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Advance directives and cancer: oncology practices in Brazil

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Abstract

Data on advance directives in Brazil are lacking. This study aims to assess the understanding of oncologists regarding advance directives and the frequency with which they discuss advance directives and advance care planning with their patients in Brazil. This is an observational, descriptive and cross-sectional study, conducted with cclinical oncologists associated with the Brazilian Society of Clinical Oncology. Participants were invited to answer a questionnaire prepared by the authors. In total, 72 physicians answered the questionnaire, of which 73% were under 45 years old and 56% worked in oncology for less than 10 years. Regarding the limits of intervention and end-of-life care during treatment, 54.2% of respondents reported not discussing it. Although 67% of oncologists know the term advance directives, they do not develop them with their patients and 57.2% do not perform advance care planning. Most oncologists in this study do not set advance care planning and advance directives for most patients.

Keywords: Advance directives. Advance care planning. Palliative care.

Resumo

Diretivas antecipadas e câncer: práticas oncológicas no Brasil

Considerando a escassez de informações sobre diretivas antecipadas no Brasil, este estudo investiga a compreensão de oncologistas quanto a diretivas antecipadas e a frequência com que discutem sobre diretivas antecipadas e planejamento antecipado de cuidados com seus pacientes. Um estudo observacional, descritivo e transversal foi conduzido com oncologistas clínicos afiliados à Sociedade Brasileira de Oncologia Clínica. Os participantes foram convidados a responder a um questionário preparado pelos autores. No total, 72 médicos responderam ao questionário, dos quais 73% tinham menos de 45 anos de idade e 56% trabalhavam em oncologia há menos de 10 anos. Com relação aos limites de intervenção e cuidados de fim de vida durante o tratamento, 54,2% dos entrevistados relataram não discutir o assunto. Embora 67% dos oncologistas conheçam o termo diretivas antecipadas, eles não as discutem com seus pacientes e 57,2% não realizam planejamento antecipado de cuidados. A maioria dos oncologistas deste estudo não estabelece planejamento de cuidados antecipados e diretivas antecipadas para a maioria dos pacientes.

Palavras-chave: Diretivas antecipadas. Planejamento antecipado de cuidados. Cuidados paliativos.

Resumen

Directivas anticipadas y cáncer: prácticas oncológicas en Brasil

Dada la escasa información sobre directivas anticipadas en Brasil, este estudio analiza si los oncólogos conocen las directivas anticipadas y si discuten el tema con sus pacientes o realizan la planificación anticipada de atención. Este es un estudio observacional, descriptivo y transversal, realizado con oncólogos clínicos afiliados a la Sociedad Brasileña de Oncología Clínica. Se aplicó un cuestionario elaborado por los autores. Participaron 72 médicos; el 73% tenían menos de 45 años y el 56% llevaban trabajando menos de diez años en oncología. Respecto a los límites de la intervención y los cuidados al final de la vida durante el tratamiento, el 54,2% de los participantes no trataban del tema. Aunque el 67% de ellos están familiarizados con el término, no lo comentan con sus pacientes, y el 57,2% no realizan una planificación anticipada de atención. La mayoría de los oncólogos no hacen la planificación anticipada de atención ni las directivas anticipadas.

Palabras clave: Directivas anticipadas. Planificación Anticipada de Atención. Cuidados paliativos.

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Advance directives (AD) were regulated in 2012 in Brazil by the Federal Council of Medicine (CFM) Resolution 1,995[1], which provides for the registration of AD in medical records based on the patient´s will regarding the type of care and treatment a patient wants, or not, to receive when they are unable to express their will freely and autonomously. The resolution consolidated discussions taking place in Brazil since 2006, when CFM, through Resolution 1,805[2], recognized palliative care and the restriction of medical investments in incurable, progressive and terminal diseases as an ethical and humane practice.

Cancer patients who set AD and discuss advance care planning (ACP), end-of-life care and quality of death and who are more involved in decision-making about their care are more likely to receive care according to their choices, undergo fewer intensive care unit admissions and unnecessary life extension measures, present higher hospice care and death at home rates[3-6].

The frequency of AD among cancer patients is widely different between countries. While little data about AD exist for the Brazilian population and patients with cancer, in the United States, where AD has been discussed within society since the 1970s, the frequency of AD in patients with cancer can be as high as 88%[7] and, in Canada, between 45% and 53%[8,9].

Nonetheless, studies with patients with cancer in the United States, since the 1990s, have shown a very low preference (only 9%) of patients for discussing ACP with their oncologist[10] and only 7% for discussing the preparation of AD[11]. Likewise, the study by McDonald and collaborators[9], in Canada, demonstrates the even lower participation of oncologists, in which only 1% prepared AD with patients with cancer.

