

Ethical analysis of breast cancer diagnosis

Análise ética do diagnóstico do câncer de mama

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ABSTRACT

Objective: To assess awareness of breast cancer diagnosis, and how it was disclosed to patients seen at a university hospital in São Paulo City. **Methods:** From January 2003 to July 2004, 102 patients were interviewed on the day before surgery if they were aware of their diagnosis, how it was disclosed, and level of satisfaction as to the information provided on their disease. **Results:** Twenty patients (19.6%) were not aware of their diagnosis. A significant association of unawareness of diagnosis with low schooling ($p = 0.027$) and older age ($p = 0.014$). Among 82 patients who were informed of their diagnosis, 70 (85.4%) were satisfied as to how the diagnosis was informed, where 12 (14.6%) were not. Dissatisfaction was also associated with low schooling ($p = 0.012$). **Conclusions:** Most patients were aware of their diagnosis and satisfied with information provided. Unawareness and dissatisfaction were directly related to age and schooling.

Keywords: Breast neoplasms/diagnosis; Ethics; Health knowledge, attitudes, practice; Ethics; Patient satisfaction

RESUMO

Objetivo: Avaliar o conhecimento e a forma de revelação do diagnóstico de câncer em pacientes com câncer de mama atendidas no serviço de mastologia de um hospital universitário de São Paulo. **Métodos:** Cento e duas pacientes foram entrevistadas entre janeiro de 2003 e julho de 2004, no dia anterior ao da cirurgia. O pesquisador perguntou se a paciente tinha conhecimento do seu diagnóstico, como este foi revelado e o nível de satisfação das informações obtidas acerca da sua doença. **Resultados:** Vinte pacientes (19,6%) não sabiam do seu diagnóstico. Houve uma associação significativa entre baixo nível de escolaridade ($p = 0,027$), idade avançada ($p = 0,014$) e maior taxa de não conhecimento do diagnóstico. Entre as 82 pacientes informadas do diagnóstico de câncer, 70 (85,4%) se mostraram satisfeitas da

forma como este foi revelado e 12 (14,6%) insatisfeitas. A insatisfação demonstrou associação significativa com baixo nível de escolaridade ($p = 0,012$). **Conclusão:** A maioria das pacientes entrevistadas sabia do seu diagnóstico e estava satisfeita com a forma de revelação. O não conhecimento do diagnóstico se relacionou com idade avançada e baixo nível de escolaridade, assim como esta condição também demonstrou associação com insatisfação da forma de diagnóstico.

Descritores: Neoplasias mamárias/diagnóstico; Ética; Conhecimentos, atitudes e prática em saúde; Satisfação do paciente

INTRODUCTION

Among all assignments, physicians have the difficult task of disclosing the diagnosis of severe diseases, such as cancer. When giving this information to patients, feelings of helplessness, failure, and vulnerability influence the attitude of physicians, who may be superficially involved, or empathize with the patient, sharing his/her suffering. This allows the physician to decide for an extreme professional, almost technical attitude, exposing the truth with details that often seem to be cruel for laypeople. Physicians may also omit the diagnosis, or reveal only a few details, according to their perception of what may harm the patient at that moment.

In the 1960s, when facing patients with cancer or incurable diseases, physicians were divided into those that believed in the benefits of disclosing the diagnosis and those that did not communicate at all to patients⁽¹⁾. Approximately 90% of North-American physicians preferred not to reveal the true diagnosis⁽¹⁻³⁾. Forty

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years ago, most cases of cancer were diagnosed at an already advanced stage, and treatment was based on radical, mutilating surgeries, with low probability of cure. Adjuvant treatment through radiotherapy and chemotherapy played a secondary role, and caused high morbidity and mortality. In the last few decades, in addition to diagnosis of many types of cancer at an early stage, treatment morbidity presents acceptable rates, and life expectancy has increased. Therefore, the opinion of many physicians changed significantly, and despite still feeling uncomfortable, most tend to disclose the truth in many cases⁽⁴⁾.

