Chapter 190

Advanced Directives in Cancer Patients in Brazil

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ABSTRACT

Cancer is a health problem in the world. Scientific advances and precision medicine have demonstrated how cancer is a heterogeneous disease, requiring diagnostic, prognostic, and therapeutic individualization and personalization as well as more effective communication between doctors, patients, and families, to allow patients to express care preferences. The prevalence of AD in cancer patients varies widely among countries and Brazil has a paucity of data on Advance Directives (AD). OBJECTIVE: This study aims to describe the perception of cancer patients about topics such as Palliative Care (PC), Advance Care Planning (ACP), and Advance Directives (AD) in their oncologic care. METHODS: This was an observational, descriptive, cross-sectional study with cancer patients undergoing outpatient treatment in a private tertiary teaching and research hospital in the city of Salvador, Brazil. RESULTS: of the 50 patients involved, 37 answered the complete questionnaire; 18% of the patients refused to participate when they became aware of the content involving the themes PC and AD. Most of the participants were women, with higher education levels, a mean age of 64 years, and more than one year of oncolog-ic follow-up. More than 70% had not heard about Palliative Care (PC) and 78% were not approached about refractory conditions to treatment and ACP by their oncologist. Only 10.8% understood the terms Advance Directives (AD) or Living Will and only 8% had AD before cancer diagnosis. CONCLUSION: 90% of the patients did not know about AD. Advance Directives were not a topic of discussion between patients and physicians.

Keywords: Cancer, Advance Directives, Advanced Care Planning, Palliative Care.

1 INTRODUCTION

Cancer is a health problem worldwide and accounts for the first or second cause of death after age 70 [1]. In 2018, 18.1 million cancer cases were reported worldwide, affecting 1 (one) in 8 men and 1 (one) in 10 women worldwide with 43.8 million people worldwide living with cancer diagnoses [2]. Brazil ranks 6th among the countries with the highest incidence of cancer with 559,300 new cases in 2018, 7th in cancer mortality with 243,500 deaths, and 7th highest prevalence of cancer [2]. In this scenario of high disease burden, scientific advances, and precision medicine have demonstrated how cancer is a heterogeneous disease, requiring individualization and personalization in diagnosis, prognosis, and therapy, as well as more effective communication between doctors, patients, and family members to allow patients to participate in decision-making and express care preferences [3,4].

Advance Directives (AD) are the prior expression of wishes and care that patients want to receive when they are unable to do so[5-6]. Although there is a legal and regulatory system for AD that allows advances in medical practices in defense of autonomy, better patient interest, and dignity[7-9] the prevalence of AD in cancer patients varies widely between countries, ranging from 88% in the United States[10], 45% in Canadian[11] and only 23% among cancer patients in Germany[12]. Brazil has a shortage of data on Advance Directives (AD) due to the lack of data, which makes this assessment very difficult.

Since 2012, the American Society of Clinical Oncology (ASCO)[13] and European Society for Medical Oncology (ESMO)[14] have been recommending a medical approach to patients regarding the expression of preferences and wishes for care, as early as possible, after a cancer diagnosis, highlighting Advance Care Planning (ACP) as an instrument for implementing this approach, which involves communicating with the clinical oncologist, listening, understanding and expressing the patient's decision about how he or she wants to be treated and cared for when it becomes impossible for him or her to make such a decision and elaboration of AD [14].

This work aims to identify whether cancer patients in Brazil, specifically in a private cancer treatment service in the city of Salvador, recognize or have some familiarity with the terms Advance Directives, Living Will, and their perception of Palliative Care and Advance Care Planning for cancer diagnosis.

2 METHODOLOGY

This is a descriptive cross-sectional observational study, conducted on patients diagnosed with cancer who were undergoing outpatient oncology treatment, in a private oncology service of a tertiary teaching and research hospital, in the city of Salvador, Bahia, Brazil, from July to October 2019. Patients older than 18 years old, of both sexes, diagnosed with cancer, and who was under treatment at the oncology service of Hospital São Rafael S.A. were included in the study and agreed to participate in the research after invitation and signature of the Informed Consent Form. Patients answered a questionnaire containing their personal information (age, sex, marital status, race, education, religion), their cancer diagnosis and treatment modalities, autonomy (discuss diagnostic, prognostic, and treatment), and participation in decision-making, Palliative Care offered throughout diagnosis and follow-up, your knowledge of the term AD or Living Will and ACP and AD offers.

