*Original Article*

# ETHICAL ISSUES OF DIAGNOSIS DISCLOSURE AND TREATMENT IN PATIENTS WITH GENITAL OR BREAST CANCER

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**ABSTRACT**

**Objective.** To verify how communication between physicians and patients takes place during diagnosis, treatment and prognosis of women with genital or breast cancer, using bioethics as a reference for analysis.

**Methods.** Descriptive/analytical epidemiological cross-sectional study of 120 patients randomly selected at Hospital de Base do Distrito Federal, Brazil. Patients were given a questionnaire with nine closed-ended questions distributed as follows: three related to diagnosis, four to treatment, and two to prognosis.

**Results.** The results showed that 73.3% of patients considered the quality of initial information received on the diagnosis of cancer as "negative"; 54.2% of patients understood information received on diagnosis and treatment; approximately 60% were aware of the prognosis of cancer; and less than 10% did not want additional information. However, for almost 40% of respondents, there was a problem in physician-patient communication regarding the process involving cancer. Age and extent of the disease did not influence the patients' degree of understanding about diagnosis, treatment, and prognosis.

**Conclusion.** Communicating information about diagnosis, treatment and prognosis to patients with genital or breast cancer was adequate in about 60% of cases. However, problems were detected concerning the language used by physicians, lack of systematic consideration towards patient autonomy, and absence of mechanisms that could provide decision-making power to patients.

Key words: Communication. Bioethics. Genital neoplasms, Female. Breast neoplasms. Disclosure.

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## Introduction

Cancer is a leading cause of death in human history, accounting for 12.5% of deaths worldwide each year. More than 70% of all cancer deaths occur in middle- and low-income countries. About 11 million people are diagnosed with cancer each year, with an estimated global incidence of over 16 million new cancer cases in 2020, 60% of which will occur in developing countries.[1] According to Parkin et al.,[2] the most prevalent cancers among women are breast tumors and tumors of the uterine cervix, accounting for 1 million and 471 thousand new cases per year, respectively. According to the Brazilian Ministry of Health, cancer is the second leading cause of death in women. In 2004, 64,723 women died of cancer, accounting for 17.6% of all deaths.[3]

Cancer is a complex disease that, in order to be tackled properly, requires an appropriate infrastructure support and should be evaluated within a multidisciplinary approach by skilled professionals. Approaching patients with malignant neoplasm is not an easy task in clinical practice, because it involves transmitting the medical information about their diagnosis, prognosis, risks and benefits of treatment, in addition to the possibility of disease progression. In such circumstances, the process of delivering bad news to patients is challenging, difficult and the sole responsibility of the phsysician.[4] Bad news has been defined as any information which drastically and negatively affects an individual's view of his/her future.[5,6] Moreover, assimilation of the information given by the physician and how patients experience their disease vary widely from individual to individual, involving several phenomena of the disease, such as pathological, psychosocial, anthropological, and sociocultural aspects, which must be understood.

When working with advanced cancer patients, troubled communication between the patient and healthcare team

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becomes even more evident when compared to early-stage cancer cases.[7] The aspect that draws the most attention is the vulnerability of the patient to the content of communication and the sensitivity resulting from the information received. Concerning communication of prognosis information, patients least likely to want information are those who have the worst prognosis and avoid thinking about death.[8]

Communication may be defined in several ways, according to the context. In the present study, communication is understood as any situation of interrelationship between people who interact with each other. A crucial aspect in communication refers to the opposition often found between the linguistic aspect itself (information giving) and existential aspects (emotions and values). This polarization may negatively affect the process of communication as a whole. A way out of this polarity is seeking to unite both situations without mixing them up. Consequently, communication becomes understood as a dynamic way of acting and may be considered in its bioethical dimension.[9]

Bioethics deals with principles and, based on this perspective, this study aimed to analyze physician-patient communication considering its importance to the cure, improvement or patient acceptance of the disease. Faced with dilemmas regarding truth, respect, the responsible exercise of autonomy, the right to qualitative information, benefits of information sharing, and the possible non-harm from some information not disclosed, this study attempted to address the importance of understanding the different needs of patients. Therefore, the objective of the present study was to verify, in light of bioethics, how communication between physicians and patients takes place during diagnosis, treatment and prognosis of women with genital or breast cancer under the care of Hospital de Base do Distrito Federal (HBDF), Brazil.

