Advance directives in cancer patients

Abstract

Introduction: Advance Directives (AD) represent the patient's expression about end-of-life care. Patients who have AD and discuss quality of death, take part in decision making about their care more often and have their choices respected. The diagnosis of cancer seems to favor the establishment of DA and discussions about end of life care.

Methods: It is a systematic literature review that aims to assess the prevalence of AD among cancer patients and the attitude of patients and physicians across AD in the context of oncology. 10 articles were selected for the analysis in the data source of PubMed and BIREME / LILACS.

Results: The prevalence of AD among cancer patients ranged from 88% among Americans at 55% in Canadian. In Europe was low, only 5% cancer patients in one study. Age, level of education, high income, worse Performance Status (PS), prolonged treatment and follow up with a team of palliative care was positive factors related to the development of Advance Directives by cancer patients. The oncologist had the lowest representation among health professionals and family in the formulation process of Advance Directives. **Conclusion:** The discussion on AD involves, among other things, special attention to the models of physician-patient relationship, particularly the right of choice of patient and respect for their best interest.

Keywords: advance directives, cancer patients, attitudes, prevalence

Volume 2 Issue 2 - 2018

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Received: February 07, 2018 | **Published:** March 12, 2018

Introduction

Advance Directives (AD) represents the patient's expression about end-of-life care. Indeed, it is accepted that patients may refuse or set limits on treatment and medical interventions in end-of-life care planning,¹ or determine a legal representative who decides for them.² These wishes can be expressed in several documents among them Living Will (LW),³ adopted since the 70's in the USA as a legal instrument known as "*Testamento Vital*"⁴ in Portuguese speaking countries. In Brazil, advance directives has been regulated in 2012 by the Federal Council of Medicine through the Resolution 1,995/2012,⁵ allowing the registration of the patients choices in the medical record as a tool to promote the patient's right to self-determination.

Talking about Advance Directives in plural democratic societies implies considering specific social, cultural and economic factors that affect the behavior of patients, family and doctors, inserted in a state of law based on human dignity and self-determination of the individual. In general, discussions about AD and end-of-life care can be hampered by any of the actors involved in the process. These difficulties reflect emerging issues of bioethics involving the human being's ability to intervene on life and death, changing the concept of death in Western societies, as well as the need for new models of medical-professional relationship taking into account the right and dignity of the patients. Biotechnological advances have brought human beings' ability to manipulate life, interfere with health and disease conditions, and prolong the time of death. Death moves from a natural condition to become an undesirable event, maximally preventable, that people cannot talk and want to drive out of their lives, in contemporary societies.⁶

Even in a not very favorable scenario, studies show that patients who have AD and discuss end-of-life care and quality of death participate more in decision making and are more likely to receive care according to their choices. These patients also tend to have fewer ICU admissions, fewer measures of unnecessary life extension

interventions, and increased frequency of hospice care and death at home.⁷⁻¹⁰ Cancer represents more than 100 different types of diseases, according to WHO,¹¹ with different prognoses. However, the diagnosis of cancer, in itself, is involved in a very big stigma of aggressive and fatal disease. This "closeness" to death, caused by the disease, probably explains at least partially the results of the studies, demonstrating that advanced age and diagnosis of cancer are factors associated with a greater filling of AD and discussions about end-of-life care.¹² Cancer patient who receive multidisciplinary care since the diagnosis of cancer, seeking a better quality of life, more often discuss the modalities of care and treatment and establish their AD.¹³

Objective

The aim of this study is to review the literature on the use of Advance Directives in cancer patients, assessing issues such as the prevalence of AD among these patients before and after the diagnosis of cancer, and the attitude of patients and physicians to DA.

Methods

This is a systematic review of the literature. A search was performed on the data sources of PUBMED and BIREME / LILACS using the descriptors: advance directives and cancer patients and attitudes and prevalence. The research resulted in a total of 22 articles in the sources of BIREME and 24 articles in research by PUBMED. The selection criteria for inclusion of the articles in this review were original quantitative studies, written in the English language, discussing the topic Advance Directives (AD) in the cancer patient, with a descriptive or analytical methodology on prevalence of AD, attitudes of the physician or patient related AD and end-of-life care.