The sample was convenient with the selection of 50 patients to participate in the study, between acceptance and response to the entire questionnaire, in the end, 37 patients were included.

After collection, the data were tabulated and analyzed using Software R version 3.6.1. Initially, absolute and percentage frequencies of categorical variables and descriptive measurements (mean, standard deviation, maximum and minimum values) of continuous variables were calculated. In the Bivariate analysis, Fisher's exact test was used to compare the frequencies of End-of-Life Care and The Elaboration of Advance Directives with those of Demographic and Clinical Characteristics. For this Bivariate analysis, a significance level of 5% ($\alpha = 0.05$) was used.

The research was carried out following the Declaration of Helsinki and was approved by the Research Ethics Committee of the State University of Bahia and Hospital São Rafael SA. under no. CAAE 99488718430010048.

3 RESULTS

Of the 50 selected patients to participate in the study, 13 patients refused to participate and 37 completed the questionnaire. Of the 13 patients who refused to participate in the study, two (2) patients refused without knowing the content of the study, seven (7) patients refused to participate when they became aware of the content of the questions and four (4) patients interrupted the questionnaire during completion because they did not feel comfortable or safe to follow the answers regarding terms such as Palliative Care, refractoriness to anti-cancer treatments, Advance Care Planning (ACP) and Advance Directives (AD). 68% of the participants were women and 32% were men. The age of the patients ranged from 20 to 89 years with a mean of 64 years, with 43% of the sample being over 70 years old. 57% were married. 32% considered themselves white and 30% called themselves mixed race or black. 38% of the sample had an incomplete or complete university education and only 19% had incomplete or complete primary education (Table 1).

The time in which patients had already been diagnosed with cancer ranged from 3 months to 14 years, with a diagnostic mean of 31 months (Table 2). The frequency of cancer diagnosis by the primary place was 27% for breast cancer, 22% for colon and rectum cancer, 16% for lung cancer, 10.8% for prostate cancer followed by pancreatic and bile duct cancers, equally to female gynecological cancers, 5.7% kidney and melanoma and 2.7% for bladder cancer (Table 3). Regarding treatment modalities, 30% of the patients had undergone surgery at some point during treatment and 35% had received Radiotherapy as a treatment modality (Table 3).

When asked about discussing diagnostic, prognostic, and treatment modalities, 93% of the patients stated that they had been adequately informed and participated in the decision-making regarding their treatments. 73% of the patients had established legal representatives in the impossibility of the patient himself/herself to participate in the news and decisions related to the disease and, in most cases, the legal representatives were composed of first-degree relatives (Table 4).

When patients were asked about the offer of Palliative Care, 70% were never approached about this modality of care by their oncologist or other doctors. Similarly, 78% of patients were not approached for possible failures or refractoriness to anti-cancer treatments, limitations on investments in anti-cancer treatment modalities in this scenario, and care preferences. No patient had been approached for Advance Care Planning (ACP) or End-of-life care modalities by their doctors. However, when asked if they would feel uncomfortable talking or establishing Advance Care Planning, 32% of patients said they would like to know about refractoriness conditions, better understand the prognosis of their disease, and establish preferences regarding treatments and forms of care including End-of-life care. (Table 4).

Regarding the term Advance Directives (AD), only 10.8% (four) of the patients knew the term but for none of them, this knowledge came through their oncologist. 3 (8%) patients had Advance Directives elaborated before the diagnosis of cancer, usually in conversations with their relatives, and none in the form of a registered document (Table 4).

The variable race presented an association with Advanced Care Planning: white/Caucasian people, when compared to brown and black, were associated with a higher filling of AD. There was a statistically significant association between prior knowledge of Advance Directives and the drafting of Advance Directives. The current study failed to demonstrate any other association of the variables gender, age, education, religion, primary cancer site, types of treatments, quality of the information received by the patient, and time of diagnosis of the disease regarding the completion of Advance Directives (AD) and Advance Care Planning (ACP) (Table 5).

4 DISCUSSION

This trial was carried out on cancer patients who were undergoing anti-cancer treatment, although with a small number of patients, translated the epidemiological profile of the most common cancer sites with the majority of patients diagnosed with colon and rectum, breast, lung, prostate, pancreas, and bile duct cancers, in patients over 50 years old [1,2] and in a scenario where 60% had more than one year of a cancer diagnosis.

