Information to the patient with cancer: the oncologist's view

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SUMMARY

Objective: To identify what information is provided to patients by oncologists, assess what they take into account in the process of informing the patient, and to ascertain whom the information is provided to. Methods: The study subjects were oncologists recruited among those registered at the Brazilian Society of Clinical Oncology - SBOC. All material was mailed to the Society, which was then forwarded to the participant oncologists. The previously stamped envelopes contained: a questionnaire, the questionnaire instructions, and the informed consent form to be signed. The data obtained was statistically treated, following a 95% confidence interval. Results: 876 questionnaires were sent (total number of physicians registered at SBOC) and a 16.55% response rate was achieved. Regarding the information provided, 81% of the physicians responded they informed patients about diagnosis, treatment and prognosis; however, 73% reported that in most cases the patient is already aware of his/her disease. Nevertheless, the information is provided to the patient and his(her) family by 81% of doctors. Among the relevant aspects in the information process, the patient's gender has little influence on the information for 95% of doctors. Conclusion: Considering the results achieved, we conclude that in the study population, physicians are concerned about providing information according to the patient's profile. We could also notice that oncologists try to provide patients with the information they are entitled to — the truth, although they often resort to the family's assistance in providing that information.

Keywords: Personal autonomy; physician-patient relations; disclosure; bioethics.

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INTRODUCTION

Over the years, the physician-patient relationship has been guided mainly by charity and non-detraction principles. Specifically in Brazil, this relationship has been built under a patronizing and conservative model¹. A new behavior was adopted by physicians in view of the patients' emancipation and the formulation of their rights, especially the right to self-determination. This change also created new ethical conflicts, which can be more frequently seen in certain specialties, such as Oncology. Cancer is still known as a stigmatizing disease in people's minds, in spite of all advances reached and, for a number of physicians, cancer diagnosis might be related to death, and this could interfere with the clinical management².

Informing the patient is a doctor's obligation and a required condition so that autonomy is exerted; however, this obligation must be fulfilled by observing several aspects, including the humanitarian ones. In the case of disclosing a cancer diagnosis, depending on how the doctor communicates the diagnosis, this could lead to an interference on the patient's relationship with his/her own disease³. From the informed consent, physicians have a legal and ethical obligation to inform the patient about risks, benefits or available treatment options⁴ and either about palliative care availability as required.

Palliative care is considered an approach that improves patients' and family's quality of life in the face of a terminal illness with suffering prevention and relief through early identification, strict evaluation, and pain and other physical, psychosocial, and spiritual problems⁵. Palliative care goes beyond the traditional care model, as it advocates patient care should be whole in all health aspects⁶.

The difficult task of disclosing the diagnosis can be different, depending on each physician's individual experience, and the physician should be prepared to act in an effective way, taking into account the patient's cultural, social and psychological issues regarding the information preferences³. In a survey addressing the patient's rights in an information and autonomy setting, the subjects - patients with cancer reported they agreed the patient is entitled to be informed (86.5%)⁷. The cautious physician should evaluate each case and think thourougly on the available alternatives for action: telling the patient the whole truth, partially telling the truth, not telling the truth or leaving some information out. In his/her appreciation, the physician should take into account that only a morally relevant fact, in terms of charity or non-detraction, could warrant a patronizing action, ignoring the patient's right to know the truth and consequently to define his/her treatment limits8.

In situations where there is a conflict between the charity and autonomy principles, some physicians believe the obligation to do good superposes respecting the patient's will – the autonomy principle. The physician must consider each situation and try to recognize the interests that might

be behind the decisions, how these decisions will interfere with the patient's life and what the patients really want¹⁰.

In view of the ethical conflict arising, this study aimed to identify: what kind of information oncologists convey to their patients; what they take into account in the information process; and whom they provide information to, all this according to oncologists themselves.

METHODS

The research project that generated this study was designed in accordance with the ethical recommendations contained in the Resolution 196/96 CNS/MS, approved by the Ethics and Research Committee at *Universidade Estadual de Ciências da Saúde de Alagoas* and all the subjects in the study gave their consent and received a copy of the informed consent.