After reading the title and abstract of 46 articles, 34 articles were excluded from the data source LILACS/ BIREME and 19 PUBMED articles. Subjects whose sample was not cancer patients, who did not address AD in oncology patients or whose attitudes assessment

referred to non-medical professionals and those in Asian populations were excluded. 04 articles were selected in the sources of BIREME / LILACS and 05 articles in PUBMED; 04 articles were repeated in the two different sources. The study included five articles, randomly found in literature reference readings that meet the inclusion criteria. At the end, a total of 10 articles were selected for analysis considering

the specific information of each article (Figure 1). The quantitative data on the prevalence of AD in cancer patients before and after the diagnosis of cancer, patient's attitudes regarding the diagnosis of cancer in relation to AD and end-of-life care and the attitudes of medical oncologists to define end-of-life care and discuss AD with their patients were analyzed for the description in this study.

Figure 1 Flowchart of article selection.

Results

Studies in cancer patients over the past decade in the United States show that around 70% of patients knew or had information about Advance Directives and only 35% to 49%¹⁴ had completed DA documents before the diagnosis of cancer. In Canada, studies show that 45%¹⁵ to 55% of patients had AD completed.¹⁶ After the diagnosis of cancer, the prevalence of AD among patients increased to 88% in American studies¹⁷ and remained at 45% to 55% in the Canadian studies.^{15,16} In Europe, the prevalence of AD was 23% among cancer patients in a German study¹⁸ and only 5% in cancer patients in Vienna, Austria.¹⁹ In the German study,¹⁸ although only 23% of the patients

had AD, 62% of them showed desires to perform their AD, while 85% of cancer patients hospitalized in the city of Vienna did not wish to have AD.¹⁹

Retrospective data of patients with advanced cancer in US cities, between the years 2002-2008, showed that 88% (413 patients) had AD and care settings at the end-of-life. Documents completed by the patients were the Living Will (LW) or Durable Power of Attorney (DPA) in 53% (with 33% of patients had both) and do not resuscitate orders (DNR) in 41%.¹⁷ In the state of Maryland, of 100 patients with advanced stage cancer, 49% had LW or DPA.²⁰ In the MD Anderson Cancer Center in Houston, of the 110 women diagnosed

with gynecological cancer, 49% (54 patients) had AD, but only 37% of them had copies of these documents in hand if necessary.¹⁴ In this same study, 73% of patients who had cancer recurrence had more access to information on AD, but this condition did not increase the proportion of AD filling, remaining at 48%.¹⁴ In Baltimore,²⁰ United States, 93 patients with end stage cancer were asked about their own perception of prognosis and desires for end-of-life care. Although all patients were informed about the prognosis and terminal stage of disease, provided by their physicians, only 43% of them confirmed this understanding of terminality. 25% of patients had talked with their oncologist about their care wishes at the end of life, but most patients (56%) did not want to discuss this topic with their doctors. Do-not-resuscitate Orders (DNR) were best accepted in patients with an expected 1-month life expectancy (61.7%), allowing for a natural course to occur". Allow natural death - AND" (47.8%).²⁰ Garrido et al.¹⁷ also demonstrated that the presence of Do-not-resuscitate Orders was associated with significantly better quality of life in the weeks before death, which was not observed for those who had only LW / DPA.

In Canada, a study of 193 cancer patients treated in the Princess Margaret Cancer Center, Toronto, from 2011 to 2012, showed that 55% of them had done an AD. AD documents were a LW in 33%, 49% DPA and 18% DNR. Of the 99 patients who had AD, 53% had made it before the diagnosis of cancer, 24% up to 1 year of cancer diagnosis, 10% between 1-2 years of diagnosis of cancer and 10% after recurrence or progression of cancer.¹⁶ The study also showed that both the family and the lawyer were references in assisting the filling of an AD: 47% of the patients had family assistance, 43% of a lawyer; 5% of the palliative care team; only 1% of the oncologist. 25% of the patients had no help. Regarding the expression of wishes of care at end-of-life, 66% of patients had talked with the family; 9%, with lawyer; 6%, with the palliative care team; 3% with the oncologist; 2% with the family physician and 31% had not discussed their end-of-life care wishes with anyone.¹⁶ Age,²¹ level of education and high income, worse Performance Status (PS),^{14,16,18} prolonged treatment and follow up with a team of palliative care, were positive factors related to the development of Advance Directives by cancer patients. The oncologist had the lowest representation among health professionals and family in the formulation process of Advance Directives.

