Mal manejo de información diagnóstica en pacientes con cáncer: calidad de la información y factores asociados

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Propósito: El objetivo de este estudio es determinar la relación entre la información correcta relacionada con el diagnóstico de cáncer y la que los pacientes tienen sobre el mismo.

Pacientes y métodos: A 150 pacientes con cáncer que acudían por primera vez al departamento de oncología médica, derivados de los departamentos clínicos y de cirugía, se les hicieron 3 preguntas: a) ¿qué tipo de enfermedad tiene usted?; b) ¿quién le ha comunicado su diagnóstico?, y c) ¿dónde le han dado la información? Se analizó la presencia de factores asociados a un mal manejo de la información que tenían los pacientes sobre su diagnóstico y la correcta sobre el mismo; la información incorrecta e inespecífica se consideró errónea.

Resultados: La muestra estuvo compuesta por un 50,7% de varones, con un rango de 23-82 años de edad; 102 (68%) pacientes tenían información incorrecta sobre su diagnóstico. Un análisis de regresión logística mostró que era más probable que los pacientes más ancianos tuvieran información incorrecta (*odds ratio* = 1,07; p = 0,001; intervalo de confianza del 95%, 1,17-42,71).

Conclusiones: Las características sociodemográficas de los pacientes y el tipo de cáncer afectan el tipo de información que los oncólogos proporcionan a los pacientes. Estos resultados indican que los pacientes remitidos al departamento de oncología médica tienen una información incompleta sobre su diagnóstico.

Palabras clave: Información. Diagnóstico. Cáncer.

Inaccurate diagnosis information in patients with cancer: quality and associated factors

Purpose: The objective of this study is to determinate the relationship between the accurate information related to the diagnosis and the information that the patients know about it.

Methods: Three questions were asked to the patients: a. What kind of disease do you have? b. Who told you the diagnosis?, and c. Where did they give you the information? We have analyzed the presence of associated factors to an inaccurate information in 150 patients with cancer attended for the first time in a medical oncology department referred from clinical and surgical departments. The quality of information has been defined as the relationship between the patients information about their diagnosis and the accurate information about it, being the incorrect and unspecific information the inaccurate information.

Results: There were 50.7% of men, with a range of 23 to 82 years old; 102 (68%) patients had an inaccurate information about their diagnosis. Logistic regression analysis showed that older patients (odds ratio = 1.07; p = 0.001; 95% Confidence Interval = 1.02-1.11) and patients with ovarian cancer (odds ratio = 7.08; p = 0.033; 95% Confidence Interval = 1.17-42.71) were more likely to have an inaccurate information.

Conclusion: Then, the sociodemographic characteristics of the patients and the type of cancer affect the information given to the patients by the physicians. These results indicate that the patients referred to the medical oncology department have an incomplete information about their diagnosis.

Keywords: Information. Diagnosis. Cancer.

Inaccurate or unspecific information about the cancer diagnosis to the patient decreases the degree of confidence in his/her oncologist and increases the patients susceptibility to psychological disorders. In general, the Spanish patients declare to receive partial information or a diagnosis different from cancer by their relevant consultant physician; and their families wish information about the diagnosis to be withheld from them[1]. Once information is received, it is not easily understood by the patient who might have difficul ty understanding ambiguous and uncertain information[2]. Most cancer patients want information about their disease but did not wish to make treatment decisions[3]. Schain (1980) proposed that physician-patient communication about breast cancer should be tailored to the patient's desire for, and ability to handle, information[4]. Previous work attempted to categorize patients as either monitors (information seeker, seemed to benefit psychologically from data presented to them) or blunters (information avoiders, would rather not be told all the information relevant to their diagnosis, care, and treatment)[5]. Young women, who are under a lumpectomy or mastectomy for treatment of breast cancer, are more likely to want their doctors to make a recommendation about to practice one or another intervention (p = 0.023)[6]. Likewise, the risks of not giving enough information, or the inaccurate information are just as bad as giving too much information to someone who is not seeking facts[7]. Using a heterogeneous group of cancer patients, Butow et al (1997) observed as, by the second visit, the majority of patients wanted significantly less information about illness, less feedback on what was happening to the cancer and less information about the goals of medical care than the first visit[8]. As Brown et al. (1997) indicate, the majority of cancer patients prefer a doctor who provide positive emotional support in preference to a doctor who provi de positive information[9].