The study subjects were oncologists recruited among those registered as members of the Brazilian Society of Clinical Oncology — SBOC. This particular professional group was chosen because they work directly with oncological patients and routinely face the conflict of disclosing diagnosis, prognosis, treatment alternatives and further information relevant to this group of patients.

Initially, SBOC was contacted via e-mail and telephone in order to obtain the entity collaboration with the survey; SBOC was responsible for mailing its members the sealed envelope containing the documents for the survey. Thus, the investigators had no access to the oncologists' addresses.

Next, all sealed and stamped envelopes to be addressed to the oncologists were mailed to the Society. The envelopes were individual and contained the following: a document with information about the technical aspects of the survey and instructions on how to complete the data collecting questionnaire; the form; the informed consent required so that the oncologist could obtain a full explanation on the survey through means of direct contact with the responsible investigator including telephone numbers and address to be used in case there were any doubts or when the respondent deemed necessary; two additional stamped envelopes addressed to SBOC and each one should be returned with the questionnaire and the informed consent inside, respectively. After receiving the sealed envelopes mailed by the investigators, SBOC mailed them to the members after adding the address tags. All envelopes were previously stamped and thus there was no cost to either SBOC or the subjects.

The oncologists who agreed to participate in the survey returned the sealed envelopes with the informed consent and the completed questionnaire to SBOC. Later, the investigators received a parcel mailed by SBOC and containing all the sealed envelopes previously completed by the oncologists participating in the survey. As the envelopes were sealed, SBOC had no access to the identity of the on-

cologists who were subjects in the survey. The Society had no access to the envelope contents in any step of the survey either.

This was a descriptive cross-sectional study with a quantitative approach by using the data collecting questionnaire with objective questions. The questionnaire initially addressed aspects related to the profile of the study subjects: age, gender, time from graduation, medical residency (yes or no), and Brazilian region where he/she has worked. The second part of the tool addressed the following topics: when the doctor informs the patient about the diagnosis; who the doctor informs; which aspects regarding the patient, the prognosis, the treatment, and the chance of cure, the oncologists take into account when providing the information; what is informed by the doctor; information properties; psychotherapy and palliative care. The data collecting questionnaire consisted of 27 (twenty-seven) questions; the first five questions addressed general data concerning the profile of the study subjects and, the remaining questions were specific about the topics previously mentioned. For this part of the questionnaire, the reply options were always the same: always, most of the time, half the time, seldom, never, I do not know and I do not want to reply.

Descriptive statistics with 95% confidence interval (95% CI) calculation was used to calculate the data frequency.

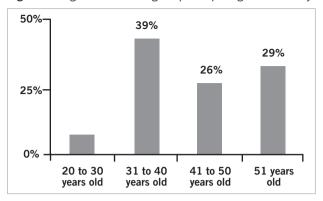
RESULTS

876 sealed envelopes were mailed to SBOC, corresponding to the number of members of the society. Out of these, 145 study subjects returned the questionnaire appropriately completed and the informed consent signed, with a reply rate of 16.55%. Eight additional questionnaires were returned, but their addresses were not found. The collected data were stored in a database software, in which there was no element that could identify the subjects, so ensuring total confidentiality for the volunteer participation. Upon copiling the data, the alternatives "always" and "most of the time" were summed up and turned into "most of the time", since the difference in meaning is very small. The same conduct was adopted for "seldom" and "never", whose result was described as "seldom".

The study oncologists were mostly males (60%), and the Brazilian region with the highest participation was the Southeast (40%). Figure 1 shows the age groups. Among the subjects, 26% had less than 10 years of graduation, 30% stated to have between 11 and 20 years of graduation, and 26% reported between 21 and 30 years of occupation as physicians. The absolute majority of study subjects had a medical residency in clinical oncology (89%).

