



ADVANCE CARE PLANNING IN ONCOLOGY: CHALLENGES IN CLINICAL PRACTICE

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“You may not control life's circumstances but getting to be the author of your life means getting to control what you do with them.”

Atul Gawande

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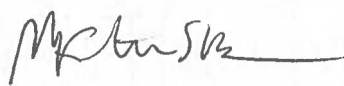
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I dedicate this thesis
To God, my guide
To my family, a great motivator
To patients and health professionals, the reason for this study.

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PRESENTATION

This thesis was motivated by my concern in clinical practice as a geriatrician and palliative care physician. In the assistance of patients with advanced disease and complex end-of-life care needs, especially in oncology settings, I often observe patients who are without the opportunity to talk about their values and preferences of care before the disease becomes critical, and who are sometimes receiving treatments that are not always compatible with their wishes, especially in the case of extraordinary treatments.

Advance care planning is an instrument that aims to ensure respect for patient autonomy, one of the fundamental principles of bioethics. This thesis focuses on this intersection, showing the need to increasingly access the patients' priorities to promote a value-aligned medical care through shared decision-making, guaranteeing the exercise of patient autonomy.

To study alternatives to facilitate the integration of advance care planning in Brazilian clinical practice is urgent and necessary. There is sufficient evidence stating that advance care planning is a good indicator of high-quality palliative care. However, it is still little performed in oncology practice.

This thesis is the result of a collection of studies that aim to explore the main barriers to carrying out advance care planning in cancer patients, making a parallel with the need for continuous education on this topic, described in two empirical studies that compose this thesis. Furthermore, a systematic review of the literature on therapeutic refusal by elderly people with cancer was carried out to understand the reasons associated with the refusal of treatment, which may also reflect, in some situations, communication failures about prognosis and end-of-life care. An integrative review about advance care planning was also carried out, which comprised a chapter for the Encyclopedia of Palliative Care. Lastly, based on the results of studies developed within the scope of this thesis and on the existing literature, a proposal of a guide to Brazilian physicians was developed to facilitate the initiation and the conduction of advance care planning in clinical practice.

This project does not end here. I hope to continue expanding my knowledge on this topic, exploring ways to improve my practice and try to change the current reality of low rates of advance care planning, not only in oncology but in other areas as well, such as geriatrics, based on the academic path initiated here.

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ABSTRACT

Advance care planning is a process of discussion by which patients with serious illnesses are empowered to articulate their personal preferences and goals to make decisions regarding current and/or future care. It is an important domain in providing high-quality palliative care. Therefore, physicians must have skills to adequately discuss the prognosis, the uncertainty of treatment outcomes and provide recommendations for end-of-life care options, when it is appropriate for each individual and his or her disease course. Though widely recognized as an integral component of oncologic care, advance care planning has not been systematically implemented into clinical practice.

Given the scarce literature on advance care planning and on its difficulties in oncology practice in Brazil, this thesis aims to explore physicians' barriers in performing advance care planning in patients with cancer, thus enabling as a final goal to propose a guide for discussion of advance care planning for Brazilian physicians.

A literature review about advance care planning and a systematic review of the literature about therapeutic refusal by elderly patients with cancer was carried out, as a preamble for the main objective of this study, in order to better investigate the autonomy of elderly cancer patients and to identify the reasons related to therapeutic refusal, since it is a topic frequently discussed in advance care planning and is still a challenge in daily practice. Two empirical studies were performed, using the "*Decide-Oncology*" questionnaire, an instrument used to identify the perception of physicians' barriers about goals of care discussion and advanced care planning. In one study, the adaptation to Portuguese and validation of the content of the "*Decide Oncology*" questionnaire was carried out, and a pilot study with resident physicians to explore the barriers to addressing advance care planning was performed. In the second study, the "*Decide-Oncology*" was administered, and a quantitative and qualitative methodology was used in order to explore Brazilian oncologists' perceived barriers to discussing goals of care and advance care planning.

For most clinicians, advance care planning and goals of care discussions are challenging and often avoided due to a variety of factors, namely lack of training, insufficient time to have a conversation, patients' and families' difficulty

in accepting a poor prognosis, uncertainty about prognosis, and lack of palliative care teams, that were important barriers perceived by physicians to initiate and conduct advance care planning discussion in the two empirical studies. A positive impact on the willingness to participate on goals of care discussion was associated with previous training in this topic. Finally, considering the need for practical guides for advance care planning adapted to the Brazilian reality, based on empathic communication strategies, a guide with recommendations of current evidence, which contains information about when and how to do it - the step by step from preparation, exploration of patient's values and perception about disease, to the advance care planning registration, including advance directives records- and instruments already validated to Portuguese language (Brazil), to encourage its elaboration and then, facilitate the practice.

Exploring physicians' barriers to performing advance care planning could help prioritize the next steps for future studies aimed at improving this issue, helping clinicians better support patients and families through shared decision-making based on patient values and self-identified goals.

Keywords: Advance care planning; autonomy; communication; end-of-life care; oncology; shared decision-making.

RESUMO

O planejamento antecipado de cuidados é um processo de discussão entre médicos e pacientes que objetiva emponderar os pacientes a expressarem suas preferências de cuidados e objetivos de vida para tomar decisões sobre cuidados atuais e/ou futuros junto à equipe de saúde. Atualmente, é considerado um domínio importante na prestação de cuidados paliativos de alta qualidade. Os médicos devem ter habilidades para discutir adequadamente o diagnóstico e prognóstico com seus pacientes e recomendar as melhores opções de cuidados, não só baseada na doença, mas também de acordo com as preferências de cada indivíduo. Embora amplamente reconhecido como um componente do cuidado oncológico integral, o planejamento antecipado do cuidado ainda não foi sistematicamente implementado na prática clínica.

Dada a escassa literatura sobre planejamento antecipado do cuidado e a necessidade de aumentar sua implementação na prática oncológica no Brasil, esta tese tem como objetivo explorar as barreiras dos médicos na realização do planejamento antecipado do cuidado em pacientes com câncer. Como objetivo final, foi elaborada a proposta de um guia para facilitar a discussão sobre planejamento antecipado de cuidados.

Inicialmente foi realizada uma revisão de literatura sobre planejamento antecipado de cuidados e uma revisão sistemática da literatura sobre recusa terapêutica por pacientes idosos com câncer, como preâmbulo para o objetivo principal deste estudo, a fim de melhor investigar a autonomia de pacientes idosos com câncer e identificar os motivos relacionados à recusa terapêutica, pois é um tema frequentemente discutido no planejamento antecipado de cuidados, e ainda é um desafio na prática clínica diária. Foram realizados dois estudos empíricos, utilizando o questionário “Decide-Oncology”, instrumento utilizado para identificar a percepção das barreiras dos médicos sobre os objetivos da discussão do cuidado e do planejamento antecipado de cuidados. No primeiro estudo, foi realizada a adaptação para o português e validação do conteúdo do questionário “*Decide Oncology*” e um estudo piloto com médicos residentes para explorar as barreiras à realização do planejamento antecipado de cuidados. No segundo estudo uma análise quantitativa e qualitativa foi utilizada para explorar as barreiras percebidas pelos oncologistas brasileiros

para discutir metas de cuidado e planejamento antecipado de cuidados, também utilizando-se o “*Decide Oncology*”.

Para a maioria dos médicos, o planejamento antecipado de cuidados e as discussões sobre os objetivos dos cuidados são desafiadores e muitas vezes evitados devido a uma variedade de fatores, como falta de treinamento, tempo insuficiente para conversar sobre prognóstico e preferências de cuidados, dificuldade de pacientes e familiares em aceitarem o prognóstico ruim, incerteza sobre o prognóstico e falta de equipes de cuidados paliativos. Essas foram importantes barreiras percebidas pelos médicos para iniciar e conduzir a discussão do planejamento antecipado de cuidados nos dois estudos empíricos. Um impacto positivo na disposição em participar da discussão dos objetivos do cuidado foi associado ao treinamento prévio sobre esse tema.

Por fim, considerando a necessidade de facilitar a implementação do planejamento antecipado do cuidado adaptado à realidade brasileira, baseado em estratégias de comunicação empática, foi elaborado um guia com recomendações de evidências atuais, que contém informações sobre quando e como fazer - o passo a passo desde o preparo, exploração dos valores e percepção do paciente sobre a doença, até o registro do planejamento antecipado do cuidado, incluindo as diretivas antecipadas de vontade e instrumentos já validados para a língua portuguesa (Brasil).

Explorar as barreiras dos médicos na realização do planejamento antecipado de cuidados pode ajudar a focar em intervenções destinadas a minimizar esse problema, desde educação continuada até a priorização de instrumentos e estudos futuros que foquem nessas barreiras, para que a tomada de decisão compartilhada, com base também nos valores e prioridades do paciente, seja cada vez mais frequente na prática clínica.

Palavras-Chave: Autonomia; comunicação; cuidados de fim de vida; oncologia; planejamento antecipado de cuidado; tomada de decisão compartilhada.

INTRODUCTION

The incidence of cancer in the last decade increased by 33% in the world, with 24.5 million incident cases (16.8 million without nonmelanoma skin cancer) and 9.6 million deaths due to cancer. This rate is higher in developing countries (1). Brazil is expected to register 625.000 new cases of cancer for each year of the 2020/2022 triennium, according to National Cancer Institute- INCA (2). Although cancer-related mortality has declined slightly over the past decade, being currently recognized as a chronic disease with advancements in early detection and treatments, a cancer diagnosis still represents a life-altering and potentially life-threatening diagnosis (3). Many people nearing the end-of-life may not be physically or mentally capable of making their own care decisions, and family members and clinicians may not be able to accurately determine what a person's care preferences may be. Therefore, advance care planning is critically important to ensure that patients' goals and needs are met (4). As such, engaging cancer patients in discussions around advance care planning to elucidate their preferences for future or current medical treatment is an essential task (5).

Whilst evidence shows that most patients want to discuss end-of-life plans with their doctors, this kind of discussion is still uncommon in clinical practice (6). Communication about end-of-life care has been reported as one of the most difficult tasks in oncological practice, often associated with lack of training in this matter, and so, many physicians do not communicate these issues effectively with their patients (7).

In the last decade there has been increasing recognition that many cancer patients receive aggressive medical care at the end of life, including cancer-directed treatments; admissions in emergency room and in intensive care units; and in-hospital deaths (8,9). Between 5 and 55% of patients with advanced cancer receive chemotherapy in the last month of life (10) and up to 29% in the last two weeks of life (11–13). In a large population-based prospective cohort study of patients with metastatic lung and colorectal cancer, nearly half of patients received at least one marker of aggressive end-of-life care, including chemotherapy in the last 14 days of life (16%), intensive care unit care in the last 30 days of life (9%), and acute hospital-based care in the last 30 days of life (40%) (14). Moreover, the overuse of chemotherapy or targeted therapeutic agents

as well as radiotherapy in terminally ill cancer patients in the last months of life is associated with an increased risk of undergoing cardiopulmonary resuscitation, mechanical ventilation, or both, and of dying in an intensive care unit. Nonetheless, evidence clearly establishes that early provision of palliative care for patients with incurable cancer is a feasible and effective approach to improving the quality of life. Therefore, doctor-patient communication is critical to avoid disproportionate overtreatment at the end of life. Not only the patient's wishes and priorities should be clarified, but also his or her understanding about the approach in this context (15).

Whilst patients commonly make plans for future practicalities such as finances and their funeral, they rarely discuss future medical care plans with doctors (16). It is estimated that between 33 and 38% of inpatients will receive futile treatment (17). In addition to clinical criteria, inappropriate hospital admissions at the end-of-life have been attributed to poor availability of alternative care options, failure of preventive actions by healthcare providers; family requests; or too late referral to palliative care to be of benefit. Whilst aggressive medical care often results in disproportionately greater health expenditure, it may not correspond to increases in survival or quality of life for patients (9,17). Although some evidence suggests that 70% of patients want comfort care rather than life-prolonging measures (18), up to 63% of patients over 80 years of age received one or more life-sustaining therapies (19). Moreover, unwanted treatment at the end-of-life is associated with negative outcomes, such as reduced quality of life, low satisfaction with care and depression in patients and their families. Thus, it is important to understand patients' perspectives about cancer treatment (20,21).