Beauchamp and Childress, when discussing lying, omitting, or disclosing the truth when faced with severe diseases, mention the utilitarian and the Kantian theories⁽⁵⁾. The utilitarian theory proposes that actions are right or wrong if their consequences are good or bad. Therefore, lying or not disclosing the diagnosis, despite the lack of sincerity and honesty of the physician towards the patient, is justified because disclosing the diagnosis would cause suffering to the patient. This attitude is patronizing, as the physician is making decisions about the patient's life, although sometimes this is shared with relatives. This is the case particularly when life expectancy can be estimated based on cancer staging data. The negative side of this attitude is that the patient hardly participates in the choice of therapy, and perhaps he/she will not have this information at any stage of his/her life.

Kant's theory advocates that some actions, regardless of their consequences, are right or wrong. The physician should value truth, disclosing all consequences derived from a cancer diagnosis. Therefore, the moral responsibility of the Kantian theory would be fulfilled; in other words, the aim of telling the truth is not what happens, but what it should happen. When acting according to this theory, the physician runs the risk – often harmful – to disclose disease information when patients are feeling fragile. This information is hardly absorbed without psychological trauma, which can influence the proposed therapeutics. The most feared reactions are isolation and refusal of any treatment, despite hope being presented next.

There is a trend frequently found in medical ethics literature that suggests that physicians should clearly and objectively inform patients about diagnosis, prognosis, and treatment options. Although it seems adequate, this rationale does not include patients who do not want to know anything about the disease, or those that initially wanted to, but change their minds during treatment, being incapable of coping with the problem⁽⁶⁻⁷⁾.

This study proposes to discuss how cancer diagnosis is conveyed, using a sample of patients seen at the breast disease department of a university hospital.

OBJECTIVE

This study aimed to introduce the reflection on ethical aspects of the physician-patient relationship for medical students, regarding particularly the disclosure of breast cancer diagnosis.

METHODS

From January 21st to July 15th, 2004, 102 patients admitted for surgical treatment of breast cancer to a university hospital participated in this study. Patient's age ranged from 25 to 89 years (mean of 57.7 years; standard deviation of 14.7 years).

All patients answered a questionnaire the day before the surgery.

The questionnaire included the following questions:

1. What was the reason for hospital admission and treatment?
2. Was diagnosis made at the appointment for confirmation of diagnosis, or did you indirectly discover through a third party?
3. Were you pleased with how the diagnosis was informed, and did you get all the necessary information?

The last two questions were asked only to the patients who knew they had cancer.

The questionnaire was applied by a fourth-grade medical student. Personal information included age, place of origin, ethnicity, and schooling. Data were compiled and classificatory and quantitative variables were presented in descriptive tables presenting absolute and relative (%) values. Patient's age and schooling were related to diagnosis information. The following age groups were considered: 25 to 45 years, 46 to 60 years, and older than 60. Association tests were based on Pearson's chi-square tests. A significance level of $\alpha = 5\%$ was used, and the descriptive levels (p) of all tests were calculated and presented.

This study was approved by the Medical Ethics Committee of the Regional Medical Council of the State of São Paulo (CREMESP).

RESULTS

Among the patients who answered the questionnaire, 48 (47.1%) lived in São Paulo city, 51 (50%) came from another state, and 3 (2.9%) from other countries. Seventy one (69.6%) were Caucasian, 17 (16.7%) were black, and 14 (13.7%) were mulatto.

As to schooling, 12 (11.9%) were illiterate, 45 (44.6%) had incomplete elementary school, 16 (15.8%) had complete elementary school, 17 (16.8%) had partially completed or completed secondary school, and 11 (10.9%) had partially completed or completed college education.

The question about being aware of the diagnosis that led to admission to hospital and surgery was answered by 102 patients, and 20 (19.6%) did not know they had breast cancer.

The level of understanding and awareness of the diagnosis was correlated with age and schooling, as shown in Tables 1 and 2, respectively.