The first topic was related to whether the oncologists informed their patients about the cancer diagnosis, and the absolute majority (92%) answered yes, with only 5%

Figure 1 – Age of the oncologists participating in the survey.



giving a negative answer. When the question was whether they asked the patient what he/she desired to know about the disease, 85% of the oncologists reported they asked that question, and 12% said this approach did not occur often in their routine.

The other subject in the questionnaire concerned the moment when the doctor informed the patient about the diagnosis, and 89% of the volunteers answered the information was provided mostly at the first visit; however, 73% of the oncologists reported that, in most cases, the patient had already been aware of the disease. When the patient was not aware of the diagnosis, 61% of the volunteers stated they usually waited until the patient ask any question about the disease at the first visit, and 43% of the physicians answered they did not have that conduct. The third topic addressed by the questionnaire was whom the oncologists informed the diagnosis to; the result is shown in Figure 2.

The other part of the data collection tool was about the influence of certain aspects – patient characteristics, treatment, prognosis and chance of cure – on the process of informing about the disease. The results are shown in Table 1.

Following, the content and coverage of the information the oncologists provided to the patients were asked, and 81% of the physicians told they informed

Figure 2 – Who receives the information about the cancer diagnosis.

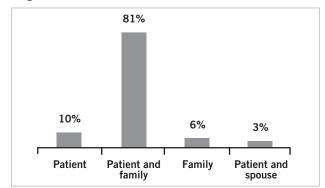


Table 1 – Patient characteristics, prognosis, treatment and chance of cure and how they influence the oncologists in the process of informing

Aspects related to the patient and considered by the physician upon providing the information	Influences most of the time	Seldom influences
Gender	5%	95%
Age	26%	65%
Socioeconomic status	22%	71%
Education level	37%	58%
Prognosis	27%	59%
Possibilities of treatment	19%	72%
Possibilities of cure	23%	68%

about the diagnosis, the treatment, and the prognosis. When the prognosis is poor, 28% of the respondents reported they informed only the family about the prognosis, and the family would decide whether or not they would tell the patient the real situation; 30% of the oncologists answered they informed the family and the patient together; and 7% informed only the patient, and he/she would decide whether to tell the family or not. Regarding the information about the patient's lifetime expectancy, 25% of the physicians answered they informed about it most of the time and 66% do not provide this information often. The volunteers were asked about any physician-patient relationship problem arising from informing the patient about all the aspects of the disease, and the absolute majority (91%) answered that they face trouble seldomly or even never for appropriately informing the patient.

The information characteristics formed the fifth topic addressed in the data collecting questionnaire and 91% of the oncologists evaluated the information they provided to patients was complete. Regarding the use of medical terms when they informed the diagnosis, the prognosis and/or the treatment to patients, 70% of the volunteers stated that most of the time they used those terms, but 94% of the respondents answered they explained the medical term meanings to the patient.

Last, but not least, the topics psychotherapy indication in cancer patient care and palliative care were specifically addressed. Sixty per cent of the physicians participating in the survey referred their patients to psychotherapy. Twenty-three per cent of the respondents informed they seldom indicated it. Regarding palliative care, 89% of the oncologists told they informed patients about palliative care "most of the time" and only 7% of the doctors did not provide this guidance.

DISCUSSION

The number of subjects in the survey that returned the questionnaire appropriately completed was similar to the number of volunteers in other surveys using the same data collection technique and requiring the return from the survey subjects. The reports in literature addressing this technique state the response obtained is around 21.5% of return¹¹; thus, the number of subjects returning the data collecting questionnaire appropriately completed was as expected. In addition, it is important to stress that this data collection technique depends on the address of likely volunteers and a number of them changed their address, but did not update the information with the SBOC. Thus, the contact with the likely survey subjects was unintentionally lost.

