Perception of oncology patients on the terminality of life

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Abstract

With the aim of analysing the perception of cancer patients towards the end of life, a questionnaire was applied to 100 oncologic patients, of which 85% were unaware of living will/advance directives, 81% were unaware of the terms palliative care and 70% were unaware of order to not reanimate. After clarifying the meaning of the terms used, 62% agreed to make living will/advance directives, 82% to receive palliative care at home and 64% to be reanimated in any situation, but the majority (73%) disagreed with the practice of futility. Only 11% reported inadequacies in the communication of their diagnosis by the physician. The fact of having metastases elicited a broader reflection on the termination of life. The results allow to infer that it is necessary to encourage the discussion about termination of life to the population during patient care, as well to promote the respective training to health professionals since the undergraduate course.

Keywords: Terminally ill. Oncology service, hospital. Palliative care. Living wills. Resuscitation orders.

Resumo

Percepção de pacientes oncológicos sobre terminalidade de vida

Objetivou-se analisar, por meio de pesquisa descritiva, a percepção de pacientes oncológicos diante da terminalidade da vida. Aplicou-se questionário para 100 pacientes oncológicos, dos quais 85% desconheciam testamento vital/diretivas antecipadas de vontade, 81% desconheciam cuidados paliativos e 70% desconheciam ordem de não reanimar. Após esclarecimento sobre os termos empregados, 62% concordariam em elaborar testamento vital/diretivas antecipadas de vontade, 82% concordariam em receber cuidados paliativos no domicílio e 64% em ser reanimados em qualquer situação, mas a maioria (73%) discordou da prática de distanásia. Apenas 11% referiram inadequação na forma de comunicação de seu diagnóstico pelo médico. A presença de metástases suscitou reflexão mais ampla sobre terminalidade da vida. Os resultados permitem inferir que é necessário incentivar a discussão sobre terminalidade da vida na população durante a assistência aos pacientes, bem como estimular o debate sobre o assunto durante a formação de profissionais de saúde.

Palavras-chave: Doente terminal. Serviço hospitalar de oncologia. Cuidados paliativos. Testamentos quanto à vida. Ordens quanto à conduta (ética médica).

Resumen

Percepción de los pacientes oncológicos sobre la terminalidad de la vida

Con el fin de analizar la percepción de los pacientes con cáncer frente al final de su vida, a través de una investigación descriptiva, se aplicó un cuestionario a 100 pacientes de cáncer, entre los cuales el 85% desconocía las directivas anticipadas de voluntad, el 81% desconocía los términos de cuidados paliativos y el 70% desconocía la orden de no reanimar. Después de la clarificación del significado de los términos utilizados, el 62% estaba de acuerdo para elaborar su testamento vital/directivas anticipadas de voluntad, el 82% para recibir los cuidados paliativos en el hogar y el 64% para ser restablecido en cualquier situación, pero la mayoría (73%) no estuvo de acuerdo con la distanasia. Tan sólo el 11% consideró inadecuada la comunicación del diagnóstico por el médico. El hecho de portar metástasis amplió la reflexión sobre el final de la vida. Los resultados muestran que es necesario fomentar la discusión del final de la vida en la población durante la atención al paciente, y promover la respectiva formación a los profesionales de la salud desde el pregrado.

Palabras clave: Enfermo terminal. Servicio de oncología en hospital. Cuidados paliativos. Voluntad en vida. Órdenes de resucitación.

Aprovação CEP-Unoesc 752.502/2014

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Declaram não haver conflito de interesses.

http://dx.doi.org/10.1590/1983-80422017252199

During the termination of life, the patient may be faced with unusual situations in which it is difficult to decide about health care, among which are: receiving bad news, palliative care, advance directives (living will), order not to reanimate and dysthanasia. In Brazil, the communication of bad news had a significant advance with the dissemination of the Spikes Protocol, but its insertion in undergraduate education is recent[1]. The creation of an area of medical activity in palliative care by the Conselho Federal de Medicina - CFM (Federal Council of Medicine)[2] reflects the present intention to encourage its development with the goal to improve the care of patients that need them.