## METHODS

This is a descriptive/analytical cross-sectional study based on interviews with patients treated at HBDF Gynecologic Oncology Service or Breast Cancer Service, a high-complexity tertiary public hospital. The project was approved by the Research Ethics Committee of Distrito Federal Department of Health, in compliance with the Resolution 196/96 of the National Health Council/Brazilian Ministry of Health.

Sample size calculation was based on the number of patients attending HBDF Gynecologic Oncology and Breast Cancer Outpatient Clinic. Patients usually referred to the hospital with breast cancer, cancer of the uterine cervix, vulva, and vagina, ovarian cancer, and endometrial cancer were invited to participate voluntarily in the study after being informed, individually, of the study project, objectives, non-mandatory participation, and confidentiality in the use of information.

Regarding eligibility of patients to participate in the study, the following inclusion criterion was defined: patients with genital or breast malignancy. Exclusion criteria were: patients who refused to participate, patients with more than five years of diagnosis and treatment, patients from private practice, and patients seen by any of the researchers involved in the study.

To validate the questionnaire, a pretest was conducted with 10 patients confirming that the data collected were actually relevant and vocabulary used was intelligible to the study population.

Patients were randomly selected. At first, personal data (age, educational level, diagnosis, and clinical and surgical staging) were abstracted from the patient's medical record. Patients were then given a questionnaire with nine closed-ended questions related to information of diagnosis, treatment, and prognosis and the patient's expectations and perception of the subject. Some questions required only one answer – yes or no – and other questions presented with a scale ranging from most negative to most positive situations. The nine questions were distributed as follows: three related to diagnosis, four to treatment, and two to prognosis (Chart 1).

The associated variables analyzed were: age and patients' understanding of their diagnosis, extent of the disease and patients' understanding of their diagnosis, educational level and patients' understanding of their diagnosis; age and patients' understanding of treatment options, extent of the disease and patients' understanding of treatment options, educational level and patients' understanding of treatment options; age and whether patients wanted to know everything about their disease, extent of the disease and whether patients wanted to know everything about their disease, educational level and whether patients wanted to know everything about their disease; whether patients knew how the their disease progresses if not treated and whether patients wanted to know everything about their disease.

The chi-square test was used to verify an association between these variables. Significance level was set at 5% ($p < 0.05$). Statistical analysis was performed using StatCalc software.

## RESULTS

The mean age of the 120 patients studied was 40.3 years (21-78 years). Regarding educational level, 12 (10%) participants were illiterate and seven (5.8%) had higher education. Therefore, 101 (84.1%) respondents had an educational level between incomplete elementary school and high school graduate. Regarding primary diagnosis, 58 (49.1%) participants had breast cancer, 44 (36.7%) had cancer of the uterine cervix, 10 (8.3%) with suspected ovarian cancer, four (3.3%) with cancer of the vulva, and four (3.3%) with endometrial cancer. With regard to clinical and surgical staging, early-stage cancer was observed in 40 (33.4%) cases and advanced cancer was found in 80 (66.6%) cases.

In the question about initial information received on cancer diagnosis in primary healthcare units (healthcare centers, local hospitals, and other state hospitals), most patients rated the information as "very poor" and "poor", i.e., 57 patients, accounting for 47.6% of the total sample. On the other hand, 31 (25.7%) patients rated initial information as "fair", 26 (21.7%) as "good", and six (5%) as "excellent". This means that 88 (75%) patients chose one of the three negative items to answer the question (Question no. 1).

When asked about how difficult it was to understand a specialist speaking about their diagnosis (Question no. 2), the majority – 65 (54.2%) respondents – answered that they had no difficulty in understanding; 19 (15.8%) felt that the physician spoke using difficult terms, i.e., technical words; 18 (15%) thought that the physician spoke clearly, but they did not want to pay attention; 11 (9.2%) answered that they paid attention, but the physician

**Chart 1 - Questionnaire applied to patients with genital or breast cancer**

Question no. 1: How do you rate the quality of the initial information that you received about your diagnosis?