93% of the patients in the current study considered that they had been adequately informed about their cancer diagnosis and participated in their treatment decisions. However, 78% of the patients had not been approached about prognostic discussions such as failure or refractoriness to anti-cancer treatments, disease recurrence, and line of care preferences beyond the current ongoing treatment. Most patients (67.8%) would not feel comfortable being approached about end-of-life care but 32% would feel comfortable being informed about disease refractoriness, realistic prognosis, and establishment of advance care planning. Some studies with cancer patients show that the majority of patients (96%) want to know about cancer diagnosis but a lower percentage (85%) want to know about a realistic severe prognosis of the disease [15,16] and how patients' perception and expectations about cancer prognosis may not correspond to reality. An American study conducted on patients with incurable lung and colorectal cancer, undergoing chemotherapy treatment, found that 69% of patients with lung cancer and 81% with colorectal cancer had expectations regarding the prognosis of their disease that did not correspond to reality and did not understand that their treatment would not cure cancer [17].

In this trial, 18% of patients refuse to participate when they become aware of the content of the research involving Palliative Care and Advance Directives. 92% of patients had no familiarity with the term Advance Directives, Living Will, or Advance Care Planning. In this study, only 8% of patients had Advance Directives that were elaborated before the diagnosis of cancer, which represents a far lower proportion of those observed throughout the world. Brazil has a lack of data and studies on the topic of AD. The available data show comparable results, as in a study carried out in the South region of Brazil, in 2012, with only 4.6% of cancer patients knowing the terms Living Will and Advance Directives [18].

Studies on cancer patients in the USA show that 70% of cancer patients have information or knowledge about Advance Directives and 35% to 49%[19] have elaborated AD documents before cancer diagnosis. After cancer diagnosis, the prevalence increases to 88% [19]. In Canada, studies show that 45 to 55% of patients have AD before and when diagnosing cancer [11]. In Europe, the prevalence of AD ranged from 23% in Germany [20] to only 5% in cancer patients in Vienna, Austria [21]. In Austria, 85% of cancer patients hospitalized in Vienna did not express a desire to have AD and the greater justifications were that they had complete confidence in their doctors, leaving the decision to them and only 7% reported not having the necessary information to perform an AD [21].

The present study showed an association between the Caucasian race and a higher frequency of acceptance of Advance Care Planning when compared to other races and this association has also been demonstrated in other studies [22,23}. High educational level and advanced age were also variables related to a greater performance of AD [22,23] In this trial, considering that patients were seen at a private health center and that most had a high level of education, the results of the data should be closer to studies in developed countries. In the literature, high education level increased by 6 times the chance of patients having information about AD and, for each 1-year increase in age, there was an 11% increase in the chances of patients elaborating or filling out their AD [19], as well as the association between Advance Care Planning (ACP), follow-up with the palliative care team and their Advance Directives [24,25].

Other studies in the literature show that a worse Performance Status (PS), which is a factor with a worse oncological prognosis, and a longer course of treatment, around 2.5 years, were also factors related to the filling of AD [20,21].