Although there is no federal law about this, the approval of CFM Resolution 1995/2012[3] made the acceptance by physicians of the advance directives feasible and favored their acceptance by patients. The Carta dos Direitos dos Usuários da Saúde (Health Users' Rights Charter)[4] assured to the patients the right to choose the place of death, appointment of a representative and the possibility of refusing treatment. Concerning the order not to reanimate, there is no explicit official guideline in Brazil, but there are ethical[5] and legal[4] norms with the goal of preventing the practice of dysthanasia. In this context, the importance of investigating the perception of patients in relation to different aspects of health care arises, especially when there is no therapeutic possibility. Thus, the goal of the present study was to describe the perception of oncology patients in the face of several aspects of the terminality of life.

Methods

This was a cross-cutting quantitative, applied and descriptive study, in which 100 oncology patients of both genders and above the age of 18, present at the oncology sector of the Santa Terezinha University Hospital ("Hospital Universitário Santa Terezinha", HUST) in Joaçaba, Santa Catarina, Brazil, were interviewed between August and November 2014. The type of cancer and the treatment were not relevant for the purposes of this study. The inclusion criteria included patients on cancer treatment at HUST during the study period who agreed to participate after reading and understanding the informed consent form (ICF), presented by the researchers and approved by the CEP HUST / Unoesc.

The exclusion criteria were restricted to cases in which the participant did not have an interest in collaborating with the research or in accepting the ICF content. Literate patients received questionnaires to respond on their own; the questions were read by the researchers to those who could not read, and the answers were recorded in the assessment tool. The choice of this hospital was due to the fact that it is classified as a high complexity service for cancer treatments in the health care network of the Sistema Único de Saúde - SUS (Unified Health System).

This institution is a reference service in the area for the municipalities that comprise the macro health region in the Midwest of the State of Santa Catarina, a condition that allowed access to patients coming from different municipalities. In Santa Catarina, this macro region is composed of the midwestern, Alto Vale do Rio do Peixe and Alto Uruguai Catarinense regions, comprising 59 municipalities and encompassing an estimated population of 623,446 inhabitants, according to a projection of the Instituto Brasileiro de Geografia e Estatística - IBGE (Brazilian Institute of Geography and Statistics) for 2016[6].

For data collection, a structured questionnaire with 21 multiple choice questions was elaborated. These questions comprised socio-demographical data, the type of cancer, the presence of metastases and self-assessment of the quality of life after the cancer diagnosis. Also, these encompassed the physician-patient and physician-family relationship and the knowledge of the patient on living will and advance directives, palliative care and order not to reanimate. The questionnaire was applied through a direct interview with participants in a private environment, adequately prepared for this purpose.

The statistical analysis was performed using the Microsoft Excel software, using the chi-square test with a 95% confidence interval. Based on the results, the following statistical correlations were investigated: dysthanasia and advance directives × gender, age and knowledge; place where palliative care was received × knowledge; and a reflection on the terminality of life × presence of metastases.

Results

According to the socio-demographical data, females prevailed among the research participants (63%), as well as the age groups from 20 to 39 and 40 to 49 years of age (both with 44% of participants), followed by the group above 60 years old (12%), and the marital status "with partner" (63%). About schooling, 68% had elementary school studies, 23% had high school studies, 6% had college studies, and 3% declared to be illiterate. The predominant religion was catholic (77%), followed by evangelical (18%), spiritist (1%), protestant (1%) and others (3%). About the location of the cancer, the most affected organs/ tissues were the breasts (39%), followed by the intestines (13%), uterus (7%), lymphomas (5%), lungs (5%), stomach (4%), prostate (4%), bladder (3%), skin (3%), cervix (2%), throat (2%), bones (2%), rectum (2%) and others (9%). Metastases were reported by 35% of the patients at the moment of the interview.

In the self-assessment on quality of life after the cancer diagnosis, performed through a scale from 0 to 10 points, the average was 7.74 – zero meaning (poor quality of life) and ten (meaning excellent quality of life). In this self-assessment, 16% marked a grade less than or equal to 5 points and 84% marked a grade greater than 5, it is noteworthy that 32% opted by the grade 10. In what concerns the communication about the disease, according to 89% of the patients the physician was careful when informing the diagnosis and provided adequate explanations to their understanding, while in the other extreme of the scale, 11% understand that the physician did not fulfill these requirements.