The relationship among healthcare professionals (who assumably have higher knowledge about the evidence on health and the disease process) and patients (disease carriers) used to be quite asymmetric. However, it has been slowly changing over the course of the 20th and 21st centuries. Sick people are no longer mere patients or objects of care; they have taken on a much more predominant role in their relationship with healthcare professionals regarding procedures, interventions and treatment alternatives. This change reflects the promotion of the patient's autonomy, empowerment and right of self-determination, but it does not mean a transfer of decision-making responsibilities.

It is a *listening exercise* during which healthcare professionals have a chance to understand their patients' needs. Thus, it becomes necessary to place patients back in the centre of the process, focusing on their dignity and autonomy (22,23). In this context, the bioethical principle of autonomy, one of the cores of modern bioethics, has great importance. Autonomy can be defined as the human capacity for self-determination. This concept supports the idea that each person has the right to select from the best alternatives according to a self-chosen plan (24). Respecting patient autonomy means ensuring the right of well-informed patients to participate in the decision-making process related to their medical treatments and being able to accept or refuse the proposed treatments. However, this does not mean the patient has the right to demand interventions which are not medically indicated (25). It recognizes that medical decisions are complex and influenced by many factors that go beyond those related only to diseases, and that individuals weigh the risk and benefits of medical interventions through their own set of values, goals, experiences, and social relationships. These variables influence the decision-making process and that is why for the same clinical condition, different patients may have different treatment goals (25,26). Therefore, it is the physician's responsibility to help the patient explore treatment options, according to their preferences and values based on a risk-benefit analysis whenever circumstances allow (27,28).

Although recognized as an integral component of cancer care, advance care planning has not been systematically implemented in clinical practice (29). In the past, some concerns have been raised that advance care planning may have a negative effect on the psychological wellbeing of patients and relatives, since the advance care planning process may be more focused on fulfilling criteria than on the personalized care that is required in such sensitive end-of-life conversations. Nonetheless, a randomized controlled trial in 2019 found that advance care planning was well received by patients and relatives and the levels of anxiety and depression were not increased by discussions about sensitive issues, such as approaching death and end-of-life preferences (30).

There are documented barriers regarding advance care planning and goals of care discussions in clinical practice. Healthcare provider factors include the concerns of causing distress to a person or decreasing hope for life-sustaining outcomes, personal discomfort with death and dying, personal discomfort

regarding their skills and knowledge related to these discussions- especially with young patients, lack of experience in discussing end-of-life issues and lack of good mentorship. Patient factors are also at play and include family's reluctance to address end-of-life care, patients who are not ready to engage in these types of discussions. Other important barriers include lack of guidelines and protocols around end-of-life issues as well as a lack of tools and training that could contribute to overcoming these barriers (31–33).

Given the scarce literature on advance care planning and its guidelines in Brazilian oncology clinical practice, and also the barriers to its implementation in the Brazilian context in particular, this thesis aims to study the main difficulties in performing advance care planning with oncological patients, from the perspective of Brazilian physicians who assist cancer patients, and to develop a guide to facilitate the discussion and implementation of advance care planning in clinical practice.

This doctoral thesis is structured into: Introduction, Theoretical framework, Aim, Methods, Results, Discussion, Conclusion, References and Appendix. Five articles comprise this thesis: a book chapter of advanced care planning, to be published in the Encyclopedia of Palliative Care, Ed. Almedina; a systematic review on the refusal of medical treatment by older adults with cancer, published in Annals of Palliative Medicine journal, 2021; an article entitled "Advance care planning and goals of care discussion: barriers from the perspective of medical residents", submitted for publication; an article entitled "Advance care planning and goals of care discussion: the perspectives of Brazilian oncologists" published in BMC Palliative Care journal; and a guide about advance care planning accepted for publication in *Revista Bioética-CFM*, 2022.

The introduction contains an overview of the importance of advance care planning in medical practice. In the theoretical and conceptual framework, the topic of advance care planning and its definition, prevalence, engagement, benefits and interface with palliative care is introduced, followed by a book chapter that presents a synthesis of an integrative review about this topic since its origin and further developments, and lastly, a systematic review of literature that explores the refusal of medical treatment by elderly people with cancer, as a basis for investigating autonomy and the decision-making process of these group of patients, followed by the objectives

of this thesis and methodology. The results section is composed by two studies on the difficulties of advance care planning in oncology practice, in addition to an article with a guide proposal to facilitate the discussion about advance care planning. Finally, there is a general discussion and conclusion about our findings and the current literature. Understanding the decision-making related factors and its challenges in clinical practice is essential, since it is a topic seen frequently in clinical practice and still challenging for healthcare professionals.

THEORETICAL AND CONCEPTUAL FRAMEWORK

The aim is to introduce the relevant topics of advance care planning based on the existing literature.

Advance Care Planning Definition

Advance care planning is justified as an instrument that enables respect for patient autonomy. The definition and contents of advance care planning varies substantially (26). Originally, advance care planning was associated only with the completion of an advance directive, to be used when the individual's capacity to indicate preferences had been lost. However, it involves much more than this. Advance care planning is increasingly considered to be a complex process that includes personal reflection and discussion about the patient's wishes, the appointment of a healthcare representative, completion of an advance directive and changes in the provision of care to patients with chronic and serious diseases (34,35).

In 2017, an international consensus supported by European Association of Palliative care defined:

“Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. Advance care planning addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preference can be taken into account should they, at some point, be unable to make their own decisions” (34).

Another international consensus panel (35) described advance care planning as a process that occurs on a continuum. Since a patient's situation changes over time, advance care planning is defined as a process that should be modified at any time according to the patient's health status changes, including becoming more specific about medical care and treatment preferences when needed. Revisiting a person's wishes over time, and especially during times of transition, is critical to this process. Moreover, this panel decided that it would be

important to broaden advance care planning to prepare people in varying health states for medical decision-making, not only at the end-of-life but at any time, including healthy people or those who are facing chronic and serious illness in the goals statement (35).

Best practices in advance care planning and discussing goals of care include the sharing of prognostic information, discussing decision-making preferences, understanding fears and goals, exploring views on trade-offs and impaired function, and wishes for family involvement. There are some proposals to systematize conversations with patients about serious illness goals of care, namely: better education of physicians; systems to identify and trigger early discussions for appropriate patients; patient and family education and structured formats to guide discussions (36).

Advance care planning is a process of several voluntary discussions between an individual and any healthcare professional, and may include various aspects, such as: (37)

- Discussing the individual's understanding about their illness or prognosis.
- Exploring the options available to them.
- Identifying their wishes, preferences, priorities and concerns.
- Refusing specific treatment, if they wish to, that may be part of an advance directive.
- Appointing someone to make healthcare decisions for them, using a durable power of attorney for healthcare.
- Letting people know their wishes for their future care.

Prevalence and Engagement of Advance Care Planning

Despite the robust literature on the benefits related to the topic, the proportion of cancer patients who engage in advance care planning has been low (38). For example, a cross-sectional study based on the Quality Data Collection Tool for Palliative Care (QDACT-PC), a registry that includes specialty palliative care consultations across the care settings in the United States of America, shows that nearly half (47%) of the patients with cancer lacked advance directives, with deficits in advance care planning noted particularly in younger patients and non-white patients (39). In the United States of America, with the possibility of

Medicare paying for advance care planning services, there was a greater adherence to its realization, especially in the elderly (40). In Australia, while most perceived advance care planning as an important instrument to ensure patient autonomy, few people had discussed end-of-life wishes with a doctor (11%), recorded their wishes (15%), chosen a surrogate (28%), discussed life expectancy (30%), or discussed end-of-life wishes with their families (30%) (9). A study in the United Kingdom from 2017 stated that only a small percentage of patients (17%) had prepared an advance care planning document (16,41). In Brazil, there are no population surveys on the rates of advance care planning or advance directives, but a retrospective study involving cancer patients from a Brazilian metropolis showed that advance directive had only been discussed with a few patients (22%) (42).

While the reasons are likely multifactorial, the low participation rate may be partly due to circumstances related to cancer treatment including patient misunderstanding around goals of treatment (e.g., believing treatment is curative when that is not the intent), as well as the desire to be a “fighter” and remain optimistic about treatment options (43,44). In addition, institutional and provider-related factors, including lack of training and variable resources, and lack of palliative care teams at some services, may contribute to low rates of advance care planning. Establishing preferences for future medical treatment without engaging in the process of advance care planning is often not patient-centered, as it fails to consider important contextual factors that influence patient decisions (5).

Benefits of Advance Care Planning

Advance care planning enables patients and their families to consider what care and treatments may or may not be acceptable, and to try to plan their care according to their wishes. Advance care planning primarily focuses on planning for the possibility of decisional incapacity, but it can also serve as a basis for decision-making in patients who retain capacity (45). Besides ensuring that patients receive care consistent with their preferences and reducing the family's decision-making burden involved in healthcare, studies point to other benefits of advance care planning, especially among patients with serious illnesses, such as less moral distress for healthcare professionals; higher advance directive rates; more likelihood that doctors and family members understand and comply with the patient's wishes; reduction of hospitalization and intensive care at the end-of-life;

more follow-up by palliative care teams; greater probability of the patient dying in their preferred place; greater satisfaction with the quality of care and lower risk of stress and depression in family members during grief (44,46–54). Furthermore, there is emerging data showing that advance care planning is related to lower healthcare-associated costs without increasing mortality (54).

Advanced cancer patients may benefit from end-of-life care planning. Recent studies show that the discussion about advance care planning has increased in the scientific and clinical communities. However, it is not yet a universal practice and the discussion about goals of care is still not routinely integrated into clinical practice (54). Social, cultural and emotional difficulties, such as the communication and discussion about prognosis, the influence of institutional culture and the previous experience of healthcare professionals, as well as the complex concept of autonomy, mean that advance care planning still has some obstacles in the medical routine (27,44,47,55,56).

Advance Care Planning and Goals of Care

Advance care planning and goals of care discussions involve the exploration of a person's values, wishes, beliefs and what is most important to each person to ensure concordance between the clinical care received and the clinical care the person wished (54). Although in clinical practice these communication tasks are often conflated, important distinctions exist among these types of discussions, all of which encompass a unique set of skills. The purpose of advance care planning is to enable a person to express healthcare wishes with the aim that this information can be used to guide future decision-making if the person becomes incapable, either by a substitute decision-maker or by a living will (26). After a patient is diagnosed with a serious illness and experiences a change in health state, additional exploration of the patient's values and preferences to help guide medical decision-making may be necessary and occurs in the context of goals of care conversations. As patients navigate transition points throughout their illness trajectory, clinicians are often called upon to deliver serious news or updated prognostic assessments, which lead to further goals of care conversations. So, goals of care discussion focus on current healthcare decisions and also facilitate decision-making, however, more directly

by either the person or their surrogate decision-maker at the time a decision is being made (21).

Advance Care Planning and Advance Directives

Knowing that the focus of advance care planning is the discussion of patients' values, desire and beliefs that can influence the decision-making of medical treatments, some instruments are extremely important in documenting the main goals in these conversations, and therefore reinforce the objectives previously defined among patients, family members and healthcare professionals. These instruments are represented by advance directives, which include "Durable Power of Attorney for Healthcare" to designate a surrogate decision-maker, and a "Living will" that typically documents the individual's own care preferences (29). Thus, advance care planning discussion enables patients to compose an advance directive, which is an important part of advance care planning. The purpose of advance care planning is to enable a person to express healthcare wishes with the aim that this information can be used to guide future decision-making if the person becomes incapable, either by a substitute decision maker or by a living will (57). Advance directives are not always mandatory in advance care planning however they hold great value. Advance directives are written records of patients with preserved decision-making capacity on treatment and/or care decisions that should or should not be carried out, in the case of advanced and irreversible disease to be used when the patient loses his/her decision-making ability (58,59).