In 1998, the American Society of Clinical Oncology (ASCO)[12] conducted a survey on the ability of oncologists to deliver bad news and found that 45% of participants reported difficulty in talking about the end of curative treatment and starting palliative care, 58% in being honest without taking away hope, and that 42% had not received specific training in breaking bad news[12].

Since 2012, ASCO[13] and the European Society for Medical Oncology (ESMO)[14], advocate the integration of palliative care by oncologists for patients with cancer, so that patients express their preferences and wishes for care as early as possible. ESMO[14] highlights ACP, which involves communication from the physician, patient desires, as well as listening to and understanding how the patient wants to be treated and cared for if they are unable to make a decision, either in the final moments of life, as a do-not resuscitate (DNR) order, or in the course of oncological monitoring. ASCO focuses its guidelines on oncology patients with metastatic disease and prognosis between 6 to 24 months of life, suggesting the need to approach such individuals, ideally in the first 8 weeks of monitoring, regarding the disease's diagnosis, treatment and prognosis, and on the patients preferences regarding care or interventions—whether to receive them or not—and filling out their AD[15].

The aim of this study is to assess the understanding of oncologists regarding AD and the frequency with which they discuss AD and ACP with their patients.

Method

This is a descriptive, cross-sectional study, with a convenience sample composed of clinical oncologists who are members of the Brazilian Society of Clinical Oncology (SBOC), work in Brazil taking care of patients diagnosed with cancer and aged over 18 years. SBOC currently has 2290 clinical oncologists associated. Invitations to participate in the study were sent by email through SBOC, with a consent form and the questionnaire attached.

The authors formulated the questionnaire based on the recommendations of ASCO and ESMO on palliative care, AD and ACP[13-15] for patients diagnosed with cancer in general and lung cancer. The latter is representative of advanced cancer, as it is usually diagnosed locally advanced or at metastatic stage, with a prognosis of between 6 and 24 months of survival.

The questionnaire included data on the physicians such as: gender, age, years of experience in oncology practice and work in the public or private health system. The questionnaire assesses the frequency of medical oncology practice regarding: early discussion of cancer prognosis and treatment, in the initial 8 weeks of monitoring, for more than half (> 50%) of their patients, or for less than half (≤ 50%), for those with general and advanced lung cancer diagnoses (stages III and IV); question patients with advanced cancer about their end-of-life care preferences and their desire or not to limit medical interventions; talk with patients about expressing care preferences and prepare ACP for more than half (> 50%) of their patients or less than half (≤ 50%) with lung cancer.

To assess the oncologist's understanding of the term AD and its usefulness in clinical practice, they were asked to choose one of four statements, which could better translate their understanding and applicability:

1. I do not know or I am not familiar with the term AD.
2. I know the term AD, but its applicability is not incorporated in my clinical practice.
3. I know the term AD but I do not elaborate AD for all patients, only about 25% of them.
4. I know the term AD and, according to the patients' wishes, its applicability is incorporated into my clinical practice.

Data collection to place between January and March 2020, then being tabulated and analyzed using the 2010 version of Microsoft Excel software and the R software version R4.0.4 for Windows. First, the absolute and relative frequencies of the variables were calculated. The medical variables were correlated with medical oncology practice variables related to the discussion of the prognosis and treatment, provision of palliative care, end-of-life care preferences and their desire or not to limit medical interventions and prepare ACP in lung cancer.

Fisher's exact test was used when at least one of the frequencies was lower than 5. For those with frequencies greater than 5, the chi-square test was applied. The confidence level of the tests was 95%, that is, the null hypothesis was rejected when $p \geq 5\%$.

The research was carried out in accordance with the *Declaration of Helsinki* [16] and approved by the Research Ethics Committee of the Universidade do Estado da Bahia (UNEB).

Results

In total, 72 Oncologists answered the questionnaire, of which 44% (n=32) were male and 56% (n=40) female. Most oncologists 73% (n = 49) were under 45 years old and 55.6% (n=40) had less than 10 years as oncologists, whereas 44.4% (n=32) had worked in the specialty for more than 10 years. In total, 96% (n=69) worked in the private health system and 57% (n=41) in the public health system (Table 1).