Regarding the doctor's attention to the family in the diagnosis, 95% of the patients understood that they were sufficiently careful and adequate, but 5% disagreed (Table 1). Faced with the hypothesis of cardiorespiratory arrest in patients with severe and terminal diseases, 64% of cancer patients stated that they wished to be reanimated in any situation and 36% disagreed. Most of the patients (51%) had never thought that the cure was no longer possible and 49% had considered the issue, of which 31% thought about it very much or occasionally. In the terminal phase of life, with severe and incurable disease, 27% agreed to be kept alive only by apparatus (dysthanasia) and 73% disagreed (Table 1).

Patients were asked about four situations that may arise during the termination of life. In response, 95% stated that they had not received any estimate of remaining life expectancy by the attending physician, 81% did not know about palliative care, 85% did not know about living will or advance directives, and 70% did not know or had heard about order not to reanimate (Table 2).

Regarding the place to receive palliative care, 82% of the participants stated that they would like to be cared for at home, and 18% at a hospital. When asked about who should decide their treatment in relation to the terminality of life, 42% of the patients would like to decide with the physician and the family, 16% would leave the decision to the physician alone, 13% would like the family and the physician to decide together, 11% would prefer to decide on their own, 7% only the family, 6% with the family and 5% with the physician. Correlations of patients' perception about the terminality of life were studied, which were not significant in relation to gender, age, knowledge and presence of metastases ($p > 0.05$). However, the occurrence of metastases led to a greater number of patients thinking about termination of life, and this result was very close to being significant ($p = 0.0772$).

Table 1. Perception of oncology patients on the communication of diagnosis of disease without the possibility of cure

Question	Possible answers	%
1. Was the physician careful when giving you the diagnosis and did th e physician explain about your disease ?	Fully agree Partially agree Partially disagree Fully disagree	58 31 7 4
2. Was the physician attentive to your family when giving the diagnosis?	Fully agree Partially agree Partially disagree Fully disagree	70 25 3 2
3. In case of cardiorespiratory arrest with serious and incurable disease, would you agree to be reanimated in any situation?	Fully agree Partially agree Partially disagree Fully disagree	36 28 17 19
4. In a situation of termination of life, with severe and incurable disease, would you agree to be kept alive only by apparatus (dysthanasia)?	Fully agree Partially agree Partially disagree Fully disagree	12 15 32 41
5. Have you ever thought about being in a situation in which the cure is no longer possible?	Very much Occasionally A little Never	14 17 18 51

Table 2. Perception of oncology patients about the terminality of life

Question	Yes (%)	No (%)
1. Did the physician give you any estimate of life expectancy?	5	95
2. Do you know or have you heard about living will or advance directives?	19	81
3. Do you know or have you heard about living will or advance directives?	15	85
4. Would you like to make your living will or advance directives and have them respected by the physician and your family at the end of life?	62	38
5. Do you know or have you heard about "order not to reanimate"?	30	70

Discussion

Most patients were women. Due to their predominance in the population, breast cancers, the second most frequent in women[7], and uterus cancer, the third most frequent, have possibly contributed to the prevalence of females. The age group over 40 years old predominated, which shows an increase in oncological diseases with age. Most of the participants had not reflected on the possibility of having an incurable disease. However, when only patients with metastasis (35%) were analyzed, it was observed that the severity of the disease elicited more frequent reflection on the terminality of life and the result was very close to being statistically significant ($p = 0.0772$).

When participants were asked about their quality of life, the average grade was high (7.74). This self-assessment has a subjective, complex and multidimensional nature, besides containing a wide variety of internal and external conditions, defined by the individual[8]. Thus, even being a cancer patient, the disease does not prevent the patient from presenting a high degree of satisfaction and well-being in their process of living. The physician was careful in giving the diagnosis and explaining about the disease in the perception of nearly all patients.

