

Meios de comunicação utilizados pelos pacientes: informações sobre o câncer após o diagnóstico e durante o tratamento

Means of communication used by patients: information about cancer after diagnosis and during treatment

Medios de comunicación utilizados por los pacientes: informaciones acerca del cáncer después del diagnóstico y durante el tratamiento

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ABSTRACT

Objective: to identify the media used by patients to obtain information about cancer after diagnosis and during treatment. **Method:** descriptive qualitative research conducted in a philanthropic hospital in the state of Paraná, Brazil; data were collected at the inpatient oncology unit and the outpatient oncology ward. **Results:** the findings were divided into four categories; information obtained by health professionals; information obtained from the internet; information obtained through friends and oncology patients; and information obtained through the print and audiovisual media. **Conclusion:** the main media used by respondents to obtain information were the printed and audiovisual media, the internet, friends and patients with the same diagnosis, and health professionals.

Descriptors: media; oncologic nursing; oncology; cancer.

RESUMO

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Objetivo: identificar os meios de comunicação utilizados pelos pacientes para obter informações sobre o câncer após o diagnóstico e durante o tratamento. **Método:** pesquisa qualitativa descritiva realizada em um hospital filantrópico no Paraná. Os dados foram coletados na unidade de internamento e no ambulatório de oncologia. **Resultados:** estruturadas quatro categorias; informações técnicas dos profissionais da saúde; a internet como meio de obtenção de informações e apoio; informações obtidas com pacientes oncológicos; e informações obtidas por meio da mídia impressa e audiovisual. **Conclusão:** os principais meios de comunicação utilizados pelos entrevistados para obter informação foram a mídia impressa e audiovisual, a internet, amigos e pacientes com o mesmo diagnóstico, e profissionais da saúde.

Descritores: meios de comunicação; enfermagem oncológica; oncologia; câncer.

RESUMEN

Objetivo: identificar los medios de comunicación utilizados por los pacientes para obtener informaciones acerca del cáncer después del diagnóstico y durante el tratamiento. **Método:** investigación cualitativa descriptiva realizada en un hospital filantrópico en el estado de Paraná, Brasil; los datos fueron recogidos en la unidad de hospitalización en oncología y en el ambulatorio de oncología. **Resultados:** los hallazgos fueron subdivididos en cuatro categorías; informaciones obtenidas por medio de profesionales de la salud; informaciones obtenidas en la internet; informaciones obtenidas por medio de amigos y pacientes oncológicos; e informaciones obtenidas a través de los medios impresos y audiovisuales.

Conclusión: los principales medios de comunicación utilizados por los encuestados para obtener información fueron medios impresos y audiovisuales, internet, amigos y pacientes con el mismo diagnóstico, y profesionales de la salud.

Descriptor: medios de comunicación; enfermería oncológica; oncología; cáncer.

INTRODUCTION

Communication is a process of understanding and sharing information that influence the behavior of people involved in course of time; being essential for caring procedures. The various forms of communication occupy a significant humanizing role, and for this, the health team must be willing and engaged to establish a relationship with the understanding that the subject is active in the caring process.¹

Complementing this thought, it is emphasized that every individual practices and maintains relationships with other individuals in their daily lives. These relationships are established when there is benefit or need to reach goals.²

Healthcare professionals provide for patients information about their condition and treatment, secondary prevention and possible complications. This information may occur through the interpersonal relationship and/or by different means such as brochures, pamphlets and, more recently, computer resources. Information technologies are present in several fields of human activity, including the area of health. In this context, the widespread use of the internet

has provided a sharp increase in access to information, with benefits to the patient's health education.³

The access to technical and scientific information, combined with the increase in the educational level of the population, is reflected in the individuals who seek the information before going to a health care professional first. Thus, the patient gets previous notions, true or not, about the diagnosis and treatment.⁴

With the increased availability of information, especially through the internet, a change in the conduct of health professionals is necessary to deal with those patients taking a more open attitude, able to work the information found by patients and indicate more reliable sources - thus leaving the old authoritarian posture.³ Therefore, with the advances in information and communication technology, the production and dissemination of knowledge among individuals is getting increasingly fast.²

Supporting this idea, it is emphasized that internet users say that before and after consultation with a health professional they seek more information about health and disease through technology.⁵ Such an attitude may contribute to the establishment of a communication link and exchange of information between the health professional and the patient - searching for a better decision about the treatment and a critical discussion of the diagnosis and, ultimately, to increase the acquisition of information about the patient's diagnosis.

