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CHEMOTHERAPY PATIENT PERCEPTION REGARDING COMMUNICATION WITH THE HEALTHCARE STAFF

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Abstract

Purpose: To qualitatively explore the communication between healthcare professionals and oncology patients based on the perception of patients undergoing chemotherapy.

Method: Qualitative and exploratory design. Participants were 14 adult patients undergoing chemotherapy at different stages of the disease. A socio-demographic and clinical data form was utilized along with semi-structured interviews. The interviews were audio-recorded, transcribed and content analysis was performed. Two independent judges evaluated the interview content in regards to emerging categories and obtained a Kappa index of 0.834.

Results: Three categories emerged from the data: 1) Technical communication without emotional support, in which the information provided is composed of strictly technical information regarding the diagnosis, treatment and/or prognosis; 2) Technical communication, in which the information provided is oriented towards the technical aspects of the patient's physical condition, while also providing psychological support for the patients' subjective needs; and 3) Insufficient technical communication, win which there are gaps in the information provided causing confusion and suffering to the patient.

Conclusions: Communication with emotional support contributes to greater satisfaction of chemotherapy patients. Practical implications: the results provide elements for the

Resumen

Objetivo: explorar cualitativamente la comunicación entre profesionales sanitarios y pacientes con cáncer a partir de la percepción de los pacientes en tratamiento de quimioterapia.

Método: diseño cualitativo y exploratorio. Participantes fueron 14 pacientes adultos con cáncer en quimioterapia en diferentes fases de la enfermedad. Los instrumentos utilizados fueron un protocolo de dato sociodemográficos y clínicos y una entrevista semi-estructurada. Las entrevistas fueron grabadas, transcritas, y fue realizado análisis de contenido. Dos jueces independientes evaluaron el contenido de las entrevistas a partir de las categorías que aparecieron, y fue calculado el índice Kappa de 0,834.

Resultados: Tres categorías fueron creadas a partir de los datos: 1) Comunicación técnica sin apoyo emocional, cuando la información dada es compuesta de forma estricta a las informaciones técnicas del diagnóstico, tratamiento y/o pronóstico; 2) Comunicación técnica, cuando la información está orientada a los aspectos técnicos de la condición física del paciente, mientras también es ofrecido apoyo emocional de acuerdo con las necesidades de los pacientes; y 3) Comunicación técnica insuficiente, cuando hay problemas en la información ofrecida y que causa confusión y sufrimiento al paciente.

Conclusiones: comunicación con apoyo emocional contribuye para aumentar la sa-

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training of healthcare professionals regarding the importance of the emotional support that can be offered to cancer patients during their treatment.

Keywords: Oncology, communication, health provider-patient relationship.

tisfacción de pacientes en quimioterapia. Implicaciones practicas: los resultados fornecen elementos para la capacitación de profesionales sanitarios relacionados a la importancia del apoyo emocional que puede ser ofrecido a pacientes con cáncer durante su tratamiento.

Palabras clave: Oncología; comunicación; relación profesional sanitario-paciente.

INTRODUCTION

The provider-patient communication in the cancer context can be considered one of the main aspects of providing this type of healthcare. The effectiveness of communication involves providing technical and accurate information (i.e. discussing test results and clinical procedures), discussing disease severity (i.e. stage) and the treatment plan (i.e. surgery, chemotherapy, radiotherapy)[1]. The concept of communication can be characterized by any means by which information is transmitted, including that which supports this process, as well as the respective situational inter-relations[2]. The main objectives of the provider-patient communication are to create a good interpersonal relationship, to exchange information and to include the patient in decision making process[3-5].

The content of the information should be informative, supportive, constructive and positive. This information is multidimensional and involves what takes place in the provider-patient interaction, including the content of the dialogue, verbal behavior, nonverbal behavior and the affective component[6].

There are many emerging themes related to provider-patient communication[7], which are more specifically focused on communication skills[7], which includes research topics such as shared decision-making[8]; shared knowledge[9]; patient-centered cancer care[10]; patient preferences[11] and breaking bad news[12]. Despite representing distinct terminologies, all of them include the description of the communication skills needed by healthcare providers in order to effectively communicate with their patients[13-15].