The research participants wish to have information that allows them to choose alternatives and control decisions during the end of life[9]. However, one study pointed out that many would like to receive more information than they had received[10]. The clarifications contribute for the previous experiences of family members about death and the end of life not to have a negative influence in the moment of decision[11]. In this study, 11% of the patients were not satisfied with the physician-patient relationship, which is, thus, a fragility to be overcome. Talking to the family about aspects of the disease contributes for the team to understand how the experience is being lived by the patient and, thus, for them to be able to help the patient to make decisions concerning his/her future[11].

Although with reservations about the consequences, informing the prognostic is the duty of the physician, which is clearly provided for in article 34 of the Code of Medical Ethics[12]. Fewer than half of the patients discussed their vital prognosis with the physician and nearly all of them (95%) did not receive an estimate of life expectancy, a fundamental condition for planning the future in the case of a serious disease. In this context, the information needs to be gradual and bearable on order for communication to bring fewer harms than benefits. This result is in conformity with a recent multinational study in which interviewees were asked if they had talked to a physician or another health professional about their desires regarding the care at the end of life. There was a negative answer from 88% of North Americans, 87% of Italians, 93% of the Japanese and 90% of the Brazilians[13].

In relation to palliative care, most of the patients stated that they did not know about them. It is inferred that in-depth discussions on issues related to the termination of life will contribute to greater knowledge and better co-participation of the patient in making decisions related to his life and the form of his end. On the one hand, the scope of palliative care goes beyond the physical and biological limits of the patient, reaching its singularity and its biopsychosocial context[14]; on the other hand, when the patient and/or his/her family are not properly oriented about the consequences of the disease and the possible behaviors to minimize them, they are prevented from assuming conscious position in the process of death with dignity[15].

However, palliative care has gradually grown as a concern for professionals, especially those in the area of oncology in the sense of allowing the patient to accept their pain and suffering, without adequately discussing the therapeutic options, and neglecting support to the family in matters of suffering for the loss of the loved one[14].

Few patients (15%) were aware of the terms "living will" or "advance directive". The terms were considered as synonymous for the purpose of the research. However, a living will consists of the manifestation of will over the care that the patient wishes to receive or not receive, whereas advance directives, in addition, include the possibility of appointment of representative and allow the manifestation of other wills, such as organ donation.

The inclusion of the two expressions in the same question allowed for bias in the result. However, an earlier study on the living will, performed with cancer patients and their companions, found similar results[16], signaling that this subject remains restricted to the academic environment, with incipient popularization, distant from the public domain. After the explanation of the terms, the interviewees were asked about the willingness to prepare the document and have it respected in an end-of-life situation, and an affirmative response was obtained from the majority (62%).

There was no significant variation between genders, age and previous knowledge about the terms. In the study by Campos et al.[16], acceptance among patients was even higher, with 9.56 points on a 0-10 scale, thus showing the desire of the patient to broadly exercise his/her autonomy. In the United States, 27% of the interviewed informed they had a written document with record of their will; among Hispanics, however, only 11% confirmed that[17]. The Brazilian society needs to intensify the debate the terminality of life, recognizing that the living will contributes to the autonomy and dignified death of the patient[18].

The elaboration of the living will favors the dialogue between family members, physician and patient in order to respect to the maximum the patient's preferences about care in the end of life[19]. A national awareness campaign on advance directives, especially associated with the clarification of physicians and other health professionals, is needed to the better understanding by families about the fulfillment of patients' wishes[20]. In this context, promoting the bioethical reflection will allow the advance directives to be consolidated as an instrument to fulfill the wishes previously expressed by the patient[21].

Regarding the order not to reanimate, 70% of the patients did not know the expression. However, after being clarified about the meaning, most of them would agree to its use if it were in the end of life. The reflection on this theme is not frequent in the literature. A previous study, conducted in the same region, showed that 10% of the physicians did not know the term[5], showing that its approach by medical schools is not systematic. The lack of ethical and legal orientation is a factor that probably contributes to the lack of knowledge in Brazil, raising the need for regulation.

Most patients never thought that they could be in a situation where a cure was no longer possible. This shows the tendency of little reflection about the end of life among the population, except when the disease gets worse, as occurred in relation to the presence of metastases. This observation is corroborated by the finding that the majority of patients - of those who have never heard of palliative care - would choose to receive them if they were terminally ill, after the interviewers clarified the term. However, it is possible that, after responding to this questionnaire, participants included death in their reflections, a fact that, among the positive aspects, could contribute to their life planning.