TABLE 1. Patient characteristics and treatment administered

Variable	N.º	%
Patients	150	
Age (years)		
Median	58	
Range	23-82	
Sex		
Men	76	50.7
Women	74	49.3
Marital status		
Married	103	71
Unmarried	47	29
Laboral Situation		
Ability to perform their job		
Yes	56	37.3
No	94	62.7
Karnofsky Performance Status		
< 70%	23	15.6
> 70%	127	84.4
Oncology treatment		
Neoadjuvant	19	13.7
Adjuvant	67	48.2
Palliative	38	27.3
No treatment	10	10.8

Our objective is to determine the relationship between the accurate information related to the diagnosis and the information that the patients know about it, and to analyze the presence of associated factors of an inaccurate information of patients with cancer attended for the first time in a medical oncology department referred from clinical and surgical departments.

MATERIAL AND METHODS

A total of 150 new medical oncology patients, 76 males and 74 females (table 1), with heterogeneous diagnoses (table 2) were recruited from a consecutive series of newly referred out-patients to the medical oncology department, Hospital Universitario 12 de Octubre. These patients, able to speak and write spanish and free of cerebral metastases, were refered from clinical and surgical departments of the Hospital Universitario 12 de Octubre, Madrid (Spain)

between January to June 1995. The mean age of the group was 58 (range 23-82) and sociodemographic and medical variables can be seen in table 1. All patients completed a structured closed-answer questionnaire by medical oncologists in the first medical patient appointment. Three questions were asked to the patients: *a.* What kind of disease do you have?, *b.* Who told you the diagnosis?, and *c.* Where did they give to you the information? Likewise, all patients gave information about age, marital status and laboral situation (ability to perform their job). Once concluded this first medical consult, the physician noted in the questionnaire the patients information related with the cancer diagnosis (World Health Organization Classification), Karnofsky Performance Status and the kind of medical treatment (neoadjuvant, adjuvant, palliative or no treatment).

In order to classify the diagnosis information given to the patients, we consider an accurate information, when the patients were informed that they had malignant tumor or cancer. If the patients received other diagnosis information different of it, we consider it an inaccurate information.

Statistical Considerations

Results were analyzed using descriptive analysis of each variable (age, sex, marital status, laboral situation, performance status and oncology treatment) and multivariated analysis (logistic regression analysis in blocks) to know the predictors of an inaccurate information.

RESULTS

One hundred and fifty Spanish oncology patients were included in the study. The sociodemographic characteristics, the performance status and the treatment administered by the physicians (medical oncologists) to the patients are listed in table 1. The mean age was 58 years old (range of 23 to 82 years), 50.7% men, 71% married, only 44.2% had ability to perform their job and 84% presented a performance status equal or higher to 80%, and the majority of them (48.2%) received adjuvant chemotherapy after the first clinical consult. All the diagnosis in cancer cases are in the table 2. Mainly were breast cancer (38 patients), lung cancer (28 patients), colon cancer (28 patients), rectum cancer (14 patients), and ovarian cancer (9 patients). About the information received by the patients (table 3), the quality of information has been defined as the relationship between the patient's information about their diagnosis and the accurate information about them, being the incorrect and unspecific information the inaccurate information. Only 32% received an accurate information about their cancer diagnosis. The main group of patients (41%) received the information by the medical specialists (gynaecologist, neumologist, internist, etc) and 32% by the surgeon. The most usual place where they received the information was in the outpatient clinic (54%). In order to know the predictors of an inaccurate diagnosis information, a logistic regression analysis was performed (table 4). The results showed as older patients (odds ratio = 1.07; p = 0.001; 95% confidence interval = 1.02-1.11) and patients with ovarian cancer (odds ratio = 7.08; p = 0.033; 95% confidence interval = 1.17-42.71) or colon cancer (odds ratio = 4.11; p = 0.078; 95% confidence interval = 0.78-97.33) were more likely to have an inaccurate diagnosis information.