Thus, research on the media used by patients diagnosed with cancer and in a cancer treatment is justified by the complexity of the disease and treatment.

Given the above, the main aim of this study is to identify the means of communication used by patients to obtain information related to cancer after diagnosis and during treatment. To meet the goal, we outlined the following question: "What are the media used by patients to obtain information related to cancer after diagnosis and during treatment?"

METHODS

This is a qualitative research, carried out in a philanthropic hospital in the state of Parana. Data were collected in the inpatient unit in oncology and outpatient center of oncology and chemotherapy.

The study began after approval by the Research Ethics Committee of the institution under study, under the CAAE 0457291290000103. The inclusion criteria of the study for participants were: patients of both sexes aware of their situation, diagnosed with cancer and in cancer treatment, aged between 18 and 65 years-old and those who agreed to take part in the study through the Informed Consent signature.

The study included ten participants. Data were collected through a recorded semi-structured interview, which contained six open questions. Participation occurred in the

period of treatment, according to the patients' schedule, so as not to damage their routine and health sector routine.

Given the recommendations of Resolution CNS in 466/12,⁶ the participants' identity was kept in secret: they are indicated by the respondent term and numbered from 1 to 10.

The answers were recorded and transcribed for analysis. For the analysis of the data we used the technique of Bardin Content Analysis,⁷ with three phases: the pre-analysis, when it was collected all the material taken in the field research and recorded interviews were transcribed; exploration of the material, when the material was read and reread and the categories of the study structured; and the inference and understanding, when the data were related to the theoretical framework of the research, seeking an answer to the main question.

RESULTS

Technical information of healthcare professionals

The subjects highlighted that health professionals have acted as major facilitators to convey information about the disease, especially the doctor, who came to prominence in the transmission of information about the diagnosis and also during treatment. The statement below shows the above:

It's only the doctor who gives us information, right? At first I had a lot of questions, because it is a disease that you're worried, right? It messes with your psychological structure. But then, over time, you will talk to the doctor and he will reassure you. (Interviewee 8)

But the narratives that stand out also revealed some challenges in communicating with health professionals. Based on this idea, the narratives below illustrate these challenges, such as: lack of communication between professionals; how to convey the information to patients; and sometimes, the fact that the professional does not talk much about the disease:

Well, maybe the doctor could talk to me more frequently, right? They don't talk with me a lot. They do not talk a lot about the disease. It's better for treatment. (Interviewee 7)

A very negative point was the INSS expert. You get there with the diagnosis and he says: "You have only a cancer." And I had the surgery and he looks you in the corner and says that there isn't cure. I think he should not say that. Who had to say that is who made the surgery because it was him who knew it would or would not cure. Someone says that there is cure and now the other comes in and says that there is not. (Interviewee 5)

The internet as a means of obtaining

information and support

In the interviews conducted the internet stood as a means of obtaining information about the disease and treatment. Permeating the use of the internet to search for information, there are issues such as: the curiosity about the disease; the need to verify the adequacy of the proposed treatment; the help of family and friends on internet searches; the support of others during treatment; and the desire to acquire more knowledge about the disease. In the statement below, the subject highlights the use of the internet as a tool to get information about the diagnosis and treatment of cancer.

I access Facebook a lot, I stay there for research. I've even been stalking Gianecchini. But on Facebook it is good! At least they give support, right? (Interviewee 5)

However, it is noteworthy that many participants still do not have internet access, while living in an era considered digital. Era in which the community is constantly looking for information on the electronic network. This fact is indicated in the statements below:

I am an Internet illiterate. (Interviewee 3)

I do not have internet access, because we live in the country. (Interviewee 1)

In the narratives of the participants some difficulties were observed related to using the internet as a means of obtaining information about the disease. Among these difficulties it's important to highlight the fact that some people do not know which website to search and doubt about the reliability of information available and the very email address. The sections below illustrate this idea.

It's frustrating because you have a lot of information on the internet. So you have to know from where that information comes and you are never sure whether it is positive or negative. If it is really a person who is giving accurate and valid information or it's a crazy person. You get the information, but it is never accurate. (Interviewee 9)

On Google, you type what you think is right. I, in this case, use to type: "breast cancer"; typed like this: "what I could eat." You have so much information! Hence, many pages pose that you cannot eat anything and then other pages say that you can eat it all. You get confused. (Interviewee 9)

There is a negative point in this diversity of information. Maybe they should be clearer as well: this information is for the patient! And this information is for the doctor!