Palliative care and discussion of care in end-of-life had a statistically significant association for AD fill after cancer diagnosis. Patients who developed their AD after cancer diagnosis were more likely to be followed up by a palliative care team (82% vs. 63%; $p < 0.0001$).¹⁶ Patients who were followed up with palliative care discussed further end-of-life care. Factors demonstrated as potential barriers to AD completion by the patients were younger age, low educational level, and a high level of anxiety related to death.¹⁴ A study of cancer patients hospitalized in Vienna found that 85% of them did not express desire to have AD and the reasons were: 22% had complete trust in their doctors leaving the decision to them; 15% considered to have no importance at that time; 8% considered that AD could lead the doctor to make the wrong decisions and 7% said they did not have the information needed to perform an AD.¹⁹ In the German study, most patients with or without AD agreed that AD facilitated medical decision-making and reduced the burden on relatives. However 36% believed that AD could be of little use, since people define their AD before they become ill and when they are ill the choices could change.¹⁸

A study at a cancer center, in New York, evaluated the different perceptions and beliefs into 03 ethnic/racial groups (21% of black, 20% of Hispanic and 59% of non-minority) of patients diagnosed with lung cancer. Of 335 patients evaluated, 80% expressed the desire that communication about their disease occur together with family. The group of Hispanic patients had a belief that LW, once performed, could not be altered and its realization would depend on the participation of a lawyer. Black patients had a significantly larger belief in relation to the other two groups that people with LW would not receive cancer treatment and a belief 2.5 times greater that life-sustaining treatments had to be maintained for religious reasons. Black and Hispanic patients attributed to hospices, the places of care for people who were close to death.²²

Two studies evaluated the attitudes of oncologist physicians in discussing end-of-life care and AD. Previous studies have demonstrated that female physicians introduced early and more frequently the discussions with patients and family on psychosocial and biomedical aspects related to end-of-life care. Crosby et al.²¹ evaluated the issue of physician gender interfering with communication and approach to preventive care practices such as discussions at the end of life. The study was conducted at the MD Anderson Cancer Center, Texas, United States, from 2011 to 2013, assessed the frequency of records of Do-not-resuscitate Orders in cancer patients and the duration of the first registration during the days of hospitalization, from the follow-up of female and male physicians. The results showed that female physicians had an earlier record, in the first days of hospitalization, of Do-not-resuscitate Orders compared to male physicians. When it came to female patients accompanied by female doctors, this registry was even earlier to hospitalization.

The study by Kierner et al.²³ used a questionnaire sent to 758 oncologists in Austria, evaluating the frequency of prognostic information given to the patient, referral of cancer patients to palliative care or hospice services and discussion of AD with their patients. Palliative care or hospice care were offered for only 8,6% and 2,6% of patients, respectively, by oncologists. The justifications were: the non-availability of palliative care services for 25% of physicians and the belief that these referrals would negatively impact the hopes of patients for 75% of physicians. 66% of oncologists talked with their patients about the malignancy characteristic of the disease and the cancer prognosis but only 28% of the patients received information about AD from their oncologists. Most physicians (66%) did not discuss AD with their patients because they believed it would bring no benefit to the patient, and 30% of them still feared to destroy the hope of patients. Depending on the timing of the disease, only 66% of oncologists would inform their patients about prognosis soon after diagnosis. 98% of oncologists considered Performance Status (KPS below 50), an important factor to communicate bad news about the prognosis of the disease.²³

Discussion

Articles of this study show that the prevalence of AD among cancer patients was very varied between countries: the Americans had a higher prevalence of AD before and after the diagnosis of cancer, reaching up to 88%¹⁷ from patients after diagnosis, followed by Canadians.¹⁶ The two European studies included in the analysis had a low prevalence of AD, especially the Austrian study where only 5% of cancer patients had AD completed.¹⁹ Articles are mostly hospital-based, not population, but reflect the different social, cultural

and economic aspects of local influencing. In the United States, the prevalence of AD among elderly non-cancer patients, for example, is around 70%,⁷ equivalent to the data for cancer patients found in the studies. The American data reflect a socio-cultural reality of a society that since the 1970s has as a standard of medical assistance the indication of resuscitation of all patients in CRP (Cardiac Arrest), except for those who have an Advance Directive or order do not resuscitate “DNR”.²⁴ Since the 70s, the Americans instituted AD instruments such as the Living will and later with advances in local legislation in the 90s, the Patient Self Determination Act (PSDA)²⁵ which establishes the obligation of treatment facilities to promote education of professionals and patients about Advance Directives and the provision of AD documents, optional the fulfillment of patients.