( ) very poor
( ) poor
( ) fair
( ) good
( ) excellent

Question no. 2: How difficult did you find it to understand the HBDF doctor when s/he spoke again about your diagnosis?

( ) The doctor said nothing
( ) The doctor spoke using difficult terms (technical words)
( ) You paid attention, but the doctor was not clear enough (nontechnical words)
( ) The doctor spoke clearly, but you did not pay attention
( ) You had no difficulties

Question no. 3: What could you understand about your disease?

( ) You could understand nothing
( ) You did not want to understand
( ) You could only understand that it is serious
( ) You could only understand that you are sick
( ) You could understand everything that was explained to you

Question no. 4: Do you want to know about treatment options currently available for your disease?

( ) no
( ) yes

Question no. 5: How difficult did you find it to understand the doctor when s/he spoke about treatment options available in your case?

( ) The doctor said nothing
( ) The doctor spoke using difficult terms (technical words)
( ) You paid attention, but the doctor was not clear enough (nontechnical words)
( ) The doctor spoke clearly, but you did not pay attention
( ) You had no difficulties

Question no. 6: Do you consider yourself competent, that is, able to make decisions about your treatment?

( ) no
( ) yes

Question no. 7: Do you feel free to choose your treatment?

( ) no
( ) yes

Question no. 8: Do you know how your disease progresses if not treated?

( ) no
( ) yes

Question no. 9: Do you want to know everything about your disease?

( ) no
( ) yes

was not clear enough, despite not using technical words; and seven (5.8%) reported that the physician did not say anything.

When analyzing age, considering patients aged less than or equal to 40 years, 20 (64.5%) out of 31 respondents answered that they had no difficulty in understanding the diagnosis. Of the 89 patients older than 40 years, 45 (50.5%) responded similarly. Therefore, no association was found between age and patients' understanding of their diagnosis (p = 0.1790). There was also no association between patients' understanding of their diagnosis and extent of the disease (p = 0.0920). Of the 30 (25%) patients who could not understand what the physician said about their diagnosis, due to the use of technical words or not speaking clearly, 26 (86.6%) were literate and only four (13.4%) were illiterate (p = 0.2410) (Table 1).

With respect to what patients could understand about their disease, excluding the seven patients who reported that the physician said nothing in the previous question, 64 (56.7%) patients could understand the seriousness of the disease, but only 19 (16.8%) could understand everything that was explained to them. Nine (7.9%) patients could understand nothing, other nine (7.9%) did not want to understand, and 12 (10.7%) could only understand that they were sick (Question no. 3).

When patients were asked whether they wanted (or not) to know about treatment options available for their disease, only 20 (16.7%) patients answered "no" and 100 (83.3%) patients answered "yes" (Question no. 4).

Question no. 5 was related to patients' difficulty in understanding the physician when s/he spoke about treatment options available for their case. Sixty-five (54.2%) patients answered that they had no difficulties. Other items in this question were chosen as follows: for 19 (15.8%) patients, the physician said nothing; for 12 (10%), the physician spoke using difficult terms (technical words); for 15 (12.5%), the physician spoke clearly, but they paid no attention; and nine (7.5%) reported that they paid attention, but the physician was not clear enough, despite not using technical words.

When considering patients aged less than or equal to 40 years, 19 (61.3%) out of 31 respondents answered that they had no difficulty in understanding treatment options. Of the 89 patients older than 40 years, 46 (51.6%) responded similarly. Therefore, patients' understanding of treatment options was not associated with age (p = 0.0930) or with extent of the disease (p = 0.6040). All 21 (17.5%) patients who could not understand what the physician said were literate (Table 2).

When patients were asked whether they felt competent, i.e., able to make decisions about their treatment, 56 (46.6%) patients answered "no" and 64 (53.4%) patients answered "yes" (Question no. 6). Of the 64 patients who answered that they considered themselves able to participate in the decision-making process about their treatment, 16 (25%) patients did not consider themselves free to express their views.