The current study failed to relate patients' variables to AD, except for previous knowledge about AD, and one of the limitations of the study was the small sample. 70% of the patients who answered the questionnaire reported that Palliative Care had never been offered by their doctors, 78% of the patients had not been approached about prognostic discussions such as failure or refractoriness to anti-cancer treatments, disease recurrence and care line preferences beyond the current ongoing treatment; and 68% of patients showed not to have been informed about disease refractoriness and setting Advance Care Planning (ACP) preferences. A survey conducted by the Center to Advance Palliative Care and the American Cancer Society[26] in 2010, in the United States, showed that 70% of the respondents were not familiar with the term Palliative Care and for most palliative care doctors were synonymous with hospice or end-of-life care; however, when clarified about the term Palliative Care, 95% of the interviewees agreed that it was important for patients with severe illness to be educated about Palliative Care and had access to it and 92% would like close people and family members to receive PC if they were suffering from a severe illness. In a study in Austria, only 6% of oncologists had involved patients in PC services and the justifications were, for 25% of the doctors, the non-availability of Palliative Care services and for 75% the belief that these referrals would negatively impact patients' hopes [27]. The American Society of Clinical Oncologists (ASCO)[13] and European (ESMO) societies [14] advocate a medical approach to patients to express care preferences and wishes as early as possible, after cancer diagnosis and the insertion of palliative care in the care-line of cancer patients, and are supported by evidence of benefit in improving the patient's quality of life[28], better management of symptoms [24] not only physical but also psychological, the establishment of intervention limits avoiding disproportionate and futile treatments, increasing the care satisfaction of both patient and families [29], better survival of cancer patients [30] and a higher frequency of discussion about active oncologic care at the end of life and filling out AD after cancer diagnosis [11]. While countries such as Canada, which give examples of health policy models with the insertion of PC in most oncology centers in the country (42 centers) [31] and data from a recent study with cancer patients in Australia show that 70% of patients knew what Palliative Care was and 71% felt comfortable with Palliative Care mainly from the understanding that cancer follow-up and anti-cancer therapies could continue concomitant with Palliative Care[32], developing countries such as Brazil do not follow this reality. According to the WHO (World Health Organization), in 2015, 78% of people in the world who needed Palliative Care were in underdeveloped or developing countries and only 14% of them had access to Palliative Care [33]. Brazil ranked 42nd out of 80 countries with the worst quality of death based on the difficulty in accessing opioids, specific public health policies for palliative care, and access to palliative care in health services [34] that are insufficient for the population. In 2014, in the WHO publication of the Global Atlas of Palliative Care, Brazil received a Classification 3 A characterized by the provision of palliative care in an isolated, irregular manner, with sources of funding heavily dependent on donations, limited availability of morphine and an insufficient number of palliative care services for the population [35]. The analysis of this mapping showed that more than 50% of the PC services were concentrated in the southeast region, and only 13 teams (less than 10% of the total teams) in the entire north-northeast region [36]. In addition to the difficulties of policy and access, the WHO highlights the scarcity of training and the awareness among health professionals about the importance of Palliative Care as one of the greatest barriers to improving patients' access to palliative care [33] and, consequently, the implementing of effective communication for the establishment of Advance Care Planning and the elaboration of Advance Directives.

Palliative care is an effective way to implement APC and AD in the care line, inserted by specialists or general practitioners, at any time of follow-up and care [37]. Not only access to health services, medical standards, and protocols recommended by specialist societies, but also the way how people and societies conceive life and death, the type of access to information and clarifications, and family support are factors that will impact the greater or lesser adherence to ACP proposals when available.

5 CONCLUSION

The frequency of Advance Directives in cancer patients in this study is very low and even more relevant is the low frequency of the insertion of Palliative Care in the line of care of cancer patients, either because of non-accessibility to services, or of the lack of medical referral or by the lack of acceptance and/or understanding of patients about Palliative Care and Advance Care Planning [38]. Such a complex and multifaceted theme needs to be at the top of discussions not only with medical (general practitioners or specialists) and non-medical health professionals but also in general daily lives. Such discussions can provide opportunities for redefining the social, cultural, and behavioral models of death, given the contemporary modern conception of "silenced" and unwanted death [39] for a natural event where patients' preferences can be expressed through instruments such as the Directives advance.

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TABLES

Table 1: Demographic Characteristics of Cancer Patients followed up at an ambulatory care, Salvador 2019.

Variables	**n**	**%**
GENDER		
Male	12	32.4
Female	25	67.6
AGE Categorized *		
20 - 50 years old	7	20.0
51 - 70 years old	13	37.1
71 - 90 years old	15	42.9
CIVIL STATE		
Single	6	16.2
Married	21	56.8
Widow	9	24.3
Divorced	1	2.7
RACE		
Black	11	29.7
Mixed race	11	29.7
White/Caucasian	12	32.4
Others	3	8.1
EDUCATION		
Primary Education complete/incomplete	7	18.9
Secondary Education complete/incomplete	16	43.3
University Education complete/incomplete	14	37.8
RELIGION		
Catholic	23	62.2
Spiritism	3	8.1
Evangelic/Protestant	7	18.9
Others	4	10.8

Table 2: Minimum, maximum value, mean and standard deviation of age and time of diagnosis of cancer patients followed in an ambulatory service, Salvador 2019.

Variables	Minimum	Mean	Maximum	Standard Deviation
Age in years	20	64.4	89	17.03
Time of diagnosis in months	3	31.1	173	35.8

Table 3: Clinical Characteristics of Cancer Patients followed up in an ambulatory service, Salvador 2019.