Table 1. Age group and awareness of diagnosis

Age group (years)	Awareness of diagnosis		Total
	No	Yes	
25 to 45	2 (9.1%)	20 (90.9%)	22 (21.6%)
46 to 60	4 (10.5%)	34 (89.5%)	38 (37.2%)
> 60 years	14 (33.3%)	28 (66.7%)	42 (41.2%)
Total	20 (19.6%)	82 (80.4%)	102 (100%)

$\chi^2 = 8.551$

$p = 0,014$ (significant)

Table 2. Schooling and awareness of diagnosis of cancer

Schooling	Awareness of diagnosis		Total
	No	Yes	
Illiterate	6 (50%)	6 (50%)	12 (11.7%)
Incomplete elementary education	10 (22.2%)	35 (77.8%)	45 (44.2%)
Complete elementary education	2 (12.5%)	14 (87.5%)	16 (15.7%)
Secondary education	2 (11.8%)	15 (88.2%)	17 (16.7%)
Higher education	1 (9%)	11 (91%)	12 (11.7%)
Total	20 (19.8%)	81 (80.2%)	102 (100%)

$\chi^2 = 11.00$

$p = 0,027$ (significant)

There was significant association between age group and diagnosis awareness: the proportion of patients that were not aware of diagnosis increased with age. Association test statistics was $\chi^2 = 8.551$, with $p = 0,014$.

Schooling was significantly associated with awareness of cancer diagnosis: the higher the schooling level, the higher the proportion of patients aware of their diagnosis. Association test statistics was $\chi^2 = 11.00$, with $p = 0,027$. Out of 20 patients not aware of cancer diagnosis, 6 were illiterate, and 10 had not completed elementary school.

The questions related to how the diagnosis was communicated to the patient and the level of satisfaction with the information provided were asked to and answered only by 82 (80.4%) patients who were aware of breast cancer diagnosis. The physician informed it clearly and directly to 64 (78%) patients. Four (4.9%) women indirectly found out about the diagnosis through relatives, whereas 14 (17.1%) discovered by themselves.

Out of 14 patients who discovered by themselves, three (21.4%) overheard physicians discussing their diagnosis, and 11 (78.6%) read the biopsy results.

Out of 82 patients who were fully or partially aware of the diagnosis of cancer, 70 (85.4%) were satisfied with the way it was disclosed, while 12 (14.6%) showed dissatisfaction.

Degree of satisfaction as a function of schooling is shown in Table 3. Based on the ratios presented in this table, only illiterate patients presented differences (50%) as to satisfaction with the information transmitted by the physician, indicating an association between dissatisfaction and illiteracy. The significance of this difference was tested, confirming a significant association between dissatisfaction with information received and illiteracy. Association test statistics was $\chi^2 = 6.357$, with $p = 0.012$.

Table 3. Schooling and satisfaction with information received

Schooling	Satisfaction with information		Total
	No	Yes	
Illiterate	3 (50%)	3 (50%)	6 (7.3%)
Incomplete elementary education	4 (11.4%)	31 (88.6%)	35 (42.7%)
Complete elementary education	2 (14.3%)	12 (85.7%)	14 (17%)
Secondary education	2 (13.3%)	13 (86.7%)	15 (18.4%)
Higher education	1 (9%)	11 (91%)	12 (14.6%)
Total	12 (14.6%)	70 (85.4%)	82 (100%)

$\chi^2 = 6.357$

$p = 0.012$ (significant)

DISCUSSION

Patients have the right to decide about themselves. According to the Principle of Autonomy, provided in articles 46 and 48, Chapter IV – which focus Human Rights – of the Code of Medical Ethics, the patient is not obliged to accept any therapeutic procedure, even if his/her physician believes it will benefit the patient. Therefore, any therapeutic regimen proposed must always be preceded by information about the diagnosis, and, in cancer cases, by information on prognosis and therapeutic morbidity.

In the last decades, patients have no longer been passively accepting proposed treatments if no detailed information is provided, particularly if there is confirmation of a precise diagnosis. About 96% of British, 90% of American, and 85% of Portuguese patients would like to be informed the truth about their disease, as well as healing probability⁽¹⁾.

In a study carried out in São Paulo with 363 cancer or AIDS patients, 96.1% of male patients and 84.2% of female patients wanted to be informed of the diagnosis, and 87.7% of male and 84.2% of female patients also wanted their relatives to be informed⁽⁸⁾.

There are three ways to disclose cancer diagnosis⁽⁹⁾. First, the “non-disclosure”, when most information about diagnosis, treatment, and prognosis remain restricted to the physician. The patient has little participation in the decisions, and the physician centralizes the control of the situation. Another way is “total disclosure”, in which the physician does not consider the patient’s need to gradually

assimilate information on his/her disease; the information is fully transmitted as the physician becomes aware of the facts. This approach may cause unnecessary suffering, as each individual patient's ability to cope with detailed information on his/her disease is not taken into account. The third way is the "individualized disclosure".