Data collecting questionnaire (attached)				
Part I – General data				
1) Age				
years	() I do not know	() I do not want to answer		
2) Gender				
	() Female	() I do not know () I do not want to answer		
3) Time from graduation in Medicine				
years	() I do not know	() I do not want to answer		
4) Medical residency in Oncology?				
() Yes	() No	() I do not know () I do not want to answer		
5) What is the Brazilian region where you work:				
() Northern	() Southern	() Northeastern () Southeastern () Mid-Western		
() I do not kn	OW	() I do not want to answer		

Part II – Specific questionnaire
6) The information is provided at the first visit as a conduct of yours: () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
7) As for the diagnosis, you let the patient know about his(her) disease at the first visit: () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
8) Do you ask the patient what he(she) wants to know about his(her) disease? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
9) How often do you inform your patients about the cancer diagnosis? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
10) At the first visit, when the patient does not know the diagnosis, do you wait until the patient asks about the disease? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
11) As for the diagnosis, to whom do you provide the information? () The patient () The patient and the family () The family () The patient and spouse () Spouse () I do not provide any information () I do not know () I do not want to answer
12) Is the information to your patient changed depending on the patient's gender? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
13) Is the information to your patient changed depending on the patient's age?() Always () Most of the time () I do not know () Half the time() I do not want to answer () Seldom () Never
14) Is the information to your patient changed depending on the patient's socioeconomic status? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
15) Is the information to your patient changed depending on the patient's education level?() Always () Most of the time () I do not know () Half the time() I do not want to answer () Seldom () Never
16) Is the information to your patient changed depending on the prognosis?() Always () Most of the time () I do not know () Half the time() I do not want to answer () Seldom () Never
17) Is the information to your patient changed depending on the possibilities of treatment? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never
18) Is the information to your patient changed depending on the possibility of cure? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never

19) Do you provide information about the diagnosis, the treatment and the prognosis? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never			
 20) When the prognosis is poor, you: () Tell it is serious, but it is not a critical illness. () Inform the family, and the family decides whether or not to tell the patient everything. () Inform the family and the patient together. () Inform only the patient, and he(she) decides whether or not to tell the family. () I do not want to answer. 			
21) Do you give information about the lifetime expectancy?: () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never			
22) Have you ever had any problem in the physician-patient relation after informing the patient about all the aspects of the illness? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never			
23) How do you evaluate the quality of the information you provide to your patient? () It is always complete. () It is complete half the time. () It is never complete. () I do not know. () I do not want to answer.			
24) Do you use medical terminology when you are going to inform the diagnosis, the prognosis and/or the treatment to your patient? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never			
25) Do you explain the medical terms to your patient? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never			
26) Do you refer your patients to psychotherapy? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never			
27) In the case of patients in a critical status, do you inform about available palliative care? () Always () Most of the time () I do not know () Half the time () I do not want to answer () Seldom () Never			

The first part of the questionnaire regards the profile of the oncologists participating in the survey, and this profile was similar to that found for Brazilian physicians¹, (Table 2), who are still predominantly males. The volunteers' age groups, as well as the time from Medicine graduation, was in accordance with the time required for the oncologist's education to be concluded – a two-year residency in internal medicine at a first step and later a three-year specific residency in clinical oncology². The clinical oncology residency requirement clearly demonstrates the

obligation to fulfill that condition to practice this undeniably important and complex specialty. The Southeastern region concentrates the highest number of physicians, compared with the other regions, with this fact warranting the result found (Table 2).

Regarding the act of informing the patient about his/ her disease, there is a consensus stating that this conduct is required from a physician. According to the article 34 of the Code of Medical Ethics – CEM¹², the physician shall not leave the patient uniformed about the diagnosis, the

Table 2 – Total of physicians registered and actively practicing in Brazil

Region	Registered physicians	Practitioners
Northern	25,415	14,667
Northeastern	85,399	58,763
Mid-western	43,799	26,328
Southern	78,004	53,707
Southeastern	294,983	201,054

prognosis, the risks and the treatment objectives, except when the direct communication might cause any harm; in this case, a legal representative must be notified. The results found are in accordance with the CEM principle, as well as with the premisse in which it is understood that telling the about the patient's illness is shown to be an important and effective therapeutic tool. This conduct generates confidence and allows the patient to consciously exercise his/her autonomy13,14 and, as a result, the feeling of isolation is reduced, contributing to a mutual cooperation in the physician-patient relationship¹⁵. A survey developed in Japan demonstrated that most patients prefer to receive all the information about their disease¹⁶. However, even in the face of this statement, the premisse does not result in universal informing practice, including even diseases as serious as cancer¹⁷.