Advance directives discussion emerged for the first time in the United States of America in the 1960s. A model of prior declaration of the will of patients with advanced disease was proposed by Louis Kutner, a lawyer who thus anticipated minimizing the conflicts between physicians, patients with advanced disease at the end-of-life and family members about the decision-making of treatments which terminally ill patients should receive (60). But only in 1976, the State of California approved the Natural Death Act - the law that became the first legal diploma to textually recognize the living will (61). In 1990, there was the emblematic case of Nancy Cruzan whose parents requested the removal of the devices that kept her alive because she was in a permanent and irreversible coma after a car accident, claiming that the patient had previously manifested

that she wouldn't want to be kept alive when she retained less than half her normal abilities. Therefore, under strong public outcry, in 1991 the Patient Self Determination Act was approved – the first federal law to recognize the patient's right to self-determination and the patient's right to make an advance directive, in its two modalities: a living will and the durable power of attorney for healthcare, by which the patient can designate a surrogate decision-maker (57,62,63). With this law, the Congress deliberated that all Medicare-certified institutions should provide written information regarding patients' rights to formulate advance directives. More recently, a proposal to reimburse providers for these activities through Medicare stirred controversy and raised concern that advance directives would lead to denial of necessary care (57).

Australia and some European countries (ex. France, England, Spain and Portugal), also have legal documents that guide treatment decision-making and/or appoint health representatives. In Latin America, advance directive laws were enacted in Puerto Rico, Argentina, Mexico, Uruguay, and Colombia (22).

In Brazil, there is still no specific legislation on advance directives, but there is already a resolution of the Federal Council of Medicine (CFM resolution 1995/2012) that deals with the importance of integrating this tool into medical practice (26,59). This resolution respects the patient's wishes according to the concept of orthothanasia and does not have any relation to the practice of euthanasia, recognising the patient's right to refuse futile treatment, understood as treatments that do not offer real benefit to the patient as death is inevitable, that is, those treatments that aim only prolong the biological life, without guaranteeing quality of life. It provides some support for doctors who are in the process of following or suspending a certain therapeutic path in accordance with patient's previously expressed wishes (62,64,65). Some legal uncertainties remain, however, because although advance directives have a specific resolution, there is no legal provision for them in Brazilian legislation. All individuals over 18 years old, with preserved cognitive ability, could perform an advance directive. The resolution 1995/2012 establishes that the physician can register in the medical record, the advance directive that was directly communicated by the patient, without the need to register in a notary's office (59). It is worth mentioning that it is up to the medical doctor, as a technician, to guide the patient in detail about the therapeutic options and procedures that are most

adequate and available to the patient's condition (26). Therefore, the medical doctor acts as a guide to carry out the advance directives, so that, in the face of this information, patients can actually exercise their autonomy and have their will respected. The Resolution 1995/2012 represents a great advance in the discussion of this subject in Brazil, but even so, it demonstrates the need for specific legislation on advance directives in order to regulate issues related to perception of the patient, to an exemplification of care and treatments that may or may not be refused and to criteria for their acceptance and refusal (62).

Terminology, types, scope, and legal standing of advance care planning documentation vary considerably. Spain became the first European country to legalize advance directives in 2002, named as "*Instrucciones previas*" (Law n.41/02), which contain guidance for medical teams about the desire to receive or not artificially prolong life support, the non-use of extraordinary or futile treatments, the suspension of the therapeutic effort and the use of drugs to reduce pain, among others. This law allows the patient to appoint a surrogate in this document, so that when he/she is unable to express his/her will, the appointed surrogate can do so on behalf of the subscriber of the document (66). Therefore, Spanish and Portuguese law presents a true advance directive, with the possibility of containing, in a single document, the living will and the durable power of attorney for healthcare, which in the USA are different documents. In Portugal, the Law on Advance Directives (Law no. 25/2012) also contains the registration instructions of the Living Will that can be done in a platform - RENTEV, which allows the timely availability of the living will information for consultation by doctors everywhere in that country (67). Despite this, the prevalence of advance directives existing by 2020 was still low, with fewer than 30,000 Portuguese citizens with registered living wills (68). Therefore, the Portuguese Bioethics Association, led by Prof. Rui Nunes, who actively participated in the process for parliament to approve legislation on advance directives, suggested that the Assembly of the Republic amend the Law 25/2012 in order to make it mandatory for all Portuguese hospitals to inform patients at the time of admission of the possibility of making their advance directive (69).

Advance directives can minimize the difficulty for family members to make decisions during patients' complications as they are often emotionally vulnerable and unprepared to answer for their loved one. Therefore, it is justified that the

advance care planning be performed as soon as possible, when the patient still has preserved cognitive capacity to determine what is important to him/her (26,53,54).

The documentation of advance care planning conversations and/or completion of legal documents is needed to ensure that the medical care provided aligns with a patient's preferences. Although advance directive documents can be useful, they should allow healthcare agents and care providers to make informed decisions in certain circumstances and should not replace open and continuous communication (26). The advance care planning process can begin at any age or state of health and should centre on frequent conversations with patient, family members and care providers (4). Given their importance, both ongoing conversations and documentation were included as strategies for supporting adults in advance care planning. It is specifically noted that conversations should be documented in the medical record to provide context about the patients' decisions, even though different jurisdictions internationally have varying laws concerning the use of oral advance directives (70).

Advance Care Planning and Palliative Care

The growing field of palliative care and the rapidly aging population underscore the importance of advance care planning, given longevity may be accompanied by serious illness, uncertainty of prognosis, symptom burden, functional dependence and frailty, caregiver burden, and high healthcare utilization (45). The need for palliative care has never been greater and is increasing at a rapid pace due to the ageing of the world's population, increases in cancer and other chronic illnesses, and the recent emergence of COVID-19. By 2060 the need for palliative care at the end-of-life is expected to double (45,71). Palliative care is a holistic approach that aims to improve the quality of life of both patients and their families who are facing a life-threatening illness, through the prevention and relief of suffering by means of early identification and adequate assessment and treatment of pain and other physical, psychosocial and spiritual factors. It includes as main principles: death as a natural process, and doesn't aim to speed or delay this process; to offer a support system for both the patient to live as actively as possible until death and the family to cope during the

patient's illness and during bereavement; a multidisciplinary team approach to address the needs of patients and their families, including bereavement counselling; and to enhance quality of life, which may also positively influence the course of illness. All these principles are related to the exercise of autonomy and improvement of the patient's quality of life and can be addressed through the involvement of patients in care and a good professional health-patient relationship that permeates the advance care planning (71).

Provided in parallel with therapies focused on treating the underlying disease, the integration of palliative care is appropriate for any stage of illness and a responsibility of all clinicians caring for the seriously and critically ill (27). The National Coalition for Hospice and Palliative Medicine and the European Association for Palliative Care emphasize the importance of addressing therapeutic goals in advance care planning, as part of primary palliative care, which promotes stronger clinician-patient relationships and reduces fragmentation of care (27,34).

The Institute of Medicine's (IOM) 2014 *"Dying in America"* report (4) highlighted the need for new models of care that promote advance care planning conversations. Nowadays, advance care planning is considered an important domain of high-quality palliative care. So, healthcare professionals should clearly discuss prognosis, the uncertainty of treatment outcomes, and provide recommendations for end-of-life care options, at an appropriate time for each individual relative to his or her disease course. This task is critical in helping patients achieve their goals of care, enjoy more time with their loved ones, and maintain dignity until death (29).

To improve care at the end-of-life, providers and patients must engage sooner in conversations which explore patients' understanding of their disease status, treatment preferences, and goals of care through shared decision-making (72). Assessing patients' decisional needs, conflicts and strategies may help provide effective support in the decision-making process. This support may reduce conflict related to decision-making, which is considered a psychological state of uncertainty regarding a specific choice that can lead to regret and distress (27,73). There are various strategies when having conversations about goals of care, including discussing prognosis, responding to patient emotion, exploring values and often making a recommendation for medical treatments that fit those

values (6). By reducing decisional conflicts, palliative care health professionals can enhance patients' outcomes in terms of care and wellbeing. Besides, giving patients the rights of self-determination and autonomy are essential to an ethical and appropriate end-of-life care (73).

Regarding advance care planning historical background, development and application, it follows a book chapter "Advance Care Planning" of the Encyclopedia of Palliative Care (74), that was based on an integrative review carried out on this topic. It describes when and how to initiate and conduct the discussion about goals of care and advance directives - the step by step from preparation, exploration of patient's values and perception about disease, to the advance care planning registration, including advance directives records.

Advance Care Planning

(In Encyclopedia of Palliative Care-2o Ed.)

LAIANE DIAS MORAES

1. Introduction

The remarkable technological and scientific advances in the health area are associated with an increase in patient survival, regardless of their conditions. The physician's power of intervention at the end of life has grown significantly, where invasive support measures often prolong lifetime, without necessarily improving the individual's quality of life, and many times without taking into consideration the patient's preferences and values (Siqueira JE, 2005)

In this context, the bioethical principle of autonomy assumes great importance. Respecting autonomy means guaranteeing the patient's right to participate in decision making related to his/her care. It is important to recognize that medical decisions are complex and influenced by many factors which go beyond those related only to disease. For each treatment one must consider the risk and benefit as well as the patient's values and experiences. Evidence suggests that unwanted treatment at the end of life is associated with negative outcomes such as decreased quality of life, low satisfaction with care, anxiety and depression in patients and their families (Dias et al., 2021; Fromme EK, 2020; Silveira MJ, 2021)

In this sense, advance care planning (ACP) is justified as a tool that enables the respect for the patient's autonomy. This planning is a process that helps patients to share their personal values, life goals and preferences regarding current or future medical care. Regardless of the disease or clinical situation, ACP should be proactive, timely and integrated into routine care (Sudore & Fried, 2010)

ACP requires effective communication between health professionals and patients and/or their family. Treatment decisions discussed in ACP may also include the recording of an advance directive of will (ADW), written instructions made by the patient with autonomy, on how medical treatment decisions should be made when this person is no longer able to do so, although the ADW is not mandatory for the realization of ACP(Silveira MJ, 2021).

2. Historical Background and Development

ACP was originally associated with the completion of an advance directive of will, to be used at the time when the patient no longer has the capacity to express their preferences. It is known today that ACP is a much more complex process that includes not only the completion of an advance directive, but a whole reflection on the individual's values and preferences that allows for the shared determination of care goals, and that can be discussed at any time during the trajectory of the disease, from diagnosis to the most advanced stages (Sudore & Fried, 2010). This discussion on care preferences is still held more frequently among carriers of chronic-degenerative diseases such as cancer, dementias and organic insufficiencies (heart failure, chronic obstructive pulmonary disease, among others), although it is valid for any other disease.

Historically, ACP emerged from the discussion on the legal recognition of the right of patients or their families to refuse extraordinary life-prolonging support measures, together with discussion of the legalisation of advance directives of will, which occurred in the 1990s in the United States of America (*Patient Self Determination Act of 1990*, 1990). In 2012, Portugal approved the Law 25/2012 that provides for advance directives, an important milestone regarding the guaranteed preservation of personal autonomy (Ferreira C & Nunes R, 2019). In Brazil, there is still no specific legislation on the topic, even though the Federal Council of Medicine approved, in 2012, the Resolution 1995/2012 which recognises the patient's right to manifest his/her will about medical treatments or designate a representative for such purpose, as well as the doctor's duty to respect this will (*RESOLUÇÃO CFM No 1.995/2012*, n.d.)

Although data is limited, documented ACP discussion rates fall short of ADW completion rates, which are still around 10-15% in countries such as Germany, the Netherlands and England. Wright et al (Wright, 2008) showed in a prospective longitudinal study that only 37% of patients with advanced cancer had an ACP conversation before their death. In response, some services have implemented programmes to improve access to ACP and ADWs. One example is Australia's "Advance Care Planning" program that aims to integrate ACP into the routine of emergency and urgent care hospitals, in long-stay institutions for the elderly, and in primary care.

3. Definition and Conceptual Clarification

3.1 Concepts

Advance care planning is a process that helps patients prepare for current and future decisions about their treatments and define their care goals together with the healthcare team, based on the patient's wishes and values and technical issues (Rietjens et al., 2017; Silveira MJ, 2021)

To ensure their autonomy, patients need to be well informed about their diagnosis, prognosis and treatment options, the risks and benefits of each of them. Therefore, communication skills of health professionals are essential for the realization of ACP, as they allow from the proper communication of bad news (diagnosis and prognosis), the discussion about therapeutic options and care goals, including palliative care, to the realization of advance directives of will. All these communication tasks, although often confused in clinical practice, are different stages of advance care planning (Jain & Bernacki, 2020).