Shared decision-making includes presenting to the patient, treatment options based on high quality information so that the patient may take an active role in the respective care provided. Decision-making involves the patient's consent to decide on therapeutic approaches following diagnosis[7]. Shared knowledge includes the ability of the provider to provide information in a technical manner, while transmitting and sharing his or her knowledge about cancer with the patients, in order to provide guidance from the technical perspective so that the patient has greater ownership of the treatment. In addition, providers should consider the patient as a whole (biopsychosocial) based on their lifestyle, culture, family and behavior, in correlation with becoming ill with cancer[12,16,17].

Patient-centered cancer care involves aspects related to the provider-patient communication and relationship characterized by trust, good relationships, respect and mutual understanding, which serves to promote the patient's well-being[12]. In addition to clinical and therapeutic procedures adopted for appropriate treatment, the providers should offer guidance

on aspects of the disease and emotional support. There is a positive relationship between the quality of patient-provider communication and outcomes such as satisfaction with treatment, emotional health, symptom management, treatment compliance, difficulties with comprehension and retention of the information transmitted, as well as better transition of patients from curative to palliative treatment along with reduced oncologist burnout rates(18). Patient-centered communication is one of the basic ingredients of a quality provider-patient relationship[19,20].

This communication encompasses the patient's preferences considering their cognitive and emotional aspects both in terms of communicating the diagnosis as well as the treatment planning[12]. It is known that the diagnosis communication depends on the provider's communication skills when reporting bad news. The term bad news refers to any patient information that implies a negative change to the patient's life[21]. The communication of bad news involves the discussing the prognosis and decision-making regarding therapies that serve to ensure the patient's well-being[9,22].

With the above providing the background, the objective of this study was to explore the communication between healthcare professionals and oncology patients, based on the perception of patients during chemotherapy.

METHODS

Study setting and participant recruitment

Participants were recruited from a hospital specializing in cancer treatment. These participants were invited (face to face) to participate while undergoing outpatient chemotherapy. The nursing staff indicated cases of patients who were pain free and sufficiently lucid to participate in the study. Thus, the selection of the participants was conducted by way of the convenience method and the number of interviews was defined by the criterion of theoretical saturation (no new themes were identified during initial analysis)[23].

Participants were 14 cancer patients undergoing chemotherapy (mean age=52.36 years, SD=13.09), of which eight were men and ten were married. Regarding cancer types: intestine/colon/rectum (8), gynecological (3), testicle (1), melanoma (1) and stomach/esophagus (1). Half of the patients had metastatic cancer. Besides chemotherapy, eight patients had undergone surgery and three had undergone radiation therapy.

Data collection

The project was approved by the Research Ethics Committee. Informed Consent was obtained among those eligible and agreeing to participate. Participants voluntarily participated in this study and received no compensation. Only one patient that was invited refused to participate. All interviews were audio-recorded and transcribed. Individual (face-to-face) interviews were conducted lasting about 20 minutes, while the chemotherapy was being administered. All interviews were conducted by the same person using a semi-structured interview guide. The interview was concerned with the overall provider-patient relationship, of which the communication was examined in the context of oncology. The guiding questions were about: emotional distress, importance of the healthcare staff in the treatment, communicating the diagnosis and the provider-patient relationship.

Data Analysis

Qualitative content analysis was performed to analyze the data from the interviews. Audio-recordings were listened to and the transcripts reads several times

in order to identify emerging themes. The analysis consisted of four steps: 1) initial nonjudgmental reading *("naive")*; 2) structural analysis; 3) categorization; and 4)critical interpretation[24,25]. The first two authors developed a preliminary coding scheme early in the analysis process and based on the discussion with the other two authors, revised it using an iterative process. The critical interpretation consisted of reorganizing the data into categories which served to answer the research question and establish conclusions.

Two independent judges evaluated the relevance of the interview content in relation to the emerging categories. The degree of agreement between the judges was assessed (Cohen's Kappa coefficient=0.834), indicating excellent agreement[18].