Articles of this study made references to some documents used as AD, among them: the Living Will (LW), Durable Power of Attorney (DPA) and the records of do not resuscitate orders “DNR” and death in natural course “AND”. An important aspect that constitutes a barrier to ensure the choices of patients is unavailability of AD documentation addressed in one of the studies.¹⁵ In Portugal, the public discussion on AD culminated in 2012 with the approval of the Law 25/2012 that also created the National Registry of the Living Will, called RENTEV, allowing real-time access to the patients’ AD within the healthcare system intranet.²⁶

Articles of this study demonstrated that advanced age,²¹ education level and high income^{14,16,18} worsen Performance Status (PS) and also originated a prolongation^{18,19} of the duration of treatment and follow up by a team of palliative care were factors that were positively related to the filling of AD in cancer patients. Some of these findings are also found in the literature, in non-oncological and oncological patients.^{14,27,28} On the other hand, the lack of accessibility, information and understanding related to social conditions constituted obstacles to the performance of AD by the patients^{14,19} as in the study by Jonnalagadda,²² demonstrating the belief of American racial minorities about AD as tool that does not guarantee adequate treatment against cancer. Religion was a valued aspect and also highlighted in the study toward healing beliefs and miracles attributed to God as barriers to establishing their wills or restriction.²²

Only one article¹⁶ demonstrated an increase in the proportion of AD after the patients were diagnosed with cancer. This same study showed that patients talk mainly with their families about their care wishes at the end of life, and only a very small percentage, around 6% talk to the palliative care team and only 3% with their oncologists. Follow-up with a palliative care team was a factor associated with increased AD, as well as a discussion about the care patients would like to receive at the end of life.¹⁶ In the literature, intervention studies have shown that cancer patients, accompanied by an interdisciplinary team of palliative care, discuss and express more, significantly, their preferences and choices in AD.^{13,29} An American study in lung cancer patients showed that 44% of patients followed up by an interdisciplinary Palliative Care team had AD, whereas only 9% of unaccompanied patients had AD ($p < 0.001$). The American (ASCO) and European (ESMO) Societies of Medical Oncologists advocate comprehensive medical care for oncological patients, involving not only the management of signs and symptoms of the disease but also the emotional and human aspects, and since 2012, the expression of the preferences and desires of patient care as early as possible after the diagnosis of cancer. The ESMO (European Society of Medical Oncology)³⁰ highlights the importance of an advanced care planning (ACP) involving medical communication, listening, understanding and expression of patients

about how they want to be treated when they were unable to decide. Or during treatment, the continuation of treatment, and intervention measures for symptom relief and control, nutrition therapy, sedation and assisted suicide, allowed in some European countries. The ASCO (American Society of Clinical Oncology)³¹ focuses its guidelines on cancer patients with metastatic disease and survival between 6 and 24 months, establishing a care plan where the palliative care team can be integrated early, ideally in the first 8 weeks of diagnosis, and aspects of treatment, prognosis, and patient care preferences are discussed, filling in their AD. Since palliative care (PC) should be offered by a multidisciplinary and interdisciplinary team that includes clinical oncologist and / or palliative doctor at the center of attention.³¹

The two studies^{21,23} evaluating the attitude of medical oncologists with respect of an AD approach in cancer patients suggest that doctors themselves represent a barrier in this discussion, postponing to later stages of the disease. The literature, however, shows that talking about cancer prognosis with cancer patients allows them a better understanding and more conscious choices²⁷ without adding suffering or stress,¹³ enabling greater effectiveness of their choices²⁷ and avoiding futile treatments,³² without compromising the quality of the doctor-patient relationship.¹⁰

Conclusion

Discuss an AD with a patient means tailor medical-patient relationship models to the principles of bioethics, as regards the right to patient choices and respect for their dignity, and discuss of emerging issues related to technological scientific advancement and its effects on medical practice, in the limits of intervention on life and death by human beings. Postpone choices, by any of the actors, leaving decisions about care at the end of life for a time of greater proximity of death, can generate situations of uncertainty, additional suffering and conflicts between patient, family and physician. In some situations, the expression of the patient’s desire not to artificially prolong life and suffering may not be in agreement with that of the family, who understands his sick relative as a vulnerable and still feeds expectations of prolonging the survival to the current technological limits. The doctor finally have to weigh the ethical, human and technical dimensions in decision-making involving care at end-of-life, preventing the principle of beneficence to be confused with paternalism, avoiding interventions that are characterized as excessive and unnecessary, taking into account the desire of the patient or his legal representative, if so determined.

These discussions should be encouraged in society and among health professionals, especially among physicians. There are beliefs and uncertainties which still need to be better clarified and deepened beyond the taboo of death in the training and medical practice and represent barriers to physicians, hindering the exercise of autonomy and respect for the patient’s dignity.

Acknowledgements

None.

Conflict of interest

The author declares no conflict of interest.

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