The patient's biographical and values information added to the well clarified technical care issues form the basis for patient-centred care planning. One of the main objectives of ACP, besides ensuring that as the disease progresses the patient receives treatments in line with their preferences, is to reduce the family's decision-making burden on decision making involving healthcare (Rietjens et al., 2017)

Other well-established benefits of ACP are: reduced moral distress of healthcare professionals, higher rates of ADW registrations, reduced hospitalisation and intensive treatments at the end of life, greater likelihood of the patient dying in the chosen location, greater satisfaction with the quality of care, and lower risk of stress, anxiety and depression in family members during bereavement. Finally, there are emerging data showing that ACP reduces the cost of end-of-life care, without increasing mortality(Silveira et al., 2010; Silveira MJ, 2021)

3.2 Elaboration of ACP

To elaborate the ACP some points should be discussed previously with patients, which are: patient's life values and care wishes; possible clinical situations and respective outcomes; treatment options; advance directive, and end-of-life care options.

Advance care planning is a complex process, not always carried out in a single conversation, and which may be initiated at any time of the individual's life. The content of the planning may vary according to the patient's health condition, from a context of absence of symptoms, initial phase of the disease, to a terminally situation. And it should be reviewed regularly, especially when there is a change in the clinical picture or after the

patient's admission to the hospital, to ascertain whether they maintain their care preferences or would like to add any new information (Rietjens et al., 2017)

Some instruments can be used to facilitate discussion about ACP and to document wishes regarding end-of-life care. An example is the Physician Orders for Life-Sustaining Treatment, which has the basic premise of specifying patients' preferences regarding medical interventions, such as cardiopulmonary resuscitation, artificial nutrition, end-of-life antibiotic use (Hickman et al., 2021).

Another instrument used with the aim of facilitating the conversation about end-of-life care preferences is the Go Wish Cards (Menkin ES, 2007) that allows the construction of the advance directive. This instrument has 36 cards, where each one represents a wish related to healthcare. It can be played individually or in pairs, to simplify the conversation about goals of care in a playful way. It had already been translated and adapted to Portuguese for the Brazilian population (SBGG, 2017)

Ideally, the ACP discussion should be followed by specific, actionable medical treatment orders (e.g., do not resuscitate or do not tube for enteral diet), reflecting the individual's treatment preferences and current medical condition. It is important that these medical treatment recommendations are written in an appropriate and standardised form so that they are readily understood by healthcare professionals during an emergency and in any modality of care (Silveira MJ, 2021)

3.2.1 Stages of advance care planning

Steps	Objectives	Examples
Permission/ autonomy check	The patient should be asked if they want to be involved in decision making or if they prefer the team to talk to a family member. Patients with decompensated symptoms should have the conversation about ACP after symptoms have cleared.	<i>"Would you like to talk about this on your own or are there other people you would like to be part of the conversation?"</i> <i>Patients with decompensated depression ideally treat the mood board before the conversation.</i>
Invite to talk about	Invite the patient to discuss their current condition and wishes regarding future medical care	<i>"Would you like to talk about what might happen going forward and how</i>

		<i>we can make sure your preferences are respected?"</i>
Establishing the starting point	Check the understanding of the patient and his family about the diagnosis and prognosis, and standardise the information so that everyone understands the current moment.	<i>"What do you understand about your illness?"</i> <i>"What have your doctors told you about your illness and possible treatments?"</i>
Provide clear information.	Avoid technical terms or euphemisms when giving information: try to be clear and objective when giving information about the patient's current health status and what choices he/she may face in the future (depending on the underlying disease).	For a patient with relapsed cancer after several lines of treatment, for example: <i>"We have not had the expected response to 1st line treatments. There is the possibility of the disease progressing, it is as if he had a chronic disease. But we will continue with supportive treatment, controlling the symptoms."</i>
Explore values and preferences	Understand what it is to live well for the patient and what the expectation is in relation to treatment.	<i>"What is most important to you in life?"</i> <i>"What worries you most about your situation?"</i> <i>"When you think about the future, what do you expect?"</i>

Talk about care preferences and possible dilemmas.	Ask the patient if they have thought about how they would like to be cared for and what types of treatment they would not like to undergo. Some people have previous experience of resuscitation and intubation from family members or acquaintances and this may be a way of introducing the subject. Explain the risks and benefits of different treatment options. Clarify when invasive and artificial life support measures are beneficial and when they are technically futile.	<i>"If you had difficulty breathing, associated with advanced and irreversible disease, would you want to be put on a machine for respiratory support, through a tube in the mouth or trachea, or would you prefer comfort measures to be adopted, such as breathlessness medications and sedatives? Both procedures have the same goal-relieving breathlessness."</i> <i>"Someone close to you has had to face end-of-life decisions, such as deciding on withdrawal of a respirator or being referred to palliative care units (hospice). If it were up to you, as the person with a serious and irreversible illness, what would you wish for in that situation?"</i>
Identify a patient's healthcare proxy, if any.	Ask the patient who they would like to be approached about treatment decision making, in case they are unable to speak for themselves.	<i>"If you were unable to tell your doctors what kind of treatment you would like to receive, who would you appoint to make the medical decisions for you?"</i> Note: If the patient names several people, try to establish a primary proxy.
Sharing Choices	If you feel it is appropriate, encourage the patient to talk to their family members about their care preferences.	<i>"It would be important for your family to know your wishes and desires for the future. This includes letting everyone know who you have chosen as the decision maker when you are incapacitated."</i>

Document	Always record preferences in medical records so that all staff responsible for the patient have access to what has been discussed. Encourage the patient to write their advance directive.	<i>"These decisions are important and will influence your treatment in the future. It would be important to write them down, if possible, so there will be no doubt about your wishes should you become unable to express yourself."</i>
Review the ACP	Remember to review the patient's preferences periodically, especially after hospitalization or in case of clinical worsening.	<i>"Would you like to review your care plans? Just to see if there are any changes or not."</i>

It is important to remember that these issues should be raised gradually. They will hardly be defined in a single conversation. Advance care planning is a construction, it is only possible to prioritize comfort measures in detriment of invasive measures, for instance, with a patient/ family who already understands his/her diagnosis and prognosis. After considering the personal and technical aspects, the ACP is built, and it must be shared between the health team and patient/ family.

4. Conclusion

Health professionals, especially physicians, have the responsibility to adequately inform their patients about their prognosis, explore treatment options and assist in decision making according to the patient's preferences, analysing cost and benefit. There is sufficient evidence to justify the integration of ACP into the routine of health services, especially for those with chronic and severe diseases, such as positive impact on the completion of ADW, improved doctor-patient relationship, greater likelihood of patients having their wishes understood and respected by health care team and family, and less futile and disproportionate treatments at the end of life.

5. Keywords

Advance care planning; communication; goals of care; personal autonomy.

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Advance Care Planning and Refusal Medical Treatment

Modern medical care is filled with a huge variety of medical choices for patients which influence quality and quantity of life. A patient's decision-making experience can be a complex combination of factors, including disease prognosis, expectations for the future, pre-existing comorbidities, disease burden, individual values and goals, cultural understand of disease, family preferences and relationships (27).

Advance care planning is a process of discussions between patients and healthcare professionals that may include different topics, from the discussion about illness, prognosis and treatment options available, identifying patients' wishes, priorities and concerns, or even simply letting people express their wishes for their future care, which may include the registration of an advance directive that may contain the refusal of specific treatments, if the patient wishes(75). In England, for example, there is a specific document about this topic named Advance Decision to Refuse Treatment, which is part of advance directives, based on a general principle of law and medical practice that people have a right to consent to or refuse treatment. The English courts have recognized that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death. A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision (76). It is a formal, legally binding document or verbal statement that allows the refusal of certain medical treatments by an individual who has capacity to make decisions. It cannot be used to demand medical treatments which are not thought to be of benefit to the individual, a request to end life (euthanasia) or the refusal of basic essential care (37).

Information on patient-specific characteristics that impact the likelihood of engaging in advance care planning among cancer patients is lacking, especially in the elderly. Understanding factors that affect preferences for medical treatment is needed to help physicians and caregivers identify patients most at risk for not engaging in this important process (54). To know these characteristics may help

target these populations to promote increased engagement around decision-making process to ensure proper care and decisional support (5).

Given the high prevalence of patients with therapeutic refusal in palliative care services and because it is still a challenge for healthcare professionals in clinical practice (77), a systematic review about the refusal of medical treatment by older adults with cancer (20) was developed in order to explore the reasons associated with refusal treatment in this group of patients. The findings of this systematic review are shown in the study described below.

Refusal of medical treatment by older adults with cancer: a systematic review

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Abstract: The literature about the factors associated with cancer treatment refusal, especially by the older patients is scarce. Therefore, this study aimed to identify predictive factors associated with treatment refusal by older patients with cancer. A systematic review was conducted using three databases, Medline, Web of Science, and Scopus with the key concepts, “refusal treatment” and “cancer” and “decision making” and “elderly” or “aged”. The search took place in July 2020 and it included articles published in the last 5 years. Of the 211 articles found, 22 were included in the review. Most studies have focused on head and neck and breast cancer treatment decisions and used a quantitative design. The majority of studies evaluated refusal of surgery interventions. Important factors associated with refusal cancer treatment include gender, marital status, race, having government insurance, advanced cancer, poor performance status (cancer stage III or IV) and Charlson Comorbidity Index ≥ 2 . Thus, there are socio-demographic and clinical variables associated with treatment refusal. More studies with the elderly are needed. Understanding these factors may be useful to recognize situations where active education and support can help elderly patients accept optimal care.

Keywords: Cancer; elderly; decision-making; treatment refusal

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Introduction

Cancer is a global health problem of great magnitude, particularly in older patients. A considerable number of older adults are diagnosed with this disease. For older adults, an increase of 67% in cancer incidence is anticipated, compared with younger adults (11% increase). Also, 60% of the mortality cases due to cancer are estimated to occur in people aged 70 and older (1-3).

To date, the perspective of older patients with cancer regarding oncology treatment is an unexplored field. A review about decision-making on cancer treatment showed that research is still poor regarding treatment decision in older adults (4). Refusal therapy and underuse of treatment are more common in older adults, and they are associated

with worst outcomes such as higher rates of cancer recurrence and worst survival, even knowing that cancer-directed treatments have evolved and that more “elderly-friendly” treatments have been developed (3). Furthermore, the heterogeneity of this population’s health and functional status may interfere in treatment preferences and must be taken into account (3-5).

Many studies have explored the actual role in the decision-making process; however, most were conducted years ago and with a relatively young population. With advances in cancer treatment and more available options for the elderly population, older adults may have different views than those included in previous studies (5).

One of the principles of good care is respect and receptivity to patients’ wishes and values; thus, it is

important to understand patients' perspectives about cancer treatment. Most studies have focused on the decision-making processes related to the choice between cancer-directed therapies and palliative care (5,6). However, little is known about the factors associated with treatment refusal in oncology. Some preliminary data suggest that therapeutic refusal is partially based on balancing the pros and cons of treatment (6).

Thus, the aim of this review was to identify the factors associated with treatment refusal by older adults with cancer. We expect that this systematic review provides knowledge regarding the clinical and sociodemographic characteristics associated with therapeutic refusal in this population.

We present the following article in accordance with the PRISMA reporting checklist (available at <http://dx.doi.org/10.21037/apm-20-2439>).

Methods

Search strategy

We conducted a systematic review starting with the search in three databases in July 2020, namely Medline (PubMed), Web of Knowledge (ISI) and Scopus, using the key concepts: "refusal treatment" and "cancer treatment" and "decision making" and "elderly" or "aged".

Inclusion criteria

Studies that included the factors or reasons for refusing cancer therapy in the elderly (65 years or older), not necessarily exclusively to the elderly as long as there are reported results on a subgroup analysis of older adults. We consider 'therapeutic refusal' any cancer treatment, such as surgery, chemotherapy, radiotherapy, as well as curative or palliative treatment.

We included studies written in English, French, Portuguese and Spanish languages. Empirical articles, quantitative and qualitative studies were also included. Given that a similar review was conducted in 2015, we considered studies from 2015 until July 2020 for updated scientific and research developments in this area.

Exclusion criteria

Editorials, letters to the editor, reviews, comments and narrative case reports were excluded. Studies on other

related topics, such as transition of care and no indication of active treatment for advanced disease, were also excluded. We considered only those studies related to a patient's refusal of therapy.