Question no. 7 was related to whether patients felt free to choose their treatment: 58 (48.4%) patients answered "no" and 62 (51.6%) answered "yes".

In Question no. 8, which was related to cancer prognosis, patients were asked if they knew how the disease progresses when left untreated. Forty-four (36.6%) patients answered "no" and 76 (63.4%) answered "yes". Of the 44 (36.6%) patients

**Table 1 - Correlation between age, educational level, and extent of the disease and patients' understanding when the specialist spoke about their diagnosis**

| Understanding of diagnosis | Age | | Educational level | | Extent of the disease | |
|---|---|---|---|---|---|---|
| | ≤40 (n=31) | >40 (n=89) | Literate (n=108) | Illiterate (n=12) | Early-stage cancer (n=40) | Advanced-stage cancer (n=80) |
| The doctor said nothing (n=7) | 1 | 6 | 5 | 2 | 2 | 5 |
| Technical words (n=19) | 4 | 15 | 18 | 1 | 6 | 13 |
| The doctor was not clear (n=11) | 1 | 10 | 8 | 3 | 1 | 10 |
| The patient paid no attention (n=18) | 5 | 13 | 16 | 2 | 5 | 13 |
| No difficulties (n=65) | 20 | 45 | 61 | 4 | 26 | 39 |

**Table 2 - Correlation between age, educational level, and extent of the disease and patients' understanding of treatment options**

| Understanding of treatment options | Age | | Educational level | | Extent of the disease | |
|---|---|---|---|---|---|---|
| | ≤40 (n=31) | >40 (n=89) | Literate (n=108) | Illiterate (n=12) | Early-stage cancer (n=40) | Advanced-stage cancer (n=80) |
| The doctor said nothing (n=19) | 1 | 18 | 14 | 5 | 3 | 16 |
| Technical words (n=12) | 3 | 9 | 12 | - | 6 | 6 |
| The doctor was not clear (n=9) | 5 | 4 | 9 | - | 3 | 6 |
| The patient paid no attention (n=15) | 3 | 12 | 12 | 3 | 5 | 10 |
| No difficulties (n=65) | 19 | 46 | 61 | 4 | 23 | 42 |

who answered that they did not know how the disease progresses, 32 (72.8%) were literate; of the 76 (63.4%) who answered "yes", all were literate (p = 0.0005).

When patients were asked if they wanted to know everything about their disease, only 20 (16.6%) answered "no", whereas most women – 100 (83.4%) – answered "yes" (Question no. 9).

The variable "whether patients wanted to know everything about their disease" was not associated with advanced cancer patients (p = 0.1660) or with the patients' age (p = 0.5140). Of the 100 (83.4%) patients who answered that they wanted to know everything about their disease, 90 (90%) were literate; of the 20 (16.6%) who answered "no", 18 (90%) were also literate (p = 0.00005).

## DISCUSSION

Bioethics was used as a theoretical reference in the present study to assess moral conflicts generated within women as a result of circumstances surrounding genital and breast cancer. In addition, bioethics also plays an important role in providing medical ethics with the means to establish discussions and foster further reflection on the importance of the act of communicating and of linguistic and existential aspects in the physician-patient relationship.

The mean age of patients in this study was consistent with the average age at which genital and breast cancer appears, i.e., young women during their most productive years. The level of education may also influence the late diagnosis of the disease, since the lack of knowledge exposes women to risk factors. This situation, coupled with non-care, causes cellular changes with oncogenic potential which, added to the delay in seeking health care and lack of access to specialized healthcare services, increase even further the possibility of the patient developing cancer. For never having attended school, 10% of respondents were considered illiterate; however, 38.4% of all participants had not finished elementary school and could have been classified as functionally illiterate.