TABLE 2. **Diagnosis in cancer cases**

Diagnosis	N.º	%
Breast	38	25
Colon	28	19
Lung	28	19
Rectum	14	9
Ovary	9	6
Stomach	7	5
Larynx	5	3
Esophagus	4	3
Kidney	3	2
Testis	3	2
Cervix	1	1
Uterus	1	1
Brain	2	1
Tongue	2	1
Hypopharynx	1	1
Lymphoma no Hodgkin	1	1
Miscellaneous	1	1
Nasopharynx	1	1
Pancreas	1	1

TABLE 3. **Information received by the patients**

	N.º	%
1. What kind of disease do you have?		
Accurate information about their cancer diagnosis?	48	32
Inaccurate information about their cancer diagnosis?	102	68
2. Who told you the diagnosis?		
Medical specialists (gynaecologist, neumologist, internist, etc.)	62	41
Surgeon	48	32
Others	40	27
3. Where did they give to you the information?		
Outpatient clinic	78	52
Hospital (Inpatient)	39	26
Others	15	10
Nobody	18	12

DISCUSSION

The patients referred to the medical oncology service from other medical services have an incomplete information about their diagnosis. The age (older patients) and the diagnosis of ovarian and colon cancer are the three factors associated to an inaccurate diagnosis information in Spanish oncology patients attended for the first time to a medical oncology department. Other factors, as the short-time available for the regular clinical consult, the intention to prevent anxiety and the fear to manage the emotional reactions of the patients, could explain that this group of physicians and surgeons avoid to inform correctly to the patients about their cancer diagnosis. But, as Fallowfield et al. (1995) pointed, very few individuals with cancer can possibly exist in a state of blissful ignorance for long[10].

TABLE 4. **The predictors of an inaccurate diagnosis information**

	Information diagnosis model (independent variables)		
	Odds Ratio	Probability	Confidence interval (95%)
Age	1.7	0.001	1.02-1.11
Ovarian cancer	7.08	0.033	1.17-42.71
Colon cancer	4.11	0.078	0.78-97.33

Multivariated analysis (logistic regression analysis in blocks) to know the predictors of an inaccurate information.

All the professionals who are working in cancer care know that the patients don't retain all the diagnosis information given by the physicians. The anxiety that the patient experience at the moment of giving the information reduce the understanding of this information provided and could affect the capacity of the cancer patient for retaining in their memory this diagnosis information.

We do not know the reasons that would explain that the colon and the ovarian cancer patients were the group worst informed. Poor training in communications skills, in this group of physicians (gynecologists) and surgeons who attend and refer to these patients to the medical oncology department, would be the cause of this deficit in the information management.

Similar data have been reported in other Spanish studies. Arraras et al. (1995) reported as the majority of cancer patients included in his study received a diagnosis different from cancer[1]. Estapé et al. (1992) reported data on the knowledge status of a sample of 142 cancer patients. Only 15% of this sample have been informed of the diagnosis of cancer[11]. About the desire to obtain information about the diagnosis, Fallowfield et al. (1995) indicate as the overwhelming majority of the patients (94%) express a general desire for as much information as possible, be it good or bad. Very few people declined to have specific information about their diagnosis and treatment. Those who declined were mostly in the poor prognosis category and tended to be elderly[10]. In this last study, as we have got in our study, the age is an important variable which determine the information received by the patients. So, it is possible, that our older cancer patients have declined to receive information, or the advanced age of the patients is considered as a disadvantage for the physician in order to provide information. The relatives, children, brothers and sisters, could be another barrier that makes difficult the amount and the accuracy of the information provided by the physicians to older patients.

Likewise, the use of shared care records, where the patients could write down information that they wanted to transmit to their caregivers, help to the professionals be more aware of patient's feelings, and it would allow patients and relatives feel more involved in their care[12].

Also, an adequate training in communication skills (counselling) could help to the physicians to answer the information and emotional demands presented by the patients. Then, the physicians could avoid the insatisfaction produced with a cancer consultation handled insensitively, which cause high level of anxiety and depression to the patients[13].

In summary, the data pointed out in this study indicate the necessity to alert to medical specialists and surgeons about the convenience to attend, truthfully, the information demands that the oncology patients present.

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