Transmitting bad news, as in the case of a cancer diagnosis, is an exceedingly complex situation and preparation and sensitivity are required to face it. Disclosing the diagnosis or not is until the present day an ethical conflict often experienced by the health team³. The moment to provide the information should be chosen by the physician from the patient's psychological condition. This moment requires sensitivity and must be carefully developed or it will turn out to be a cold report, in which the patient is not comfortable to ask all the questions he/she might have^{2,3,18}. In cases the patients have already been informed about the diagnosis, it should be the responsibility of the oncologist to provide further information on the disease, as well as the possibilities of treatment, prognosis and other kinds of care¹⁸.

Even experienced practitioners may have concerns about the best moment to inform the patient on the diagnosis. Most volunteers admitted providing this information at the first visit; however, the report that the patient is commonly aware of the diagnosis when he/she goes to the oncologist is frequent. This occurs because the patient sees first a doctor from another specialty and then, when a cancer is diagnosed, the patient is referred to an oncologist. Actually, there is no consensus about the best moment to provide the information on the disease; however, it is a consensus on always telling the truth to the patient^{3,19}.

Apart from the setting described above, in cases when the patients are not aware of the diagnosis, many oncologists admitted they wait until the patient asks questions about the disease in the first visit. By so doing, the physician's caution and the patient's time are considered, with the information becoming something not mandatory at first²⁰. Another option is to ask the patient what he/she wants to know about his/her illness, as receiving the information is a right, not an obligation. The patient should be asked about his/her desire to receive the information and, in case of a negative answer, he/she would tell to whom the information should be provided¹⁹.

The oncologists usually provide the information to the patient and the family together, probably because many patients come to see them accompanied by a family member. Such a situation could lead the physician to consider the patient implicitly authorizes the physician to provide all information in front of the companion²¹. However, the physician should always ask the patient if he/she can speak openly in the presence of the companion, as the confidentiality and privacy principles²² require such a precaution and attention; furthermore, some patients do not want other people to be aware of their condition, even family members. Other patients let the family make all decisions, even if they are fully capable²³. The patient and the family should be considered as having dynamics to cope with problems, but, in a setting like this, the system might be corrupted²⁴. The "cancer journey", the stages through which the patients and their caretakers go, may bring consequences for all people involved25 and, before the new facts, the family relation could undergo changes.

Another result regards the aspects the oncologists take into account upon informing the patient, and the absolute majority of respondents informed they had never given importance to the patient's gender, as the influence comes from the quality of autonomy the patient shows. In some special situations, the oncologists take into account the patient's socioeconomic status before informing him/her; however, what is to be considered is the education level, as it either can or cannot have a causal connection with the socioeconomic status and, as a consequence, with the patient's understanding the information that will be provided³.

Age is an often considered factor, as for too young or elderly patients, physicians, as well as the family usually have a patronizing attitude. In a study conducted with cancer patients about the diagnosis and prognosis comprehension, 79.3% of the subjects fully understood it was a malignancy; when this result was associated with age, the patients were found to be < 70 years old²⁶. However, it is important to stress the elderly and the too young patients will only have a reduced autonomy quality when their cognitive function is affected¹; otherwise, they must be considered entirely autonomous.

The prognosis is also considered by oncologists, as in more severe cases, the physician will be prone towards patronizing, considering it difficult to inform the patient and demonstrating an old prejudice regarding oncological patients - the idea that they would not like to know about their illness2. Finally, the possibility of cure makes the situation more comfortable if possible, but when there is not such a perspective, the conflict about informing or not is created. However, even patients with a progressive and incurable disease need to understand what is occurring with them and their body; they need to participate in the decision-making processes on how they are going to live their remaining days². A number of oncologists admit informing the diagnosis in critical disease cases only in the following situations: the patient asks directly about the situation; the patient is observed to be emotionally stable; the treatment is not effective; when there are important decisions to be made about the treatment⁴.