RESULTS AND DISCUSSION

Content Analysis

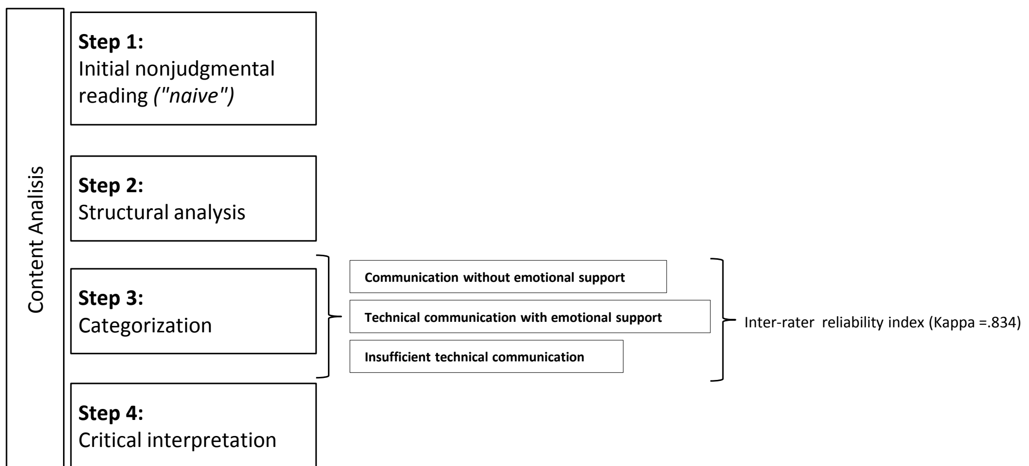
The systematization of the data made it possible identify three emerging categories related to communication: *Technical Communication Without Emotional Support, Technical Communication With Emotional Support and Insufficient Technical Communication*. The categories were defined *retrospectively* based on the patients' reports. The content analysis diagram shows the stages of the categorization process (Figure 1).

Technical Communication without Emotional Support

Type of information provided by any member of the staff to the patient about diagnosis, treatment and / or prognosis in a technical manner (professional), oriented towards procedures for evaluating the physical condition of the patient. Communication with the doctor, specifically, was directed towards the technical and morphological aspects of the cancer. The reports from the interviews showed that the communication was devoid of support for the patients' subjective aspects.

> *"When the doctor showed me the pictures of the polyps, I was like well, I became... I already suspected something, it had an ugly appearance, and the doctor said: This here is what we have to operate on, it has to be cut in order to see"* Patient#3.

Figure 1. **Content Analysis Diagram**



Some patients have reported that there was lack of sensitivity on behalf of the provider when talking about the severity of the cancer. This complaint is common in oncology, as the provider's attention is usually focused on clinical aspects of the disease, without integrating them with the psychological and social aspects of the patient[26,27]. Breaking bad news such as, for example, the appearance of nodules and polyps in test results, may represent an experience of extreme emotional impact for the patient[28]. It is necessary for providers to know how and how not to address this type of unpleasant news, so that it is less impacting and provides more space for the patient to ask questions about how, why, where and when the malignancy appeared[29].

Healthcare providers often find themselves powerless in the face of the limited capability they have to cure certain cancers. They may feel uncertain about how to report the severity of the disease and unprepared to deal with the suffering of the patients[30]. Effective patient-centered communication during the consultation primarily includes the aspects of the provider's affective quality, which may be reflected in the patient's increased quality of life and satisfaction[31].

In oncology, difficult news is constantly passed on to patients. Especially in the initial phase of treatment, patients require from the oncologist the development of skills aimed at communicating the diagnosis and prognosis[32]. The moment of being diagnosed with cancer was identified by patients as being a time of great emotional impact, which generated uncertainties. The direct, clear and objective manner in which the provider provides the information regarding the diagnosis of cancer appears to be represented by technical communication without emotional support. Some patients have reported that, despite the impact of the diagnosis and the negative feelings they held regarding the doctor's communication of the disease, they still considered his or her conduct to be appropriate. Regarding the lack of emotional support, some patients reported that, when receiving the diagnosis, the providers could have shown concern about their emotional reactions, along with the technical information about the disease and treatment guidelines:

> *"She (provider) came and said to me: 'Yeah, you really do have pneumonia, with a small pleural effusion. But you also have cancer'. Just like that, she dropped the bomb. So, I thought it was very inconsiderate. Without caring, without consideration, without anything, when giving this news."* Patient#2.