Quality assessment of studies and data extraction

Study quality and eligibility were individually assessed by the two researchers (LD, MRB). The extraction of data was done manually without extraction software. There was a critical review of the results by the researchers (LD, MRB) and coordinators (WFB, FR). In case of different opinions regarding articles' relevance, a consensus was reached by the authors. Data systematization was evaluated by the periodical (title, volume, number and year), study location country, objectives (article or search), method (type of research, sample, participants), results, and mention of treatment refusal. Final assessment of the quality and level of evidence and the recommendation force of the articles, when absent in the original articles, were conducted by the authors, according to the criteria of the Strength of Recommendation Taxonomy scale by the American Family Physician (7) ([Supplementary appendix](#)).

Results

Through the search strategy, 221 studies were initially identified: 67 in PubMed, 58 in ISI, and 87 in Scopus. Ten studies were found in other databases because they were found in the articles' references and met the eligibility criteria for this study.

The PRISMA (Preferred Reporting Items For Systematic Reviews and Meta-Analyses) flow diagram (8) is shown in *Figure 1*. Screening covered the stages of analysis by titles and summary. Based on the title and abstract, 139 articles (screening) were excluded. In addition, 45 duplicate articles were excluded. A total of 37 full-text articles were analyzed, of which 14 were excluded as they did not respect the study criteria. A total of 22 articles met the inclusion criteria and were included in this review (*Table 1*).

Characteristics of the studies and quality assessment

The included studies' characteristics are shown in *Table 1* and information about the quality assessment is described in Appendix A. Nineteen studies used a retrospective, cross-sectional analytical design, and at least thirteen had controlled data and were compared with a case

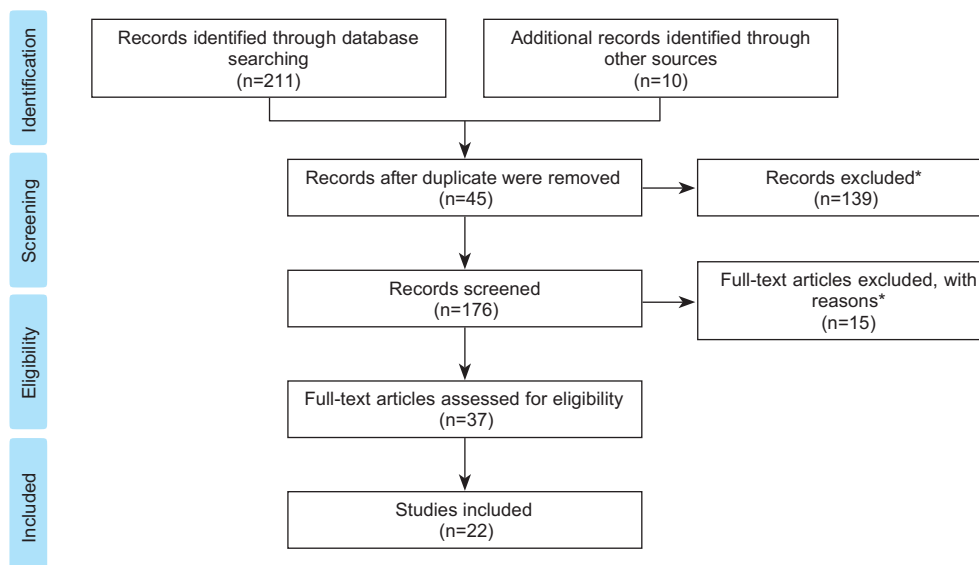


Figure 1 PRISMA flow diagram showing the literature method search. n: number of articles. Records excluded*: they did not specify the factors/ reasons of refusal treatment; or did not provide data specifically in older adults; some of them were a review/editorial/expert opinion paper.

Table 1 Study characteristics and factors associated with refusal treatment

Study	First author & year published	Title	Type of analysis	Type of cancer/ treatment	Factors associated with treatment refusal
P1 (9)	Restrepo DJ, 2019 USA	Characteristics of breast cancer patients who refuse surgery	Retrospective cross-sectional study	Breast/surgery	Non-White race, government insurance and uninsured patients ($P<0.001$)
P2 (10)	Coffman A, 2019 USA	Correlates of refusal of surgery for the treatment of non-metastatic pancreatic adenocarcinoma	Observational retrospective	Non-metastatic pancreatic adeno-carcinoma/ surgery	Old Age, female, black race, treatment at a non-academic institution/non-metro facility, government insurance, Charlson comorbidity index of ≥ 2 ($P\leq 0.01$), and advanced disease (T3-T4 stage; tumor size >20 cm ($P\leq 0.01$))
P3 (11)	Crippen MM, 2018 USA	Refusal of cancer-directed surgery in head and neck squamous cell carcinoma patients	Retrospective review	HNC**, any stage/surgery	Elderly (>75 years) and stage III or IV at diagnosis; Black race; non-married and have Medicaid insurance; primary site: larynx or base of tongue
P4 (12)	Rahouma M, 2018 USA	Consequences of refusing surgery for esophageal cancer: A national cancer database analysis	Retrospective study, cross-sectional N=18,459	Esophageal T2-T4 M0/surgery	Old age, female, non-white race, squamous histology, early diagnosis, no insurance, treatment at non-academic centers, lower income, and clinical stage I/II ($P<0.001$). Median survival was better for patients who went surgery vs. patients who declined surgery (32 vs. 21 months, $P<0.001$)
P5 (13)	Tohme S, 2018 USA	Race and health disparities in patient refusal of surgery for early-stage pancreatic cancer: an NCDB Cohort Study	Cohort retrospective study	Early-stage pancreatic cancer (T1/T2N0M0) Surgery	Old age; female; African American on Medicare/Medicaid; Charlson score ≥ 2 ; patients; treatment at non-academic centers; Significant worst survival for patients who declined surgery compared with who received surgery [median survival 6.8 vs. 24 months]

Table 1 (continued)

Table 1 (continued)

Study	First author & year published	Title	Type of analysis	Type of cancer/ treatment	Factors associated with treatment refusal
P6 (14)	Cheraghlou S, 2018 USA	Untreated oral cavity cancer: long-term survival and factors associated with treatment refusal	Retrospective descriptive	HNC**-any stage/surgery	Elderly; no insurance or have government insurance, advanced disease (P<0.001)
P7 (15)	Chiang TY, 2015 Taiwan	Factors related to treatment refusal in Taiwanese cancer patients	Retrospective descriptive	Miscellaneous/ any treatment	Elderly, poor physical condition (P<0.001), concerns about adverse effects (P<0.001), changes in medical status (P<0.001), poor performance (P<0.001), timing of case manager contact (P=0.026), methods of patient contact by case manager (P<0.001), poor social support and lost contact
P8 (16)	Gaitanidis, 2018 Greece	Refusal of cancer-directed surgery by breast cancer patients: Risk factors and survival outcomes	Retrospective study	Breast Cancer– any stage/ surgery	Elderly (age >70), ethnicity, unmarried status, advanced tumor and lack of insurance. Refusal treatment was associated with a higher risk of mortality (increase of 2.42 compared with those who received treatment) (P<0.001)
P9 (17)	Massa ST, 2017 USA	Survival after refusal of surgical treatment for locally advanced laryngeal cancer	Retrospective study	Laryngeal cancer (T1–T4M0)/ surgery	Unmarried, Black race, T3 tumors. Decreased 5-year survival compared with those who went to surgery (50.0% vs. 60.1%)
P10 (18)	Suh WN, 2017 South Korea	Risk factors associated with treatment refusal in lung cancer	Retrospective study	Lung cancer- any stage/any anti-cancer treatment	Elderly, low educational status, low weight, and ECOG 3–4. *P<0.05
P11 (19)	Gilbar P, 2017 Australia	Why adjuvant chemotherapy for stage III colon cancer was not given: Reasons for non-recommendation by clinicians or patient refusal	Retrospective study	Colon cancer stage III/ chemotherapy	Reasons for refusal were not detailed in most patients' charts (63.6%).
P12 (20)	Chen SJ, 2015 Taiwan	Characteristics of the delayed or refusal therapy in breast cancer patients: a longitudinal population-based study in Taiwan	Cohort retrospective	Breast any stage/any anticancer treatment	Elderly, higher Charlson score, advanced tumor stage, other catastrophic illness or injury, and the level of diagnostic hospitals. *P<0.05
P13 (21)	Chiang TY, 2018 Taiwan	Colorectal cancer in Taiwan: A case-control retrospective analysis of the impact of a case management program on refusal and discontinuation of treatment	A case-control longitudinal, retrospective	Colorectal cancer – any stage Any anti-cancer treatment	Elderly*, Concerns about adverse effects*, poor performance status*, changes in medical condition*, the methods and frequency by which case managers contact patients*, *P<0.001
P14 (22)	Stavas MJ, 2015 USA	The refusal of palliative radiation in metastatic non-small cell lung cancer and its prognostic implications	Retrospective database study	Metastatic non-small cell lung cancer/radiation therapy	Elderly*, non-Black/non-White*, unmarried* and female*; *(P<0.001 in all cases)

Table 1 (continued)

Table 1 (continued)

Study	First author & year published	Title	Type of analysis	Type of cancer/ treatment	Factors associated with treatment refusal
P15 (23)	Lu PW, 2020 USA	Sociodemo-graphic predictors of surgery refusal in patients with stage I–III colon cancer	Retrospective database study	Stage I–III Colon cancer/curative surgery for colon cancer	Older age*, Black race*, higher Charlson score*, have government insurance* or lack of insurance*; *P<0.001. A significant difference in survival of 5-year was found for patients who refused surgery vs. those who undertook surgery (P<0.001)
S1 (24)*	Wan J <i>et al.</i> , 2018 China	Management and survival analysis of elderly patients with a cancer in the digestive system who refused to receive anti-cancer treatments	Retrospective observational study N=57	Digestive system cancer, any stage/any active therapy	Advanced or late stage at the time of diagnosis and impairment of multiple organs. The average number of malfunctioning organs was 3.68 per patient
S2 (25)	Dronkers EAC, 2015 the Netherlands	Noncompliance with guidelines in head and neck cancer treatment; associated factors for both patient and physician	Retrospective observational study N=829	HNC**, any stage/any active treatment	Elderly, non-married, female, high tumor stage, and severe comorbidity (P<0.001). Refusal treatment was associated with lower overall 3-year survival (34% vs. 70%)
S3 (26)	Parhar HS, 2018 Canada	Patient Choice of Nonsurgical Treatment Contributes to Disparities in Head and Neck Squamous Cell Carcinoma	Retrospective nationwide analysis (cross-sectional) N=58,816	HNC** (squamous cell carcinoma) any stage/surgery	Age (67.1±12.6 vs. 63.6±13.1, P<0.01), non-white; unmarried, advanced stage tumor, and having a primary site in the hypopharynx or larynx (P<0.001)
S4 (27)	Wallace SK, 2016 USA	Refusal of Recommended Chemotherapy for Ovarian Cancer: Risk Factors and Outcomes; a National Cancer Data Base Study	Cohort retrospective N=147,713 (2,707 refused treatment)	Ovarian-any stage/ chemotherapy	Older age (>70), comorbidities (≥2 vs. 0; OR, 1.8), have no insurance (OR, 1.4–2.9), later year of diagnosis (OR, 1.3), Higher Stage (I vs. IV; OR, 2.2), P<0.005
S5 (28)*	Sowerbutts, 2015 UK	Why are older women not having surgery for breast cancer?	Qualitative case study N=28	Breast-any T/ surgery	These patients rejected surgery as they were not interested in maximizing their survival, referring to their age or concerns about impact of treatment on their functional level
I1 (29)	Rapp J, 2019 USA	Disparities in surgery for early-stage cancer: the impact of refusal	Observational cross-sectional N=498,927	Surgery	Increasing age*, non-Hispanic Black race/ ethnicity*, uninsured*, unmarried*, and stage disease*. *P<0,001. Patients who refused surgery were more likely to experience mortality in comparison to those who received surgery
I2 (30)	Islam KM, 2015 USA	Prostate cancer patients' refusal of cancer-directed surgery: a statewide analysis	Retrospective cross-sectional N=14,876	Surgery	Early-stage prostate cancer (P<0.0001), older age (P<0.0001), Black race (P=0.024), unmarried (P=0.0003), have Medicaid/Medicare (P<0.0001)

*Studies with elderly patients with cancer exclusively; **Head and neck cancer (HNC).

group (patients who refused treatment) and case control (patients who received treatment). Thirteen studies (9-14,16,20,22,23,26,27,30) were non-randomized but with a large sample size, with data collected from National Database, thus representing a nationwide population. Almost all of the studies used retrospective chart reviews and/or an administrative database. There was just one study with a qualitative design (28), with a sample size of 28 patients. The sample size for quantitative studies ranged from 58 to 498,927 patients (24,29). Study quality ranged from poor to moderate for most studies (level 2 and 3 evidence; Appendix A). The majority of studies focused on head and neck (11,14,17,25,26), breast (9,16,20,28), and colorectal cancers (19,21,23). There were two studies on lung cancer (18,22) and two on pancreatic cancer (10,13). Three studies included different types of cancer (miscellaneous) (15,24,29). Most of the studies were from the United States (9-14,17,22,23,27,29,30). There were five Asian (15,18,20,21,24) and three European studies (16,25,28). There were no studies from Latin America.