A multinational survey has shown that death is a subject avoided by 69% of respondents in the United States, 63% in Brazil, 61% in Italy and 57% in Japan[13]. However, not thinking about the end of life can be a strategy for the individual to maintain a positive outlook while avoiding depression. In addition, the taboo that involves the concept of death in the population also seems to have contributed to the little reflection among the participants.

Regarding decision-making at the end of life, the patients' preference was for the joint participation between doctor and family, besides the patient. In the study by Campos et al.[16] about living will, the preference among patients was for the decision by the family, followed by that of the patient and then, the physicians. The joint decision between only the physician and the patient came in last place. Among medical students, the preference of 62% was also for the consensus among the patient, the physician and the family[21], which favors the balance in decision-making and preserves the autonomy of the patient.

In a survey comparing the population of four countries, the preference of respondents for end-of-life decisions was for sharing these between the patient and the family, whereas the preference for medical-only decision ranged from 8% in the United States and 10% in Japan to 30% In Italy and 40% in Brazil[13]. The result among Brazilian respondents was higher than that found in our study (16%), revealing a new trend in relation to the valorization of autonomy. Most patients would choose to receive palliative care at home if they were terminally ill.

In a study by Frizzo et al.[22], performed with medical students, the majority responded that the place of death should be decided by the patient with the family. In a survey of 50 students in the 5th year of medical school at the Universidade Nove de Julho in São Paulo[23], 40% of the subjects answered that the patient in end of life deserves to spend the time that he/she has left with the family. Hospitals are places that, in general, do not give the family free access to the patient, thus hindering the freedom to express the emotional state.

In cases of patients with no therapeutic possibility, this experience of withdrawal can be traumatizing, both for patients and their families, even making the mourning process difficult[24]. Dying at home was also the preference of 71% of Americans, 61% of Italians, 55% of Japanese and 64% of Brazilians[13]. In this context, it should be noted that many home visits are made by physicians in the beginning of their careers, who only have undergraduate degrees. In a survey conducted in medical school[22], only 58.9% of the students in the last year felt prepared for the practice of palliative care, showing the need for a stronger emphasis on the teaching of this subject which has recently become an area of medical activity[2].

Most of the patients agreed to being reanimated in any situation in case of cardiorespiratory arrest. This presupposes the fact that many did not know the implications of an unsuccessful reanimation. A north american study[25] showed that 79% of the patients interviewed thought that cardiorespiratory reanimation was successful in 50% to 90% of the cases and wished to be reanimated. However, after being informed that the rate of success is below 25% and that severe damages to the organs are frequent, only 52% still wanted to be reanimated in any situation, showing the importance of disseminating information about the proceeding to guide the decision.

In Brazil, in a survey performed only with physicians, 93% would disagree to reanimate a family member in any situation[5], showing the value of knowing the consequences of the proceeding. Most patients also disagreed with the possibility of been kept alive only by apparatus in a situation that configured dysthanasia. This result agrees with the study by Campos et al.[16], which surveyed the preference of patients about orthothanasia, euthanasia and dysthanasia, the preference for dysthanasia being minimal: a grade of 2.07 in a scale from 1 to 10 points.

The Health Users' Rights Charter[4], the sole paragraph of article 41 of the Code of Medical Ethics[12] and CFM Resolution 1805/2006[26] are devices that contribute greatly to protect the patient against futile and/or obstinate measures in the health care. The elaboration of an advance directive that contains the patient's wishes and the designation of a representative can preserve the patient's autonomy and avoid dysthanasia if this is his/her desire[18,27].

Final considerations

Contrary to common sense, which correlates cancer with negative implications on quality of life, this study showed that, even after diagnosis, patients can present a high degree of satisfaction and well-being in their life process. Another contribution of this study was to show that the knowledge of the meaning of the terms or expressions "order not to reanimate", "palliative care", "living will" or "advance directives" and "dysthanasia" can change the stance of patients in situations of termination of life. It was undoubtedly evidenced that the lack of positioning on these issues occurs mainly due to lack of knowledge.