Table 1. Demographic profile and clinical characteristics of physicians

Characteristics	n	%
Gender		
Male	32	44.4
Female	40	55.6
Age*		
≤ 45 years old	49	73.1
> 45 years old	18	26.9
Experience		
≤ 10 years	40	55.6
> 10 years	32	44.4
Working in SUS		
Yes	41	56.9
No	31	43.1
Working in the private sector		
Yes	69	95.8
No	03	4.2

SUS: Brazilian Unified Health System; n=66

Regarding patient autonomy based on clarification, sharing and decision making, 84% (n=61) of oncologists discuss diagnosis, prognosis and treatment within the first 8 weeks of diagnosis for more than half of patients with a general diagnosis . In advanced disease, 80.5% (n=58) of oncologists discuss prognosis, diagnosis and treatment within the first 8 weeks for more than half of patients.

Most oncologists 70.4% (n=54) offer palliative care to more than half of patients in general, even if they are receiving specific anti-cancer treatment. However, most oncologists 54.2% (n=39) do not discuss the limits of intervention in the context of advanced disease and end-of-life care for most patients; 57.2% of oncologists do not discuss care preferences for most patients and do not prepare ACP for patients with lung cancer.

Regarding the term AD, 66.7% (n=48) of oncologists knew the term but its applicability was not incorporated into their practice, 8% (n=6) do not know or were not familiar with the term, and 22.2% (n=16) knew the term and, according to the patients' wishes, its applicability is incorporated into their clinical practice. One oncologist (1.4%) reported elaborating AD for around 25% of their patients (Table 2).

No statistically significant association between the physicians' variables and medical oncology practice—such as diagnostic, prognosis and treatment discussion in general and advanced cancer—was found. No statistically significant association was found between the physicians' variables and co-variables such as limitation of interventions and end-of-life care, palliative care and ACP in lung cancer. The only significant association was between AD, knowing the term AD but not applying it in clinical practice for oncologists working in the public health system (*p*=0.003) (Table 3).

Table 2. Perception of oncologists about the term advance directives

Questions		n (%)
1.	I do not know or I am not familiar with the term advance directives.	6 (8.3%)
2.	I know the term advance directives, but its applicability is not incorporated in my practice.	48 (66.7%)
3.	I know the term advance directives but I do not elaborate advance directives for all patients, only about 25% of them.	1 (1.4%)
4.	I know the term advance directives and, according to the patients' wishes, its applicability is incorporated into my clinical practice.	16 (22.2%)

Table 3. Frequency distribution of oncologists´ perception of advanced directives according to the variables: gender, age group, years of experience, work in the public and private health system and *p*-value of Fisher's exact test

Advance directives	N	%	N	%	N	%	N	%	*p*-value**
Total	6	8.3	48	66.6	1	1.4	16	22.2	
Gender									
Male	3	4.2	22	30.6	0	0	6	8.3	
Female	3	4.2	26	36.1	1	1.4	10	13.9	0.84
Age*									
≤45 years old	5	7.5	33	49.3	1	1.5	10	14.9	0.46
>45 years old	5	7.5	33	49.3	1	1.5	10	14.9	
Experience									
≤10 years	5	6.9	26	36.1	0	0	9	12.5	0.32
>10 years	1	1.4	22	30.5	1	1.4	7	9.7	
Working in SUS									
Yes	6	8.3	46	63.9	1	1.4	15	20.8	0.99
No	0	0	2	2.8	0	0	1	1.4	

*SUS: Brazilian Unified Health System; *n=66; **5% significance*

Discussion

Oncologists' participation in the questionnaire was extremely low, since of the 2,290 physicians associated with SBOC in Brazil, only 72 answered the questionnaire (3%). The number of participants was the most limiting factor in this study. A trial carried out with American oncologists also shows how oncologists' adherence to the subject may not be expressive: in an attempt to assess the frequency with which oncologists establish their AD through the ASCO in 2007, 7,590 questionnaires were sent and only 614 were answered (8.1%)[17]. Such a small sample impacted the power of the study to establish assertive conclusions. However, the selection bias of physicians receptive to the topic may represent that data generated in this study can be of great value for the continuity of the discussion on the topic and future studies.

Most of the oncologists in this study were under 45 years old and had less than 10 years of experience in oncology practice. Although the current study found no association between the variable age range and years of experience with medical oncology practice in discussing prognosis, patient care preferences, offer of palliative care and limitation of futile interventions, studies with cancer patients show that younger age is a barrier for AD offering[18,19]. The study by Sharma and collaborators[17] with oncologists in the United States, also showed that the experience of oncologists in developing their own AD makes it easier and more routine to discuss and filling out their patient's.