As for the content and coverage of the information the oncologists provided to patients, the result showed the volunteer practice was in accordance with the ethical principles adopted by the Code of Medical Ethics12 thus stimulating the patient to exercise his/her autonomy. However, in the case of a poor prognosis, it was evident the conduct can change, as most oncologists told they did not inform the severity to the patient if he/she had no companion. When the severity was informed, they did it in the presence of a family member and, in other cases, they would tell the family members, who decided what to do. On this issue, a number of authors admit that informing the diagnosis is different from telling the prognosis, as the same patient who desires to receive all the information about the diagnosis might not desire to be informed about the prognosis14. Therefore, considering the situation is required, since considering that the non-communication as a conduct to "preserve" the patient is underestimate the reality of facts. The real objective if often the physician protection, as he/she find him/herself helpless before his/her limitations "to cure", insecure at instructing and unprepared to "care"². This phenomenon is a reflection of the physicians' background in the graduation course, as they are prepared to save lives and the opportunities to discuss themes regarding death are few, even death coming after an illness natural process pertaining to human condition².

The oncologists participating in the survey evaluated the quality of the information they provided to their patients was always or almost always complete; however, these same practitioners told they not always informed everything to the patient. In this case, an incongruity is realized among the results, and the oncologists' evaluation might be mistaken, as not providing all the information to patients should be an exception. A study conducted with adolescents surviving cancer reported these patients were aware of the disease, participated in the decisions

on treatment, including the topic end of life, made their decisions autonomously and excluded their parents from the process²⁷. Informing the patient does not assume the physicians will be in trouble; most of them never or just a few times had to go through any conflicting situation from appropriately informing the patient.

Continuing with quality of information, many oncologists admit the use of technical terms, but most of them explain the medical terminology meaning to their patients, thus avoiding communication interpretation problems. A survey showed 39% of physicians still does not succeed in explaining the problem clearly and comprehensively to their patients; in 58% of visits, the level of the patient's understanding on their diagnosis was not established³. Medical terminology pertains to the practice and the physician is responsible for explaining, in a clear and reachable language, all aspects of the disease so that the patient feels comfortable and asks the doctor what he/she wants to know and what is not completely understood.

Referring the patient to receive psychological support is a practice that should be used more often to assist the patient and the physician to cope with those situations, notably in cases with a poor prognosis. Oncological patients need to be attended by a multidisciplinary team, as they especially want psychological support, often needed by the families as well. Referring patients with cancer to psychological therapy will give them the appropriate support to face the situation and fully exercise their autonomy. Therapy targets are also the patient learning to face and managing positive and negative events satisfactorily²⁸.

The last topic discussed regards palliative care⁵, since in many cases patients with cancer will require this kind of care, being the oncologist responsible for informing the patients on their availability when they are the best option. A number of studies demonstrate physicians do not know how to address end of life themes when dealing with patients and they likely associate this conduct with a neglect of the correct prescription to relieve the symptons³⁰. In case there are no further possibilities of oncological treatment, sincerity does not mean telling the patient there is nothing else to be done, as palliative care should not be underappreciated²¹. Palliative care will ensure quality of life to patients and will supply the family with conditions to cope with the situation in the best way possible, consequently meeting the patient's needs.

CONCLUSION

In view of the results presented, we can conclude the study population noticeably has the concern to inform the patient, fitting the patient's profile and characteristics. The oncologists are noticed trying to address the information and providing the patients with that they are entitled to – the truth; nevertheless, they often resort to the family

for assistance in providing the information. The physician is responsible for providing all explanations to favor the patient's full exercise of autonomy, as information is the cornerstone for an autonomous decision making.

Palliative care experience is also recommended for most patients. Another important issue in the oncologist's conduct – referring the patients to psychotherapy – is not as valued as is should, even though an interdisciplinary team work is mandatory in the care of patients with cancer.

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