Chemotherapy can be considered the longest period of the process of becoming ill and treating the cancer[26]. At this stage, patients are exposed to different interventions and clinical procedures that are often invasive, mutilating and painful[33,34]. Even when there is little chance of cure, the patient should be advised regarding the treatment to be performed. Palliative chemotherapy should bring benefits to the patients and improve their quality of life[37]. It was noted that the information on the adverse effects of chemotherapy and the guidance on therapeutic procedures was rendered in an extremely technical manner. This communication was devoid of support for the subjective aspects of the patient, their needs and preferences in relation to the treatment:

> *"In this case he (provider) said: 'The intestine does not kill you, but the liver kills.' He made it very clear. This is also a good thing. But at the same time he said: 'Let's treat it'. Because then the person thinks: 'Whoa, if he says he will treat me, then I have a chance"* Patient#8.

Technical Communication with Emotional Support

Includes information provided oriented towards the technical aspects of the physical assessment of the patient while providing psychological support. Emotional support can be characterized by the provider's concern for the psychological well-being of the patient and the variables that may be associated with quality of care. Emotional support, in this case, includes the willingness of the provider to provide guidelines for problem solving and counseling the patient in regards to his or her concerns, including but not limited to the physical aspect, as it pertains to their well-being.

As for the reports analyzed, it was found that the provider's communication during the investigation of the possible diagnosis of cancer was positive from the perspective of certain patients. In this type of positive communication, when providing the information, the provider reassured the patient with respect to the therapeutic possibilities. It was also shown that effective patient-centered communication, promoted patient care in terms of the emotional aspects of the patients and contributed to a greater understanding of the cancer and the respective coping:

> "He *(provider) reassured me. He explained in detail how it would work, what the symptoms are, what we would do. That there was a cure, that it was one of the only lung metastases that has a cure. That I would be 100% cured."* Patient#1.

For the patients, the emotional support was felt when the professional reassured the patient about the prognosis, possibilities of cure and treatment, while ensuring that the best treatment would be utilized. Patients perceived more effective communication when the providers allowed them to be more active in the treatment, being more willing to establish a patient-centered communication.

Communication that facilitates the process, which includes active listening, is related to patient-centered communication and is reflected in the quality of care received. This differentiated listening is due to the fact that often the patient feels that communication of the diagnosis generates great emotional impact[35]. Communication with good interpersonal interaction on the behalf of the provider with the patient indicates better outcomes regarding the window of opportunity for the patient and sharing the responsibility of the treatment aimed at better health outcomes. Healthcare providers need contemplate each patient's needs in terms of information, thereby providing individualized support as a result[36].

Patients reported that in addition to the technical information, the provider offered some sort of emotional support that were demonstrated by feelings of support, trust, expectation of cure, care, concern for the well-being and quality of life during the consultation. This support was important even when the content of the communication was bad or was not to the patient's liking:

> *"Then, just as I arrived, the doctor also gave me the diagnosis, in a realistic manner. At the same time, he cared about my well-being, when he said: 'No, we will treat you so that you will have a better quality of life"* Patient#8.

The reports show the need for support, to face the diagnosis of cancer. Thus, some communication strategies can be considered positive when communicating the diagnosis, such as: the use of the word cancer, sincere communication, clarity of information, providing written information and the willingness of the professional to

talk about emotional aspects, which can reduce levels of anxiety and depression. When providers discuss information with patients regarding the severity of the cancer, prognosis and life expectancy, satisfaction levels increase[37].