Variables	**n**	**%**
DIAGNOSIS		
Lung	6	16.2
Breast	10	27.1
Stomach	1	2.7
Female gynaecological	2	5.4
Colon and rectum	8	21.6
Pancreas and bile ducts	2	5.4
Prostate	4	10.8
Penis	1	2.7
Melanoma	1	2.7
Kidney	1	2.7
Bladder	1	2.7
RADIOTHERAPY		
Yes	13	35.1
No	24	64.9
CHEMOTHERAPY		
Yes	31	83.8
No	6	16.2
SURGERY		
Yes	11	29.7
No	26	70.3
TIME OF DIAGNOSIS		
Higher or equal to 12 months	22	59.5
Less than 12 months	15	40.5

Table 4: Frequencies attributed by patients related to diagnostic and prognostic information, legal representative, Palliative Care (PC), Advance Care Planning (ACP) and Advance Directives (AD), Salvador 2019

Variable	**n**	**%**
INFORMATION		
Yes	36	97.3
No	1	2.7
LEGAL REPRESENTATIVE		
Yes	27	72.9
No	10	27.1

PALLIATIVE CARE		
Yes	11	29.7
No	26	70.3
REFRATIVENESS TO TREATMENTS		
Yes	8	21.6
No	29	78.4
ADVANCE PALLIATIVE CARE		
Yes	12	32.4
No	25	67.6
KNOWLEDGE OF ADVANCE DIRECTIVES		
Yes	4	10.8
No	33	89.2
ADVANCE DIRECTIVES (AD) ELABORATION		
Yes	3	8.1
No	34	91.9

Table 5: Results of Fisher’s Exact Test, comparison between Advance Care Planning, elaboration of Advance Directives with demographic and clinical characteristics

	ADVANCE CARE PLANNING (n= 12)			**ELABORATION OF ADVANCE DIRECTIVES (n= 3)**		
Variables	**n**	**%**	**p-value****	**n**	**%**	**p-value****
Male	3	24.3	0.71	1	2.7	0.96
Female	9	8.1		2	5.4	
20 - 50 years old	2	5.4	1	0	0	1
51 - 70 years old	4	10.1	1	0	0	0.28
71 - 90 years old	6	16.2	0.72	3	8.1	1
Single	1	2.7	0.86	0	0	1
Married	8	21.6		2	5.4	
Widow	3	8.1		1	2.7	
Divorced	0	0		0	0	
Black	3	8.1	0.03	1	2.7	0.3
Mixed race	1	2.7		0	0	
White/Caucasian	5	13.5		1	2.7	
Others	3	8.1		1	2.7	
Primary Education complete/incomplete	1	2.7		0	0	

Secondary Education complete/incomplete	5	15.5	0.48	0	0	0.13
University Education complete/incomplete	6	16.2		3	8.1	
Catholic	9	24.3	0.16	2	5.4	0.54
Spiritism	1	2.7		0	0	
Evangelic/ Protestant	0	0		0	0	
Others	2	5.4		1	2.7	
Lung	3	8.1	0.94	1	2.7	1
Breast	3	8.1		1	2.7	
Stomach	0	0		0	0	
Female gynaecological	1	2.7		0	0	
Colon and rectum	3	8.1		1	2.7	
Pancreas and bile ducts	0	0		0	0	
Prostate	1	2.7		0	0	
Penis	0	0		0	0	
Melanoma	0	0		0	0	
Kidney	0	0		0	0	
Bladder	1	2.7		0		
Yes	4	10.1	1	1		1
No	8	21.6				
Yes	10	27.1	1	3	8.1	1
No	2	5.4		0		
Yes	12	32.4	1	3	8.1	1
No	0	0		0		
Yes	8	21.6	0.69	3	8.1	0.54
No	4	10.1		0		
Yes	3	8.1	1	2	5.4	0.2
No	9	24.3		1	2.7	
Yes	8	21.6	0.78	3	8.1	0.54
No	4	10.1		0		
Yes	2	5.4	1	3	8.1	0.55
No	10	27.1		0	0	
Yes	2	5.4	0.24	2	5.4	0.03
No	10	27.1		1	2.7	
Yes	-	-	-	2	5.4	0.24

No	-	-		1	2.7	
Yes	2	5.4	0.24	-	-	-
No	10	27.1		-	-	
Higher or equal to 12 months	8	21.6	0.72	2	5.4	1
Higher or equal to 12 months 4		10.1		1	2.7	

Source: Elaborated by the author. * n= 35; ** 95% significance