Predictive factors associated with refusal treatment in the elderly

Socio-demographic factors

Only two studies included elderly patients exclusively (24,28): one included only elderly women with breast cancer and the other one included elderly people with digestive cancer. The vast majority of studies (10-16,18,20,22,23,26,27,29) showed that being elderly was an important refusal factor. The factors associated with treatment refusal were mostly unmarried status (11,16,17,22,25-27,29,30) female gender (10,12-14,22,25), non-white race (9-13,16,17,23,26,29,30) having government insurance (9-11,13,14,23,30), or not having insurance (9,14,16,23,27,29).

Types of intervention

The majority of studies evaluated refusal of surgery interventions (9-14,16,17,23,26,28-30). Two studies evaluated refusal of chemotherapy (19,27). One article included palliative treatment (radiotherapy) exclusively, and showed that older patients with non-small cell lung cancer (NSCLC) with metastases were more likely to refuse radiation therapy (22).

Clinical characteristics

Most studies showed that clinical status was a predictive

factor associated with treatment refusal. Cancer stage III or IV (10,11,14,16,17,24-27) was more associated with refusal treatment, as well as poor performance status (Eastern Cooperative Oncology Group 3 or 4) and Charlson comorbidity score >2 (10,13,15,18,20,21,23-25,27).

Discussion

Although there have been few studies on the treatment refusal of the older patient with cancer, the majority of studies analyzed described old age as one of the strongest predictive factors associated with therapy refusal. A national cohort study of lung cancer in Taiwan described that the rate of treatment refusal increased proportionally for each 10-year age increase, and among patients aged 75 and older was increased 2.6 times compared to those aged 44 or under (18,31). Administration of chemotherapy decreased with age and increasing number of comorbidities. Walter *et al.* (32) showed in a sample of patients with stage III colon cancer in Germany that old age was the strongest predictor of non-administration of chemotherapy, irrespective of comorbidity and other potential determinants. Evidence suggests that the increase in patient refusal rate corroborates with the still apparent issue of undertreatment in healthy older patients (3).

The factors associated with treatment refusal found in this review were unmarried status (11,16,17,25-27,29,30) non-white race (9-13,16,17,23,26,29,30) female gender (10,12-14,22,25), having government insurance (9-11,13,14,23,30) or having no insurance (9,14,16,23,27,29) and Charlson comorbidity index >2 (10,13,15,18,20,21,23,24,27). These results are aligned with the factors shown recently by Rapp *et al.* (29), although this British study only included patients who were recommended for surgery for early-stage disease (primary stage I and II lung, breast, prostate and colon cancers). However, the reasons behind these clinical-demographic factors were not well established in these studies, as the vast majority were descriptive studies (9-14,16,17,22,23,27,29,30).

Regarding the demographic factors, Chiang *et al.* (21), Suh *et al.* (18), and Chiang *et al.* (15) also showed that patients older than 70 years old, widowed or unemployed were more likely to refuse treatment. Poor social support and lower income were also described as factors related with treatment refusal (12,13,28). Furthermore, non-white race and female gender appeared to be strong predictive factors of therapy refusal (9,10,12-14,22,25,28). Despite the absence of a clear explanation in literature, we speculate that regional and cultural characteristics may influence the

decision-making treatment. A relationship between race, age and unmarried status and patient refusal of surgery for lung cancer was found in a US study, suggesting cultural differences in decision-making regarding treatment (33). The patient's cultural background and socioeconomic status can impact the desire to overcome cancer in a particular country or region. Low educational and economic status was considered a significant variable in treatment refusal, maybe due to difficulty in accessing health services or lack of knowledge about disease (18). Patients perceive and experience illness, care, and death according to their culture, values, beliefs, life experiences and meaning of life (34). Thus, it is argued that spirituality, culture, the socioeconomic status and policies of access to healthcare may influence patients' healthcare decision-making (35). In this review, the five Asian studies (15,18,20,21,24) did not described the female gender as a predictive factor, which was mostly described by American studies. We did not find studies that included Latin American elderly patients.

The clinical factors associated with refusal treatment reported in the majority of the studies were mainly advanced disease stage (III or IV) (10,11,14,16,17,24-27) Charlson score greater than two (10,13,15,18,20,21,23-25,27), and poor performance status (ECOG 3 or 4) (15,18,21,23,25). This may be related to the desire not to undergo treatments without a curative proposal considering advanced disease (22,25). Only one systematic review was found about factors associated with acceptance and refusal of cancer treatment in the elderly. The results showed that the physician's recommendation, trusting and having good communication with the physician, and expectations about side effects were predictive factors of therapy refusal, with the latter representing the main factor related to treatment refusal that was also found in the current review (3,21,28,29).

The majority of studies in this review did not examine the particular reasons for older adults to decline treatment (9,10,12-14,16-18,20,21,25,27). Thus, it is unclear if other factors were not reported because they were not important or because they were not been studied. Relevant characteristics of geriatric health, such as cognitive and sensory impairment, were not described in these articles, but were found in the previous systematic review (3). So, it is important that multicenter studies with a larger sample size and of higher methodological quality are conducted, considering the clinical characteristics and aspects of patients, such as their culture, values, beliefs. As well as qualitative studies to better understand the reasons for therapeutic refusal (3,24).

A 2015 qualitative study in the United Kingdom (28), including only elderly women with breast cancer who refused surgery, reported that these patients declined surgery either because they wanted to avoid treatments that could impact their current functional level or because of their age perception. These patients, who tended to be older, mentioned their age as a representation of various reasons, including having a limited life span, not wishing to prolong their life due to comorbidities or lack of desire. In this review, there is only one qualitative study that evaluated the psychological and existential aspects of treatment refusal. Juang *et al.* suggested that one of the reasons for treatment refusal is that older patients may have lack of knowledge about their medical conditions; thus, they may feel uncertain about the disease, which can lead to depression and affect patients' adherence to treatment (36).

Compared to the latest systematic review on the topic (3), we found some differences. In that review, most studies used a qualitative design based on breast and prostate cancer treatment decisions, and described as important factors associated with therapeutic refusal the concerns with the discomfort of the treatments, fear of side effects and transportation barriers. In this study, most studies used a retrospective and descriptive design and focused on breast, colorectal, and head and neck cancers. The differences related to the predictive factors between the two reviews could be influenced by the nature of the studies' design. The qualitative and prospective design prevalent in the first review (3) favors the discussion of psychological aspects such as fear of adverse effects.

It is important to consider that not all studies in this review involved only curative treatment. One study had a palliative proposal for non-small cell lung cancer, which also showed some factors of refusal described in this review such as elderly, unmarried, and female patients. Stavos (22) and Aizer *et al.* (37) compared refusal characteristics of patients undergoing curative and palliative care and they found that older and unmarried patients were more likely to decline palliative and curative radiation, demonstrating that these are stable predictors of refusal, independent of treatment indication. Regarding gender, women were more likely to refuse palliative radiotherapy (RT) and men were more prone to refuse definitive RT (22). Unfortunately, the database used in most studies in this review [the Surveillance Epidemiology and End Results (SEER) and National Cancer Database] (9-14,16,17,22,23,27,29-31) did not give further information to detail these differences. Thus, further investigation into the demographic factors

related with treatment refusal should be conducted.

Regarding the type of treatment (10-18,20,21,23-26,28-30), the majority of studies evaluated the refusal of surgery interventions, which may be associated with the nature of the cancer. Most of the studies included head and neck, breast, and digestive system early-stage cancer treatment, where surgery has a well-established role in treatment (10-14,16,17,26,28-30). Seven studies (12,13,16,17,23,25,29) described an overall lower survival rate of patients who refused treatment compared with those who received standard treatment, most of them regarding surgery intervention. Lu *et al.* (23) showed that old age was a predictive factor of refusing surgery in patients with stage I-III colon cancer. The previous study has also described that elderly patients were more likely to decline surgery for other neoplasms when compared to younger patients, even though they were suitable surgical candidates. About the reasons for declining surgery, Rothman *et al.* (38) described that most older patients with advanced illness refused a surgical/medical procedure and the main reason was the fear of side effects.

It is known that the integration of palliative care improves several outcomes, such as quality of life and symptom burden and less use of medical resources (39). The American Society of Clinical Oncology has recommended that palliative care should be offered since cancer diagnosis, together with traditional oncologic care. Although the benefits of early palliative care are already well established scientifically, there are challenges to its implementation, such as the current health care policies, limited resources, and the different clinical practice settings, which consequently lead to palliative care referrals occurring late in the illness process (40). Although all patients with metastatic disease or poor performance status would benefit from palliative care, identifying those individuals who refuse treatment is also a good indication for referral (22,39).

Further research is needed to understand why these disparities exist for treatment refusal, especially in patients with early-stage cancer. Most studies are retrospective, which makes it difficult to analyze the reasons behind treatment decision-making. Some possible explanations include the lack of healthcare literacy and mistrust of individual medical providers and of the overall healthcare system described by minority patients. The two articles (24,28) that exclusively enrolled older patients showed that in particular, patients 80 years and older may be more likely to refuse surgical intervention due to fear of decreased quality of life, as they may be affected by other conditions

that lead to frailty, while the unmarried patients might be more likely to decline treatment because of a perception of a poor social support, which also was observed in prior studies (29,41).

This review has some limitations. The methodological quality of the included studies limited some of the findings. The retrospective and descriptive nature of most of the studies made it difficult to clarify the reasons behind treatment refusal. No meta-analysis was conducted, as the studies were too heterogeneous regarding the population studied and data collected. The strengths of this study were the nature of the systematic review that included both quantitative and qualitative studies, most of which were from large nationwide and multicentric databases (9-14,16,20,22,23,26,30,31) and up-to-date about an issue that is still scarce in the literature.

Conclusions

This study reviewed the factors associated with treatment refusal in older patients with cancer. Predictive factors of refusal treatment included female gender, unmarried status, non-white race, having government insurance or not having insurance, higher disease stage, and poor performance status (9-18,20-27,30). Understanding these factors is important in clinical practice to improve treatment adherence, reduce errors, improve results and provide optimal care, considering the best interests and values of patients (3,6,10). Thus, acknowledging patients' specific demographic and clinical characteristics may help to predict patients' attitudes towards decision-making in health and allow to elaborate an adequate care plan, also considering patients' culture and personal values and beliefs. Additional studies are needed with elderly patients to evaluate decision-making, particularly regarding the psychological and existential aspects, and incorporating both health literacy and comorbidity.

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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AIMS

1. To explore the barriers to medical doctors in performing advance care planning with patients with cancer.

1.1 To assess the perception of medical residents about their difficulties in carrying out advance care planning and goals of care discussion with oncology patients.

1.2 To assess the oncologists' perception and perspectives about the barriers in performing advance care planning and goals of care discussion in their clinical practice.

2. Proposal of a guide for advance care planning discussion in clinical practice adapted to the Brazilian reality.

METHODS

The main research was approved by the Ethics Committee of João de Barros Barreto University Hospital (Nº 4.376.747), in November 2020.