In the present study, 19.6% of patients were not aware of their diagnosis of breast cancer on the day before surgical treatment. There was significant correlation between unawareness, patient age and schooling.

Patients' age probably influenced physicians as to diagnosis disclosure. As elderly patients often depend on relatives, these are informed of the diagnosis, but do not inform the patient, possibly to prevent further suffering. In general, people responsible for the care of elderly patients request that the diagnosis be omitted.

It was also observed that schooling influenced diagnosis disclosure by the physician. Patients with lower schooling were provided less information, or were not able to fully assimilate information on their diagnosis, prognosis and treatment. The percentage of patients informed of their cancer diagnosis increased according to their schooling. Perhaps physicians did not take into consideration the low level of understanding of less educated patients when informing them on their diagnosis⁽¹⁰⁾. This could be attenuated if they resorted to simpler terms when informing patients of the diagnosis, avoiding the use of technical terms.

Among the patients who were scheduled for immediate esthetic reconstruction, all were aware of their diagnosis, and suggested that an appointment with a specialist, other than the breast-cancer specialist, offers an extra opportunity to discuss, and clarify the reasons for hospital admission and surgery.

Sixty-four patients, whose diagnosis was directly informed, said the information was transmitted with no prior psychological measures. Out of 14 patients who discovered the diagnosis by themselves, 11 read the results of the biopsy examination, and the physicians did not have the chance to disclose the diagnosis. Two patients overheard physicians discussing their case, and one patient was informed by the radiologist, who is not the appropriate person to do this, since it is difficult to establish a reliable and collaborative relationship during diagnostic procedures. One of the patients, after reading the exam results, obtained information by searching the Internet. The authors observe that, although it is unusual for low-income and socially disadvantaged patients to use the Internet, the percentage of patients using the web may be higher, if a sample of patients with better social-economic conditions is considered.

Kübler-Ross studied acceptance phases in cases of lethal disease diagnosis and observed that the time

of discussing the problem with the patient should be preceded by a process aimed to strengthen patient's psychological structure⁽⁷⁾. In some cases, the physician should wait until current problems that are inherent to the disease and are causing suffering to the patient are solved. This will prevent the accumulation of negative information when the patient is fragile.

Most patients who were informed of their diagnosis were satisfied (85.4%). The discontented patients said that the main reason for their dissatisfaction was that there were not enough appointments to clarify doubts after they were informed of the diagnosis. Perhaps if the communication of the diagnosis took into account individual needs of patients, respecting each patient's capacity to assimilate the information, doubts could be clarified⁽¹¹⁾.

According to Dexeus, proper information is based on a strategy of gradually explaining the several stages of the disease, helping the patient gradually to accept it⁽¹²⁾. This opinion is shared by other authors, who believe that there is no single professional management applicable to all cases, and that communication of diagnosis should be individualized and seen as a link in the chain of events that unfold as the disease progresses^(1,4). Rinpoche asserts that truth must eventually be told, "but always as calmly, gently, sensibly and skillfully as possible"⁽⁶⁾. During the appointments that precede the cancer diagnosis communication, listening to the patient's innermost feelings, and observing each detail of his/her behavior may help us to determine the most favorable time to disclose the diagnosis.

Patients have a right to give their opinion on treatment opportunities, on how they use their body parts and functions, and the right to decide about their own life. Some studies have shown that cancer patients who had the opportunity to participate in the decision making processes about their treatment, experienced less anxiety and depression⁽¹³⁾.

After the diagnosis has been informed, it is also important to discuss and obtain patient's consent as to the treatment, which must be chosen among practices validated by guidelines and medical association consensus meetings. It is recommended that patients sign an informed consent form at each step of treatment, where all positive and negative implications of such practices must be made clear.

CONCLUSION

Most patients interviewed were aware of their diagnosis and satisfied with how it was communicated to them. Diagnosis unawareness was associated with older age and low schoolings. The latter was also associated with dissatisfaction regarding how diagnosis was communicated.

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