively modify the image that the patient makes of his future. Caregivers are the main protagonists of the "bad news" who, in addition to planning these moments, also have to manage their own desires and be prepared to accept the natural hostility of the patient and the family.

Significantly, discourses addressing the diagnosis of cancer as the eminence of death have also emerged.

When I hear the word "cancer" I do not associate it directly with death, with finitude, but many patients that we accompany, yes, they bring a lot in the first visits the fear of the continuity of life. 'I'm going to have to suspend my life projects! You will not have time to do this or that, right? 'The first impact is really very much related to that. (Participant 5)

It corroborates the literature¹³, which shows that most people see cancer as irremediable. It is as if all that the individual did after the diagnosis was in vain. She feels powerless to reverse the already established condition. Even when it comes to good prognoses, there is still a strong belief that cancer and death are synonymous.

♦ **Category 4** - "Treatment", consisting of 45 UCEs, refers to the forms of treatment to which patients can be submitted.

So well, every treatment is a world of things that happen. It is not easy, it is not something simple, the life of the whole person changes the family also as I said

change the roles, it changes the social things even. It may start with radiotherapy, chemotherapy and then undergo surgery, it can vary greatly, but it comes with many implications. (Participant 5)

It confirms studies⁶ that show that adaptation to the conditions that come from treatment such as hair loss; mutilation; the separation of family life; and the loss of the friends who were also in treatment, provoking in small patients mourning. This reality is presented in the literature¹⁴, which states that every disease is a situation of loss, health, autonomy, time, money and plans. More specifically, treatment by the public health system is also addressed, showing how failures in the public health system affect patients, who cannot be assured in the continuity and agility of treatment.

So she came in from the interior thinking she was going to start her treatment on Monday, when she arrived 'my God, you would not be hospitalized' 'no aunt, just Friday'. She spent Monday, Tuesday, Wednesday and Thursday crying, with super depressive behavior, unsure of what was going to happen. That is why the public health system simply does not work. (Participant 7)

It corroborates the literature², which shows how the services that make up the health system should have their number determined by the population coverage capacity, being appropriately distributed by the geographical area where this population lives.

♦ **Category 5** - "Psychological support for professionals", composed of 37 UCEs.

When I came in here, it was when I actually came across the issue of death that we see and we do not summarize cancer to death, but it is a reality that we see a lot then I had to go through this process of therapy to have the space to talk about it. (Participant 5)

You must seek in your therapy because it is a very heavy environment, it is a very heavy climate, you deal directly with losses, with death, right, you have to always be working with it because you want to want it or not, the death is something that messes with anyone. (Participant 8)

It corroborates the literature⁶, which shows how the fear of death also causes the health professionals to distance emotionally from patients with a negative prognosis, seeing the other in their end emerging the thought about their own death. People do not stop to talk about death and its implications, for fear of discrediting life.

♦ **Category 6** - "Image about the disease and its prognosis", composed of 69 UCEs,

portrays the image that the professionals have the disease and its possible prognoses.

So this routine is kind of scales, you get hopeful, but at the same time, you do not understand. So, as much as we want to generate a perspective when we talk about cancer, it is a word that harms. (Participant 7)

I was able to follow some cases of same victories, of people who have managed to face cancer and that today lead a healthy life, right. And unfortunately, there were those cases that really did not reach the cure and died, but that, I believe that medicine still has a lot to advance in relation to cancer and decrease this probability more and more and so I believe that it will be associated less and less to death. (Participant 8)

These affirmations are in agreement with the literature,¹⁵ which shows that cancer prevention and control need to be given the same focus and attention as the care services area since the increasing number of new cases will mean that there are not enough resources to meet the needs of diagnosis, treatment, and follow-up. The consequence will be premature and unnecessary deaths, which could be minimized with a greater focus on disease prevention and control.

CONCLUSION

The study enabled the understanding of the importance of diagnosis in the process of illness, treatment, communication, and acceptance of cancer. Because it is a disease still very stigmatized, many patients receiving this diagnosis associate it with the prognosis of death, consequently generating a lot of anxiety and uncertainties.

Patients bring the recurrent thought about their finitude when questioned about the timing of the diagnosis, the lack of knowledge about the treatment, the uncertainties in its efficacy and a large number of people dying of cancer. The professionals believe that this relationship between cancer and death is something cultural, which must be deconstructed. Although they recognize that receiving the diagnosis is a time of great catastrophe in the patient's life, they believe that moving away from these pessimistic thoughts, patients would be less likely to develop psychosomatic disorders, it would also facilitate acceptance and adherence to treatment.

According to the literature and what it was said during the interviews, how the diagnosis is communicated can be a determining factor of how the treatment will be faced and the difficulties imposed by the disease by the

patient. What is still to be seen are many doctors who do not have the sensitivity and the ability to make the communication, causing an even greater impact in the patient since these professionals often use scientific terms, thinking that the patient understood them and end up not clarifying the procedures and processes in more detail to which they will be subjected, generating anxieties and pessimistic thoughts in the situation in which they are living.

Both groups of participants reported a lack of skills by the physicians in communicating this diagnosis, providing great impact to the patients they received. It was also highlighted in the report of professionals that because they are a space where the gaze is focused on the disease, they are not to become sensitized with the patient as if it were part of the daily life of these people as well. All patients reported that at some time after receiving the diagnosis, they thought about death. On the other hand, three of the professionals highlighted the experience of mourning, which was constant in their daily lives, and emphasized the importance of the advancement of medicine, as well as the creation of more effective methods for the demystification of the cancer-death parallel.

In their interviews, the patients reported changes occurred after treatment, and not only physical. These changes led them to rethink their own lives, their priorities, their values, their spirituality, their relationships, as well as their own illness. With the experience of the treatment, his vision on the diagnosis was modified.

Regarding the professionals' view on cancer, with the passing of their performance, it was observed that, for the most part, they were modified, through the acquisition of new knowledge regarding the disease, the treatment, which they had to seek to deal with the challenges of practice. The others who did not show the same result stated that they experienced the illness of a deceased entity, as well as of patients with whom they lived, which led them to believe that cancer really is something devastating, where some can win, and so many dies.

Finally, it is necessary to highlight the importance of psychology in the process of communication and follow-up of the diagnosis of patients. The perspective of this science allows a more humanized support and care, bringing positive consequences to the patients and professionals involved.

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