During treatment, the relations established with the healthcare staff are amplified, as professionals from different fields meet with the patient when needed and upon the doctor's request. The quality of the healthcare staff's communication with the patient supports his or her needs, conveying confidence, safety and optimism when considering the types of treatment for each patient:

> *"The personnel (staff) always try, lift our spirits. 'Look, let's do it. Such treatment is going to work ', showing the high expectations that we have. Soon, you will have surgery and you will be able to get back to doing your things, soon you will not be able to do a certain activity. Always, always talking about the reality of the moment, of the situation"* Patient#3.

Patients with different informational needs may have the same need to establish a relationship of trust with the staff. An effective communication is important during the guidance consultations with the patient and for a response to the chemotherapy[45]. Patients perceived that the professional team sought to establish an assertive communication during the treatment phase, at a time when the patients demanded more from a psychological point of view, as a result of the uncertainties of the therapeutic effects and the expectations for curing the cancer. The providers have more contact with the patient at this stage since the treatment process can take years and consultations are periodic, with the same staff. We noted in the reports of the interviews, that the patients felt more confident and supported when the providers established bonds, and showed interest in how their physical and psychological health is (eg. How do you feel, how are you dealing with the treatment), especially in the case of the nursing staff.

Patients also reported that the presence of different healthcare professionals on the staff provides a greater sense of care. The perception of care and well-being was associated with the technical communication with emotional support:

> *"So the importance, therefore, of a provider that alerts you for what you will go through, the needs that you will have, that is what I think is very important. It's the guy who will give you the support that you need. I will tell you: 'You will go through this. " Or 'Do not worry about that. You don't need not worry about this, because it is not for you '."* Patient#12.

The patients emphasized the importance of communication with emotional support offered by the nursing staff, which simultaneously with the technical work provided consoling and listening. These characteristics of the outpatient clinic nurses assume the establishment of a bond that favored the interaction with patients. Communication skills need to be exercised by the multidisciplinary staff, in order to articulate an effective patient-centered communication together with the emotional issues related with the cancer, considering that the sense of well-being and care increase[16,38,39].

During chemotherapy, patients reported that adherence to treatment increased when communication the provided by the provider included support, hope, life expectancy and care during treatment. However, the providers were not always capable of balancing the hope with the reality while discussing the prognosis[40]. Thus, some patients reported that the staff

of the chemotherapy outpatient clinic were available to hear doubts and anxieties regarding the disease and the therapies and offer answers, with the objective being to provide guidance:

> *"What are my chances of being cured? The chance was small because it was a severe case of cancer. But the doctor said: 'As long as you are with me, you have a 100% chance. Because I will try to the end. I will not give up on you. You have a 100% chance of being cured. ' I think this posture with the patient, to give confidence, can be difficult, but we will treat it. I think the compliance with treatment, is much higher* "Patient#12.

It is important that the team realizes the importance of communicating the truth while it conveys optimism and affection. In this sense, effective communication between the professional and the patient demonstrates the provider's ability to be empathetic, understanding, and have compassion for the patient's disease status during his or her chemotherapy. Therefore, it is necessary for the providers to be concerned with providing a welcoming environment in order to motivate the patients to continue on with treatment and cope with the disease. These characteristics of oncology professionals can help make the treatment process less daunting for the patient(14).

Insufficient Technical Communication

This category encompasses gaps in the patient's understanding of the information. The content of the information is incomplete and the patient does not understand what he or she was told, has doubts and feels insecure.

At a certain point in the investigative phase of the disease, the patients realized that communication about the disease was insufficient, as it caused discomfort and dissatisfaction with the information given. The investigative period of the disease was considered to have insufficient technical communication when the professional did not seem to recognize the needs of patients whom at that time, were under extreme distress enhanced by pain and debilitating physical symptoms:

> *"And I said to the Doctor: Doctor, I am bleeding continuously, the whole day. Give me a medication, something, for God's sake. I cannot take it anymore. And she said: 'No, we have to wait for the immunohistochemistry'* "Patient#1.

The flaws in the communication process regarding the diagnosis for some patients also caused more emotional distress. The doctor had an attitude that was inappropriate considering the needs of the patient, demonstrating weakness and a certain insensitivity to the emotional aspects of the patient, with little empathy:

> *"The doctor told me: 'Everything with pulmonary adenocarcinoma'. You may have to operate. The more he talked, the more I cried, the less I understood what he was talking about*" Patient#2.