The results of this work corroborate the literature discussed, indicating a near consensus as to the best place for someone to finish their days, preferably at home, near the loved ones, also considering as most appropriate treatment that defined by the patient-doctor-family trinomial. Most patients said the doctor was careful in giving the diagnosis and information about cancer, in addition to being considerate of the family and the patient. However, there was some disagreement.

In addition, it is necessary to consider the fact that currently a significant portion of house calls are performed by doctors in the beginning of their careers. This points to the need and importance of improving the approach to life termination issues in undergraduate medical education. In this context, it is possible to infer that the discussions about such important subjects still remain restricted to the academic environment and, therefore, very far from the public domain.

The importance of knowing, discussing and presenting this diagnosis to the patient is fundamental to the physicians who experience this situation in their professional practice. This signals the need to adopt strategies to democratize this knowledge, between professionals and society, improving the access of users to public and private health systems. This action will broaden and qualify the patient's participation in the decision-making process related to his or her life and the form of termination.

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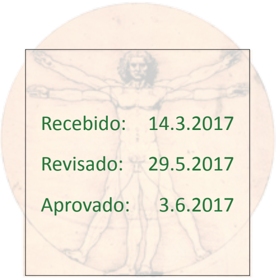
Participation of the authors

Lauren Tana Comin and Marina Panka contributed with the study design and data collection. Vilma Beltrame and Jovani Antônio Steffani participated in the data analysis. Elcio Luiz Bonamigo cooperated with the study design, research development and data analysis. All authors collaborated to the writing of the article.



Recebido: 14.3.2017
Revisado: 29.5.2017
Aprovado: 3.6.2017

Annex

Questionnaire

1. Gender:
( ) Female ( ) Male ( ) Other

2. Age: _______

3. Marital Status:
( ) Single ( ) Married ( ) Widow(er) ( ) Separated ( ) Stable Union ( ) Other

4. Schooling
( ) Illiterate
( ) Incomplete elementary school
( ) Elementary school graduate
( ) Incomplete high school
( ) High school graduate
( ) Incomplete college
( ) College graduate

5. Profession: ____

6. Religion:
( ) Catholic
( ) Protestant
( ) Spiritist
( ) Evangelical
( ) Others

7. Type of cancer: ____

8. Are there metastases?
( ) Yes ( ) No

9. Give a grade, from 1 to 10 for your quality of life after the diagnosis of the disease: ___

10. Do you agree that the physician was careful when giving you the news and explained about your disease at the time of the diagnosis?
( ) Fully agree
( ) Partially agree
( ) Partially disagree
( ) Fully disagree

11. Do you agree with the statement that the doctor was attentive to you and your family?
( ) Fully agree
( ) Partially agree
( ) Partially disagree
( ) Fully disagree

12. Did the physician give you any estimate of life expectancy?
( ) Yes ( ) No

13. Do you know or have you heard about palliative care?
( ) Yes ( ) No

14. Do you know or have you heard about living will or advance directives?
( ) Yes ( ) No

15. Would you like to make your living will or advance directives and have them respected by the physician and your family at the end of life?
( ) Yes ( ) No

16. Do you know or have you heard about “order not to reanimate”?
( ) Yes ( ) No

17. Have you ever thought about being in a situation in which the cure is no longer possible?
( ) Very much
( ) Occasionally
( ) A little
( ) Never

18. In this situation. Would you like to receive care and medication to alleviate pain and sufering (palliative care):
( ) At home, with the family
( ) At the hospital
( ) In another place. Where? ____

19. In this situation, who would you like to decide about your treatment?
( ) A physician
( ) Yourself
( ) Family members
( ) You and your family
( ) You and the physician
( ) The physician and your family
( ) The physician, the family and you

20. In case of cardiorespiratory arrest (when the heart stops functioning and the individual stops breathing, it being necessary to perform cardiac massage for the heart to start beating again), with serious and incurable disease, would you agree to be reanimated in any situation?
( ) Fully agree
( ) Partially agree
( ) Partially disagree
( ) Fully disagree

21. In a situation of termination of life, with severe and incurable disease, would you agree to be kept alive only by apparatus (dysthanasia)?
( ) Would fully agree
( ) Would partially agree
( ) Would partially disagree
( ) Would fully disagree