To explore the perception of physicians' difficulties in performing advance care planning, the instrument “*Decide Oncology*” (33) was applied. This validated questionnaire identifies and evaluates the barriers that impact the discussion about goals of care and advance care planning, according to the perception of physicians who assist cancer patients. These difficulties were further stratified into barriers related to patients, doctors and/or related to the health system or external factors. The “*Decide-Oncology*” questionnaire underwent a translation process to Brazilian- Portuguese, followed by a cross-cultural adaptation by experts in the topic to content validity and the translation's adequacy. (78)

A pilot study was conducted to assess the difficulties of resident physicians in carrying out advance care planning and a goals of care conversation in their practice, and to discuss education on communication in end-of-life care in medical residencies. All the participants (twenty nine) had already assisted cancer patients during their residency at the time of the survey. Quantitative analysis was based on descriptive statistics and performed using SPSS® Statistics (79). In all tests, values of $p < 0.05$ were considered significant. The article entitled **“Advance care planning and goals of care discussion: barriers from the perspective of medical residents”** was submitted for publication (78) (Specific aim 1.1).

Then, a quantitative and qualitative cross-sectional study was carried out with medical oncologists from all regions of Brazil, in which the participants answered the semi-structured questionnaire “Decide Oncology”, already adjusted to the Brazilian reality. It was adapted into Google forms format to be forwarded by email to the Brazilian oncologists. The sample consisted of 66 participants. Quantitative analysis was based on descriptive statistics and data analysis was performed using SPSS® Statistics (79). In all tests, values of $p < 0.05$ were considered significant. The qualitative analysis was based on content analysis by Bardin(80), and two categories - intrinsic and extrinsic factors, were analysed regarding strategies and suggestions to improve decision-making about goals of care in clinical practice. The article entitled

“Advance care planning and goals of care discussion: the perspectives of Brazilian oncologists” (81) was accepted for publication to the *“BMC Palliative Care”* (Specific aim 1.2).

Based on the results found in the studies conducted within the scope of this thesis and on the existing scientific literature on advance care planning, a proposal for a practical guide with strategies to facilitate the discussion of advance care planning for physicians was developed. This study ***“Advance care planning: a practical guide”*** (82) was accepted for publication to *“Revista Bioética-CFM”* (Aim 2).

RESULTS

This thesis aims to study advance care planning and goals of care discussions with oncology patients and its challenges in the Brazilian clinical practice. These are important tools that enable the respect for patient autonomy, especially those with a life-threatening disease such as cancer. However, they are still not frequently performed in medical routine.

Good communication skills are essential for all healthcare professionals in facilitating adaptation to illness realities, appropriate decision making, and quality of life throughout the trajectory of a serious illness (83). As patients approach the end-of-life, communication about goals of care is a key element in helping assure that patients receive the care they want, in alleviating anxiety and in supporting families. Effective communication supports not only end-of-life care, but quality of life throughout the illness trajectory, even if death is not an imminent outcome (84). Nonetheless, end-of-life care communication has been reported as one of the most difficult and stressful parts of oncological practice, which could reflect in the low rates of advance care planning (31).

There is evidence from the international scientific literature about the challenges of carrying out advance care planning, but in Brazil, studies on the topic are still scarce. Therefore, the results section of this thesis is structured by three articles that aim to explore the challenges on advance care planning performing in medical practice and propose a practical guide to try to minimize this gap in clinical context.

Two studies were developed, using the “*Decide-Oncology*” (33) questionnaire, an instrument used to identify the perception of physicians’ barriers about goals of care discussion. In the first study, the adaptation to Portuguese and validity of content of the *Decide Oncology* questionnaire was carried out, originally validated in English, that identifies the perception of physicians regarding the goals of care discussion. Afterwards, an analysis was carried out with medical residents to address their perceptions on the difficulties of discussing advance care planning and goals of care discussion and also on medical education about communication in end-of-life care (78). The second study, a quantitative and qualitative study, was developed to explore Brazilian

oncologists' perceived barriers in discussing goals of care and advance care planning (81).

Finally, a proposal of a guide to facilitate the initiation and the conduction of advance care planning in clinical practice by Brazilian physicians was structured based on the studies that comprise this thesis and existing literature. This proposal was developed in Portuguese, given its purpose to be disseminated into the Brazilian medical community (82).

1. ADVANCE CARE PLANNING AND GOALS OF CARE DISCUSSION: BARRIERS FROM THE PERSPECTIVE OF MEDICAL RESIDENTS

Dias L, Frutig MA, Bezerra MR, Barra WF, Castro L, Rego F. Barriers in Advance Care Planning and Goals of Care discussion with oncology patients: The perspective of Brazilian medical residents.

Manuscript Information Overview

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Status	Pending review
Article type	Article
Title	ADVANCE CARE PLANNING AND GOALS OF CARE DISCUSSION IN ONCOLOGY: BARRIERS FROM THE PERSPECTIVE OF BRAZILIAN MEDICAL RESIDENTS.
Journal	<i>Healthcare</i>
Section	Medics
Abstract	Background. Advance care planning (ACP) and goals of care discussion involve the exploration of what is most important to a person to prepare for health-care decision-making. Despite their well-established benefits, they are still not frequently performed in clinical oncology practice. This study aims to describe the barriers to discussing goals of care with patients with cancer from the perspective of medical residents. Methods. The Decide-Oncology questionnaire - a validated instrument to assess barriers to goals of care discussion- was applied to medical residents from three university hospitals in Brazil. Residents were asked to rank the importance of various barriers to discuss goals of care (ranging from 1-extremely unimportant to 7-extremely important). Results: Twenty-nine residents participated in the survey (30.9%). The most reported barriers were related to patients and their families' difficulty in understanding and accepting the diagnostic and the prognosis, patients' desire to receive full active treatment and the lack of an advance directive. Furthermore, the physician and external factors such as lack of training and lack of time to have these conversations were also very important barriers. To identify barriers to goals of care discussion can help to prioritize the next steps to improve shared decision-making based on patient's values.
Keywords	Advance Care Planning; Communication skills,; Medical education; Oncology.
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ADVANCE CARE PLANNING AND GOALS OF CARE DISCUSSION IN ONCOLOGY: BARRIERS FROM THE PERSPECTIVE OF BRAZILIAN MEDICAL RESIDENTS.

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Abstract

Background. Advance care planning (ACP) and goals of care discussion involve the exploration of what is most important to a person to prepare for health-care decision-making. Despite their well-established benefits, they are still not frequently performed in clinical oncology practice. This study aims to describe the barriers to discussing goals of care with patients with cancer from the perspective of medical residents. **Methods.** The *Decide-Oncology* questionnaire - a validated instrument to assess barriers to goals of care discussion- was applied to medical residents from three university hospitals in Brazil. Residents were asked to rank the importance of various barriers to discuss goals of care (ranging from 1-extremely unimportant to 7-extremely important). **Results:** Twenty-nine residents participated in the survey (30.9%). The most reported barriers were related to

patients and their families' difficulty in understanding and accepting the diagnostic and the prognosis, patients' desire to receive full active treatment and the lack of an advance directive. Furthermore, the physician and external factors such as lack of training and lack of time to have these conversations were also very important barriers. To identify barriers to goals of care discussion can help to prioritize the next steps to improve shared decision-making based on patient's values.

Keywords: *Advance Care Planning, Communication skills, Medical education, Oncology.*

Introduction

Advance care planning (ACP) and goals of care discussions involve the exploration of a person's values, beliefs, and what is most important to each person: to ensure concordance between the clinical care received by a patient and the care he or she has wished for. The context for each differs, however, as ACP conversations focus on preparing for future health-care decisions, whereas goals of care discussions focus on current health-care decisions. Thus, goals of care discussions are also an important part of the advance care planning process.^{1,2}

One of the principles of good care is respect and receptivity to patients' wishes and values; thus, it is important to understand patients' perspectives about cancer treatment³. High-intensity life support is often provided even when patients or their families may prefer to focus on comfort care, despite evidence suggesting that use of unwanted technology is associated with negative outcomes, such as decreased quality of life and low satisfaction with end-of-life

care⁴. Robust evidence shows that ACP is associated with a wide variety of benefits, such as: less moral distress by health care professionals, higher rates of advanced directives (AD) registrations, reduced hospitalization, intensive and futile treatment at the end-of-life, greater satisfaction with the quality of care, and less risk of anxiety and depression in family members during bereavement^{1,5}. All in all, it improves the consistency of care with patients' values and goals in various patient populations, including oncology patients⁶.

Notwithstanding the importance of ACP, many health-care providers are still reluctant to engage patients in this discussion. Some barriers include personal discomfort with death and dying, lack of experience in discussing end-of-life issues and limited education and training in ACP¹. Generally, the training of resident physicians on communication with patients about end-of-life decision-making is limited. Therefore, implementing interventions to improve communication and decision making about goals of care and ACP in oncology settings, especially in medical training, may improve this scenario^{7,8}. Considering the scarcity of studies about the difficulties of Brazilian medical residents on discussing ACP and about their training on this topic, this study aims to determine, from the perspective of medical residents, the barriers to the discussion goals of care and ACP with patients with cancer.

Aim

To explore barriers to goals of care and advance care planning discussion in patients with cancer from the perspective of Brazilian medical residents, and to compare such barriers according to years of medical residency.

Methods

Type and questionnaire study

A cross-sectional study was developed with medical residents. The instrument “*Decide-Oncology*”⁴ was used- a validated questionnaire that identifies and evaluates the barriers that impact the discussion of goals of care and of advance care planning, according to the perception of physicians who assist cancer patients.

Resident physicians were also included on its validation; therefore, it was the chosen tool for this study⁷. Statements about doctors' difficulties focused on three pillars: (1) barriers on the discussion about goals of care; (2) barriers on the approach of interrupting active cancer therapies (for example: chemotherapy, radiation therapy); and (3) barriers of referring to palliative care teams. These difficulties were further stratified into barriers related to patients, doctors and/or related to the health system or external factors. It is a Likert questionnaire where each session has statements about the difficulties in discussing the advance care planning, classified from 1 to 7 points, where 1 is the extremely unimportant difficulty; 2, very unimportant; 3, little unimportant; 4, neither important nor unimportant; 5, little important; 6, very important; and 7, extremely important⁴.

The questionnaire also included questions about sociodemographic characteristics (age, gender, ethnicity, religion, year of graduation and medical fellowship and specialty), and questions about the perception of the importance and the degree of formal training on ACP and discussing goals of care.

The questionnaire's cross-cultural adaptation and translation to Portuguese was conducted. The direct and reverse translation, from English into Portuguese (Brazil) by four independent translators was done followed by the evaluation of six health professionals who are part of palliative care team, invited

as judges to analyze the clarity of the language, content validity and the translation's adequacy⁹. For this, the Content Validity Coefficient (CVC) was used, as suggested by Hernández-Nieto¹⁰. At the end of the judgment, the criterion of $CVC > 0.80$ was used to consider whether the items have been semantically adjusted and to ensure that the questionnaire has an equivalent metric^{9,10}. It was observed: clarity of the language= 0.80; content validity=0.86 and the translation's adequacy=0.82.

The questionnaire was adapted into an electronic version (Google forms) and sent via email to medical residents from three Brazilian reference oncology centers of university hospitals (Belém-Pará, Recife and São Paulo).

This study was submitted and approved by the Ethics Committee of João de Barros Barreto University Hospital (Nº 4.376.747). All subjects had to give their informed consent to participate in this study.

Study population

Resident physicians who had training in oncology or palliative care units (e.g. oncology, internal medicine, geriatrics and hematology), from three University Hospitals were contacted. To assess possible differences between residents according to the time since graduation, they were divided into two groups, one with up to two years of residency, and the other with three years or more. Out of ninety-four resident physicians referred, 29 responded.

Statistical Analysis

The results of paper and electronic surveys were pooled and compiled using descriptive statistics, including median and interquartile interval [1st Q; 3rd Q] for quantitative variables and counts and proportions for categorical variables. Survey responses were presented by median scores. Distribution of scores were

compared between groups of residence years using Mann-Whitney's non-parametric test. Data analysis was performed using SPSS® Statistics (version 26.0; SPSS Inc., Chicago, IL, USA). In all tests, values of $p < 0.05$ were considered significant.

Results

Participants

The survey was distributed to a total of 94 medical residents between December 2020 and March 2021. A response rate of 31% was achieved. Respondent demographics are outlined in Table 1.