Healthcare providers have been identified as the main source of information regarding the cancer treatment. However, oncologists have been reported as being least satisfactory source of information regarding the patients' perception(41). Much of the dissatisfaction with the treatment relates to communication failures in relation to the patients' unmet needs. These needs involve external factors such as the exchange of information during the consultation, shared decision-making about treatment, clear information about the prognosis, and personal factors such as expectations, motivations, hope and trust

which need to be optimized by the providers of the cancer care[1].

Dissatisfaction and the discomfort felt by patients are related to the ineffective communication with the provider, who does not offer to listen to the suffering of the patient, making the provider-patient relationship difficult[29,40]. Failures in providing information were identified when the information provided was not sufficient regarding the therapies. In addition, based on the reports of patients, some professionals kept a certain emotional distance from the illness.

> *"The doctor is the most important. And I do not feel this importance very much, you know? Do you understand? I have not feel this much at all. The treatment here is distant, things are a bit cold around here."* Patient#3.

The lack of effective communication between the team can prolong treatment, or even hinder the actions of the providers with the patient care[42]. When the needs in regards to the care provided are not met, they reverberate negatively and cause emotional distress. To the extent that the providers not only meet the physical needs, but also provide emotional support to the patients, the communication failures decrease[40].

Cancer patients have shown interest in information about their medical condition (good or poor prognosis) and also wish to be involved in the decision making. After all, providers should consider the process of shared decision-making in order to increase the quality of patient care[43]. The major challenge faced by oncology professionals is to inform the benefits and possible risks caused by the treatment, without imposing his or her own clinical agenda[44]. The assertiveness of cancer treatment involves the provider's agility in identifying the problem and then schedule the therapeutic procedures with the patient. In this sense, when failures in the providing of information occurs, patients are at risk and their pain and suffering are increased as a result of not being treated properly.

CONCLUSION

The results obtained, allow for a greater awareness surrounding the phenomenon of provider-patient communication. From the perception of patients undergoing chemotherapy, the *Technical Communication With Emotional Support* demonstrated the greatest potential for ensuring the quality of the provider-patient interaction with respect to the communicational aspects in oncology.

When the technical information provided is accompanied by shared decision-making, active listening, recognizing the patient's preferences, respecting their decisions and understanding of the subjective needs when faced with the emotional suffering caused by cancer, communication tends to be more effective. The patient-centered communication results in them feeling valued as a person, they perceive that their subjective aspects are being recognized and become more confident when coping with the disease. From the perspective of the patients, honesty and providing hope are central characteristics, necessary for the assertive communication on behalf of the providers. More negative perceptions regarding communication with the providers were related to failures in information exchange, emotional detachment and lack of interest in the aspects of the life of the patient.

The failures in communication are generally observed in *Technical Communication without Emotional Support and Insufficient Technical Communication*. Patients diagnosed with cancer tend to project many expectations on to the providers as per how the care should be provided, due to the severity of symptoms, the uncertainty regarding the treatment and

intense fear of death. We observed the vulnerability of the patients in relation to the content of the communication when being diagnosed with cancer. Often, insufficient communication can enhance feelings of hopelessness, abandonment, fear of death and anguish when faced with the lack of knowledge about how to approach the cancer.

It should be noted that assertive communication in oncology is considered a clinical skill. In this sense, the training of communication skills can resolve failures in the transmission of information, permitting the professional to identify the emotional needs of the patient beyond the physical. In addition, it is possible to teach them how to deal with certain difficult situations, such as breaking bad news, such as in the case of relapse, disease progression, side effects of treatment, metastasis and palliative care.

Our findings support the need for the healthcare staff in oncology to maintain effective communication and provide emotional support to the patient. The results provide important elements for understanding how communication can facilitate or hinder the patient's well-being. In this sense, it shows the need and provides elements for the training of healthcare professionals regarding the importance of the emotional support that can be offered to cancer patients during their treatment.

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