Despite a majority of women oncologists in the sample of the present study, no association between gender and differences in discussing prognostic and care preferences was found. A study by the MD Anderson Cancer Center in the United States, conducted from 2011 to 2013, identified that female oncologists were carrying out DNR records in a shorter period of time compared to male oncologists, and that when female patients were accompanied by female oncologists, this record was made even earlier in relation to hospitalization[19].

Regarding the term AD, 67% of oncologists knew the term but its applicability was not incorporated in their practice, only 24% did so. A study with oncologists in Austria found similar results: 66% of 172 oncologists did not discuss AD with their patients, and most believed that discussing it would not bring any benefits to patients, and 30% feared destroying patients' hope by discussing AD. The same study also found that depending on disease progression, only 66% of oncologists would inform their patients about the prognosis as soon as it was made[20].

In the present study, the oncologists knowing the term AD but not applying it in clinical practice was significant for those working in the public health system (p=0.03) compared to the private one, which can raise hypotheses for future trials that social, economic, racial and cultural aspects may reflect in medical practice with regard to patient autonomy and expression of cancer patients' care preferences.

In this study, 70.4% of oncologists offered palliative care to most of their patients with advanced disease, even if they were receiving specific anti-cancer treatments. Current studies demonstrate and societies and expert groups recommend that the integration of palliative care should take place as soon as possible, once the oncological diagnosis is known[13-15,21,22] due to the beneficial impact on quality of life, increased survival and more frequent discussion for decision-making, early care planning and preferences for defining AD.

Despite recommendations, guidelines and a policy of integrating palliative care teams into cancer centers, a recent study conducted with palliative care specialists in Canada showed that most patients with cancer are still referred late to palliative care—only 20% of referrals are early, that is, patients with more than 6 months of prognosis[23].

A study conducted with oncologists in two centers of the National Cancer Institute in the United States identified three barriers to the referral of patients to palliative care by oncologists: the persistent impression that palliative care was an alternative care and would be incompatible for patients still receiving anti-cancer therapies; palliative care being an integral part of the care provided by oncologists; unavailability or distance from local palliative care services to oncology[24].

A meta-analysis that sought to evaluate cognitive barriers and facilitators for palliative care among oncologists and hematologists identified that an important barrier was the understanding (or lack of) about palliative care and its applicability. Regarding facilitators, the proximity of services (in the physical structure and common educational programs) was identified[25].

According to the World Health Organization (WHO), the lack of training and awareness of health professionals on the importance of palliative care is one of the biggest barriers to improve patient access to palliative care and, thus, to breaking bad news and discussing ACP and AD[26]. The WHO defines palliative care as the active care that better targets the quality of life of patients and their families in the face of life-threatening illness, which tries to rehabilitate medicine to a science that must surrender to its limits before life and death.

Even in the face of scientific and technological advances in oncology, both in the surgical and clinical fields, with increasingly minimally invasive procedures, availability of molecular targeted drugs and agnostic treatments that enable cure or increased survival, cancer can invariably progress to a condition of refractoriness[27] and medical interventions that previously modified the course of the disease may be considered futile or obstinate.

The discussion of the issue of death in the face of advanced and incurable cancer diagnoses, with a survival period of 6 to 24 months, with therapeutic response, with periods of progression, refractoriness to treatments and evolution to a terminal condition of illness or active death process, are pointed out by studies with oncologists as the major difficulties in breaking bad news[9-12].

The current model of medical training, in which death is synonymous with failure and medical error, reinforced by the contemporary concept that death is an undesirable condition and should be avoidable as far as possible, to be expelled from life[28], feed a cycle of interdiction and silencing involving themes related with AD, living will, ACP[29].

Final considerations

Incorporating AD and ACP into oncological medical practice means, according to the main oncology societies in the world—ESMO and ASCO—that an oncologist’s early action in establishing effective communication involving listening, understanding and necessary clarifications for patients to be able to express how they want to be treated and cared at any stage of their illness and in the proximity of death. Information and training for this practice are fundamental so physicians can offer this type of care and quality of life for patients.

This small, though representative, sample of oncologists impacts the possibility of making assertive conclusions. However, the selection bias of physicians receptive to the topic may represent that the data generated can be of great value for the continuity of the discussion on the topic. Cancer holds a high disease burden, affecting a significant portion of the population in many countries worldwide, including Brazil[30]. Most oncologists in this study discuss diagnosis, prognosis, and treatments with their patients and offer palliative care but do not discuss the limits of interventions and end-of-life care in the context of advanced disease and do not define ACP and AD for most patients.

The results of this study show that taboo topics such as death, AD and ACP can be discussed and provide important information about the perceptions and practices of oncologists, which may stimulate future trials.

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