Diagnosis disclosure involves suitable location and schedule, skills in informing, patients' willingness to receive information, and sufficient time to answer all patients' questions, i.e., this process is a multifaceted and complex task.[10] In a study of 103 cancer patients, 97% of respondents reported that they felt more comfortable when information about their disease was delivered by specialists, i.e., by the oncologist, because they believe in the communication skills of a specialist.[11]

In another study, 125 patients with a diagnosis of incurable cancer were interviewed, and the quality of information was evaluated as good by 80% of patients when given by the oncologist; and by 63% when given by general practitioners. Therefore, studies indicate that patients are more satisfied with the information giving by specialists.[12]

The role of companions in oncology interactions increases the degree of usefulness of information given by the physician to the patient, i.e., companions participate actively in the interaction, asking clarifying questions. However, patients have a companion in only 20% of their oncology appointments.[13]

The second information received by patients was slightly more efficient. However, for 30.8% of patients, it was clear that there was some problem in the communication of diagnosis information, since 5.8% of physicians said nothing, 15.8% used technical words, and 9.2% were not clear enough despite not using technical words. Of the 30 (25%) patients who could not understand what the physician said due to the use of technical words or not speaking clearly about their diagnosis, 26 (86.6%) were literate and only four (13.4%) were illiterate ($p = 0.2410$).

When patients were asked if they wanted to know about treatment options, 16.7% answered that they did not want to know anything. This result shows that a significant number of cancer patients do not want to participate in making decisions about their lives. This may be explained by a feeling that their autonomy is compromised, they are considered vulnerable, and thus they do not assert their right to be informed, or even as a self-protection mechanism.

When patients were asked whether they considered themselves competent, i.e., able to make decisions about their treatment, 53.4% answered "yes" and 46.6% answered "no".

When analyzing the competence of a sick person, reference is limited to decision making at the present situation, i.e., the same person may be competent to make a certain decision and incompetent to make another one. The ability to make appropriate decisions may vary depending on two factors: the degree of complexity of information required for the decision and the risks assumed by individuals as a result of their choice. Another important aspect is that competence may also be intermittent. For this reason, healthcare professionals should assess the competence of their patients according to each new situation. Consequently, they are responsible for making all possible efforts to increase the competence of their patients.[14]

When patients were asked if they felt free to choose their treatment, 51.6% answered "yes" and 48.4% answered "no". Of the patients who considered themselves able to make decisions about their treatment, 25% did not consider themselves free. The lack of power of choice is associated with the lack of empowerment to make decisions, a fact that undermines the exercise of autonomy and is related to what Paulo Freire called "real freedom to decide".[15] In such circumstances, patients do not assert their autonomy to make decisions.[16,17] Diante dessa situação, a relação entre o médico e a paciente com frequência se torna paternalista, pois o médico acaba decidindo unilateralmente.

Within this situation, the physician-patient relationship often becomes paternalistic, since the physician ends up making unilateral decisions.

When evaluating communication between physicians and patients of prognosis information, a study aiming to identify preferences of 218 patients with incurable cancer for the process of prognostic discussion found that 98% of patients wanted detailed information and preferred a realistic and individualized approach from the oncologist when discussing prognosis.[18]

Less than 10% of our participants did not want further information, i.e., data from the present study are consistent with those found in the literature, which shows that 13% of patients with severe disease do not want information about their medical condition and should be therefore respected.[19, 20, 21]

A study of 159 female patients, with the purpose of testing different physician communication styles of breaking bad news to patients, showed that different ways of delivering bad news evoked different perceptions, levels of satisfaction, and emotions in the participants. In that study, participants indicated the patient-centered communication as least emotional, least dominant, and most appropriate when it comes to conveying information and most expressive in offering hope, in addition to providing greater patient satisfaction with the visit and reducing negative emotions.[22] Another study of 214 patients corroborates this information.[23]

## CONCLUSION

The analysis and discussion of data obtained in this study on physician-patient communication of information about diagnosis, treatment and prognosis of women with genital or breast cancer allow us to point out that communication was adequate in about 60% of situations. However, for approximately 40% of respondents, there was a problem in communication between the healthcare professional and patient regarding the whole process involving cancer. One may infer that there are some conflicts concerning linguistic aspects, autonomy, lack of patients' real decision-making power, beneficence, and paternalistic attitudes exerted by the physician.

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**Conflict of interest:** No conflicts of interest declared concerning the publication of this article.

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Artigo recebido: 30/10/09
Aceito para publicação: 12/04/10