You see? (Interviewee 9)

Information obtained with cancer patients

In this category it was evidenced that the subjects seek information about the disease and treatment with individuals with similar diagnosis, as shown in the statements below:

[...] A woman, who was hospitalized with me, had a sister who had suffered cancer also in the same place [...]. She told me a lot about the treatment, gave me enough strength and information. She said it was not so scary; it was just to follow the treatment rightly. (Interviewee 2)

In this context, it is observed in the speeches below that the information from the network patients with the same diagnosis have influenced sometimes positively and/or negatively:

Sometimes when I arrived for chemotherapy, the women said: "This red serum is what causes falling hair ..." I said: "I do not want to know... I think that if you have a person in your family that couldn't stand treatment you do not need to say anything, right? Because it leads us down. (Interviewee 2)

Information obtained through the print and audiovisual media

In successive narratives presented by the patients, it was found that the subjects also used as a means of information the printed and audiovisual media to get information about their disease, as indicated in the statements below:

On television, when there is something about cancer, I try to watch it. (Interviewee 5)

I saw a lot on magazines, right? I always read a magazine about this issue, because I had an example of several people who have been through and overcome it, right? Then, if they had success, with faith in God you can also get it, right? [...] Newspaper, all that we seek, all we had seen about that subject it interested us, right? (Interviewee 8)

In this scenario, patients seeking information in print and audiovisual media relate the news with their reality, especially when using examples of individuals who may be considered "celebrities":

I was watching on television when they were speaking about Lula and Gianecchini, I paid attention ... (Interviewee 2)

I was interested in observing on television what celebrity had developed cancer. (Interviewee 3)

Information acquired by patients in the print and audiovisual media can have positive and negative impacts, as seen in the following statement:

On the magazine, I read an article about this medicine that I take, which is the Herceptin, and my doctor had said that it is the last release, so that it is expensive, right? Wow, that's great, perfect, wonderful... Then I picked up this magazine and started reading an interview about Herceptin, and it said that this is a test, they were still testing the drug to see what would be the effect of it. So that good hope that she'd given me, the magazine destroyed everything. (Interviewee 9)

DISCUSSION

In the first category, which refers to the search for information about the disease and treatment with healthcare professionals, it is important to note that the multidisciplinary team provides assistance and support to assist the individual in all stages of cancer treatment.

According to the narratives of the participants, it is emphasized that effective communication is essential between all the multidisciplinary team and the patient. Among the various compositions of the multidisciplinary team, it emphasizes the importance of effective communication for the nursing staff, since they spend much time with the patient and have great importance in the flow of information.

Because of that, this team should develop a more conscious style of communicating with patients and caregivers in order to improve health outcomes and satisfaction.⁸ It is worth noting that this attitude confirms the improvement of self-care and care in general - what is very important in the case of cancer therapy.

Thus, it is understood that communication is a skill that can and should be developed in the process of training of health professionals. But it is important to develop various forms of communication, including nonverbal communication, which can allow the expansion of health-related activities for a promotional perspective.⁹

Communication is also part of the care process in nursing and as evidenced in the narratives, it is important to coordinate actions for better communication of the nursing staff with oncology patients, since they do not have referred the nursing staff as a key piece in transmission information about the disease and treatment.

Verbal communication is still the most used type of communication employed by nursing professionals during the workday,^{1,10} thus it encourages the importance of emphasizing its use in service to cancer patients and at all stages during the service - practice that can be optimized by the use of systematization of nursing assistance.¹¹

The relationship between nurse and patient at the time of disclosure of diagnosis and prognosis is essential for the patient to face a new reality. Knowing that nursing professionals are present to assist their therapeutic steps contributes towards disease coping.

Just transmitting information about the disease for the patient is not satisfactory; it is necessary that the professional knows how to pass this information and assign the appropriate value to communication, so that we can create a bond between both.¹²

In this sense, it is important to think about the need for a multidisciplinary team, that is, the doctor¹³ is not the only one to talk to the patient and family in the sense of answering questions about the disease, about the course of treatment and prognosis; the lack of clarity of such information may cause distress, refused treatment, morbidity increase, among other health problems.

In the second category, regarding the search for information through the internet, advances in information and communication technologies have transformed the economic, social and cultural life of society, facilitating the lives of people with computers - and with access to internet - and facilitating the access to information.³ Thus, the internet became a widely used tool for patients.

The radio, television and the internet cause changes and revolutions. However, the internet cannot be recognized only as a means by which the message flows, once it also allows the interaction and the construction of new contents.²

Access to technical and scientific information, combined with the higher educational level of the population, has contributed to the rising of a patient posture towards seeking information about diseases, symptoms, medicine, hospitalization, and treatment costs. The health sector is increasing the availability of information, especially on internet.⁴

Although most part of the population consists of individuals considered 'digitally excluded', the amount of information, public and private, available on the internet is increasing because the internet is not expensive compared to other traditional means. Thus, for some time the internet has turned into a concentrator source of information, with an emphasis on the dynamic and simple way to use it.²

In this scenario, changing the way through which information is provided figures as a major cause for fostering changes in the relationship between health professionals and health service users.

Thus, the use of the internet as a source of health information became increasingly popular. Health professionals should verify that their patients use this feature to recognize this change in behavior, and prepare not only to discuss such information with the patient, but also to suggest websites with reliable information - helping them to evaluate the quality of the information available on web.³

In addition, the information found on the internet can be incomplete, contradictory, inaccurate or even fraudulent,

resulting in negative impacts on the relationship between health professionals and patients. It is necessary to point out the risks of self-treatment by the patient, which is based only on the internet sources without a medical guidance.⁴

Patients and families turn to the internet to understand or to complement the medical consultation, in order to exercise their autonomy and better understand the treatment. It is believed that much of the information available on the internet are useful to the patient, however, it is vital that health professionals assist in patients' research so they won't be guided through inadequate information about treatment - these information can lead patients to not adopt or to leave a more effective therapeutic.⁵ Nursing professionals can help in this regard.

In category three, referring to the search of information obtained from cancer patients, and to the proximity of the subject with others who have undergone or are going through the same problem - what facilitates adaptation to their condition. In this scenario, it is important to understand that the patient seeks information on network of friends and patients who also had a diagnosis of cancer.

Regarding the search for information about the disease, it allows the individual to actively participate in decision-making, enabling him to understand the challenges involved in cancer treatment, to know the types of treatment, and to identify alternatives and their consequences. Thus, the information is considered a source of security and control that favors the active participation of the patient in his care.¹⁴

Thus, the search for information with others who are in cancer treatment is considered important in fighting the disease, characterized as a social support for the patient. However, this information can have a positive or negative effect on the patient.

In relation to its positive impact, social support can significantly promote beneficial aspects in disease situation, increasing the will to live and self-esteem of the patient, thereby relieving the pathogenic effects of stress in the body - increasing the ability of people to cope with difficult situations and contributing to the success of treatment.

It should be noted that this way of acquiring information is still supported and can be considered a coping strategy against the disease and treatment; especially those related to family relationship.¹⁵

Enhancing the reflection on the theme, negative representations about cancer influence the evolution of the disease; posing as mandatory taking both the negative and the positive representations into account.

In the fourth category, regarding the search for information in print and audiovisual media, it should be noted that for some news to have an impact on the population, the public must identify with the situation and relate it to their own reality.¹⁶ The media cover topics related to the daily lives of people, aiming proximity summarized in the feelings of belonging and identity, and everyday links in order to gain acceptance of receptors.¹⁷

In the scenario showed by the interviews positives and negatives aspects are found in the search for information by patients. It is the challenge of reconciling information from different media and to ensure that they are beneficial to the recipients.

In this context, it is believed that addressing health issues on TV media can figure as an effective mechanism for informing the public, by virtue of their great reach.¹³ On the other hand, this kind of communication related to health can cause viewers to receive improper or inadequate information without a critical analysis - being open to interpretation that may result in risks to the health of patients with certain diseases.

CONCLUSION

This study collected data that indicate the need for improvement in the use of media by patients diagnosed with cancer who seek for information about their disease.

Regarding the information obtained by the health professionals, subjects indicated the doctor as the primary information source; other health professionals are seen as sources that complement the medical information. In this scenario, there is a challenge to systematize nursing care focused on cancer patients, so the empowerment of nurses should be enhanced and the quality of care improved, which contributes to better quality of care.

Another highlight observed was the search for information on the internet; however, it is noteworthy that it involves challenges such as doubts about the reliability of *websites* and the risks related to conflicting information about the treatment and the disease.

The search for information with cancer patients was very important for the participants because it provided resolution of doubts, motivation and psychological aid.

Audiovisual and print media are also very important, since the subjects observe examples of resilience in celebrity stories that faced a cancer treatment.

In view of the discussions and studies on cancer patients, there has been the need for changes in the roles of the various health professionals in order to create and recreate ways of acting in relation to communication with patients and the information they demand.

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