Table-1. Socio-demographic profile of the 29 medical residents

Variable	Descriptive	
Age, median [1°Q; 3°Q]	29 [26.3; 30.8]	
Weeks in the oncology service, per year, median [1°Q; 3°Q]	6 [4; 38]	
Sex, n(%) ^a	Female	21 (75)
	Male	7 (25)
Ethnicity, n(%) ^a	White	17 (60.7)
	Black	1 (3.6)
	Asian	1 (3.6)
	Other	9 (32.1)
Religion, n (%) ^a	Buddhist	1 (3.6)
	Catholic	15 (53.6)
	Spiritist	1 (3.6)
	Evangelical - Other Christian	4 (14.3)
	Agnostic	7 (25)

Year of medical residency, n (%)	1	7 (24.1)
	2	6 (20.7)
	3	8 (27.6)
	4	8 (27.6)
Region of medical residency, n (%)		
	Belém-Pará	20 (69.1)
	Recife	4 (13.7)
	São Paulo	5 (17.2)
Internship in palliative care, n (%)		
	No	4 (13,8)
	Yes	25 (862)
Medical postgraduate training, n (%)		
	Internal Medicine	27 (93.1)
	Geriatrics	5 (17.2)
	Hematology	6 (20.7)
	Palliative medicine	2 (6.9)
	Clinical Oncology	2 (6.9)

^a One participant did not answer this question

Barriers to discuss ACP and goals of care

Most of the residents described the patient and family's barriers as the most important, such as patients' difficulty in understanding their diagnostic and on accepting their prognosis, patients' desire to receive full active treatment, the lack of an advance directive, family members' difficulty in understanding their loved one's prognosis. About the physician's barriers, lack of training was the most important barrier described. Lack of time to have conversation and lack of availability of substitute decision maker(s) were two of the barriers described as very important. The importance given to the lack of time to have conversations about goals of care was significantly different between the two groups of years of

residency($p=0.034$), being a more important barrier among those with more years of residency (median scores of 4 and 6 for groups of up to 2 years and more than 2 years of residency, respectively, Table 2).

Table 2- Barriers according to years of medical residency

	Up to 2 years (R1+R2) Med [1°Q; 3°Q]	More than 2years (R3+R4) Med [1°Q; 3°Q]	Mann- Whitney's p-value
A.1) Barriers Related to the Patient/Family			
Patient does not have an advance directive	5 [3; 7]	6 [5.3; 7]	0.189
Patients' difficulty in understanding their prognosis/length of survival	6 [5; 7]	7 [6; 7]	0.158
A.2) Barriers Related to the Physician			
Uncertainty in estimating prognosis/length of survival	5 [3.5; 5.5]	5 [5; 6]	0.202
Lack of training to have these conversations (e.g., not sure about what to say, etc)	5 [3; 6.5]	6 [4.3; 7]	0.138
A.3) Barriers Related to the System or External factors			
Lack of time to have conversations with patients/family	4 [2.5; 5.5]	6 [4.3; 7]	0.034*
Brief therapeutic relationship with patient/family (e.g., patient newly referred to you)	5 [3.5; 6]	6 [5; 6.8]	0.073
B) Barriers to Discontinuation of Cancer-Directed Therapies			
B.1) Barriers Related to the Physician			
You are unsure of the benefits of further active cancer therapy in this patient	5 [3.5; 5.5]	5 [4.3; 6]	0.297
Difficulty estimating patient prognosis/length of survival	4 [3; 5.5]	5 [3; 6]	0.398
Patient age (for example, difficulty talking about it with younger people)	3 [2; 5.5]	5 [5; 6]	0.025*
B.2) Patient and family barriers			
Patient's poor appreciation or denial of likely survival duration	6 [5; 6]	6 [6; 7]	0.136
Patient's inflated expectation of the benefits from further cancer-directed therapy	5 [3; 6]	7 [6; 7]	<0.001*
B.3) External barriers			
Lack of decision aids for discontinuing cancer-directed therapy	5 [3.5; 5]	5 [4.3; 6.8]	0.160
Lack of guidelines for discontinuing cancer-directed therapy	5 [3; 6]	5 [3; 6]	0.768
C) Timing of Palliative Care Referral			
Lack of access to palliative care services within the hospital	6 [4.5; 7]	6 [5; 7]	0.566
Lack of sufficient allied health support (social workers, nurse practitioners, etc) to aid in patient support/referral process	6 [5; 7]	6 [5; 7]	0.838
D) Willingness to Participate in Communication and Decision-Making About Goals of Care			

Rate your willingness to initiate the discussion about goals of care with patients and their families.	6 [5; 7]	6 [6; 7]	0.305
Rate your willingness to lead the discussion with patients and their families. This includes exchanging information (disclosing diagnosis, prognosis, and eliciting values) and being a decision coach (clarifying values, assisting with weighing options for care, etc)	6 [5.5; 6.5]	6 [6; 7]	0.230

*for significant differences ($p < 0.05$); Med – median.

Barriers to discuss the discontinuation of cancer-directed therapies

The barriers with higher scores were the patient and family barriers, which were also most frequently described to the discontinuation of cancer-directed therapies. Additionally, patients' expectations regarding the benefits of therapy. Also, patients' and families' poor appreciation of prognosis or denial of likely survival duration, as well as patients' inflated expectation of the benefits from further cancer-directed therapy. The most described physicians' barriers were the discordance with other specialists in estimating prognosis/length of survival, followed by difficulty on estimating patient prognosis/length of survival, uncertainty of the benefits of further active cancer therapy, and patient age (whereby had more difficulty to suspend active treatment in younger patients). External barriers were ranked lower than patient/family and physician-level barriers. (Figure 1B). Therefore, comparing the two groups of residents, patients' expectations regarding the benefits of therapy and patient age were the barriers that presented significant different scores and higher importance in the group with more than two years of residency ($p < 0.001$ and $p = 0.025$, respectively, Table 2).

Barriers to early palliative care referrals

The external barriers such as lack of access to palliative care services in the community and in the hospitals, lack of multidisciplinary team (social workers, nurse practitioners, etc) to aid in patient support/referral process to palliative care,

and the patient or family refusal of referral, were the barriers most described to early palliative care referrals (Figure 1).

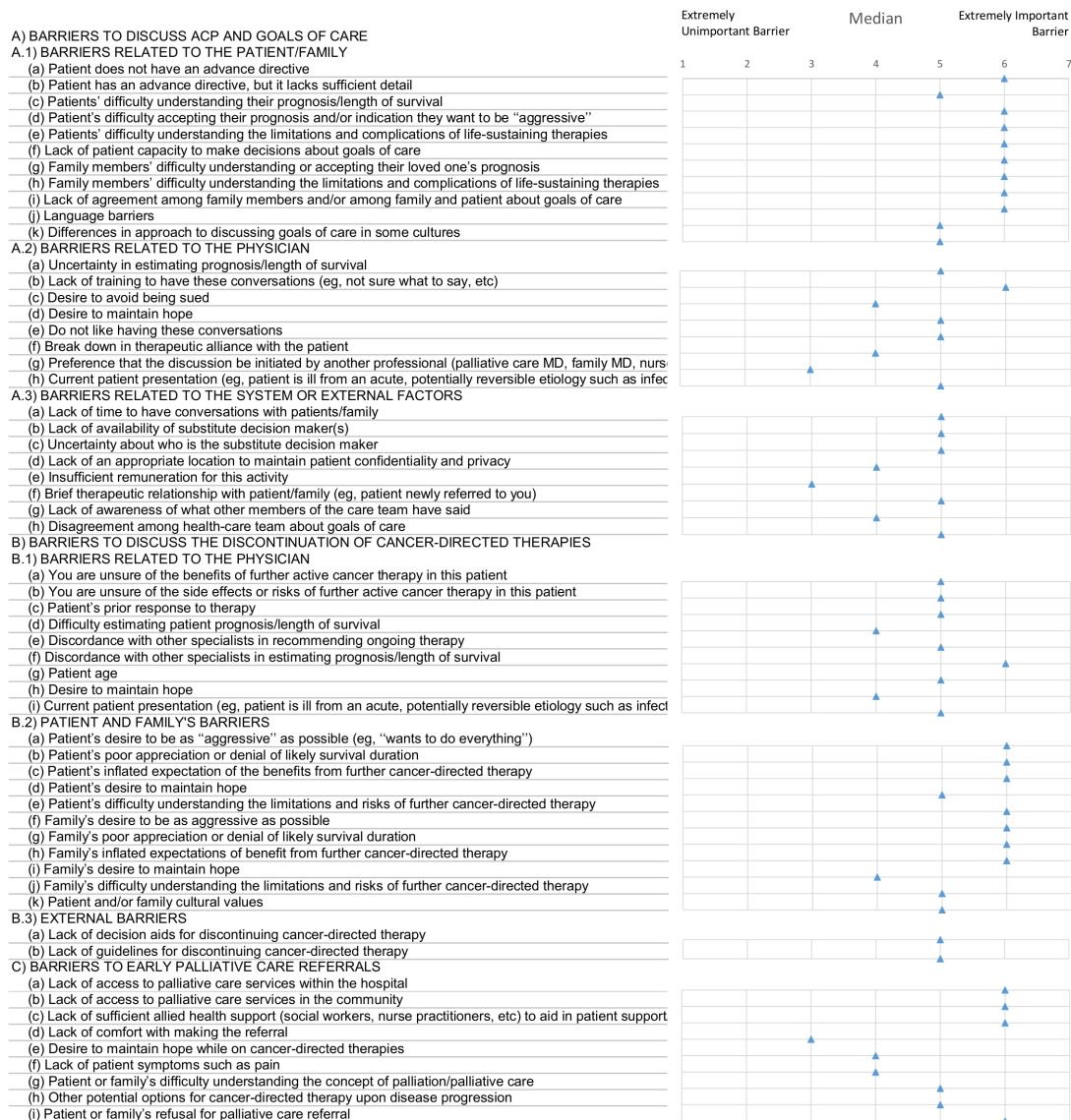


Figure 1. Barriers of patient, physician and external factors to initiating goals of care discussions (A), to interrupt cancer-directed therapies (B), and to refer to palliative care (C) (median scores).

The willingness to discuss ACP and goals of care

Most of the respondents were very or extremely willing to initiate (82.8%) and lead (86.2%) ACP and goals of care discussions.

Physician's perception about the ability to discuss ACP and goals of care and the quality of training on communication.

Most of the residents' self-reported average skill in having goals of care discussions with patients and families (44.8%); while 89.6% ranked their priority for learning these skills as high (as 4 or 5 out of 5). By contrast, 93.1% had formal training regarding communication and goals of care. Besides, 77.7% considered their quality of training from moderate to extremely high (Table 3).

Table 3- Training on communication skills

Self-reported level of skill on having goals of care decisions n (%)		
	Limited	0 (0)
	Fair	3 (10.,3)
	Average	13 (44.,8)
	Very good	12 (41.4)
	Expert	1 (3.4)
Priority (from 1 to 5) for learning the communication skill, n(%)		
	3 (Moderately Priority)	3 (10.3)
	4 (Moderately High Priority)	13 (44.8)
	5 (High Priority)	13 (44.8)
Formal training regarding communication with patients and families about goals of care? n(%)		
	No	2 (6.9)
	Yes	27 (93.1)
If yes, the quality of training, n(%)		
	Moderately low	1 (3.7)
	Neither high nor low	5 (18.5)
	Moderately high	9 (33.3)
	Very high	6 (22.2)
	Extremely high	6 (22.2)
The importance of spirituality or religion in your life ^a , n(%)		
	Extremely unimportant	2 (7.1)

Very unimportant	1 (3.6)
Somewhat unimportant	1 (3.6)
Somewhat important	7 (25)
Very important	7 (25)
Extremely important	10 (35.7)

^a One participant did not answer the question.

Suggestions for improving communication and decision-making about goals of care.

Sixteen participants (56%) suggested continuous education in communication skills, palliative care and on advance care planning as tools for improving goals of care conversations, like this one: *“Training about breaking bad news skills, palliative care and death during graduation and medical residency. Little is taught about it”*. Thirty seven percent of those who suggested how to improve this communication cited the importance of an interdisciplinary team aligned in the discussion of care: *“Constant training of the medical and multidisciplinary team, as well as regular meetings with a multidisciplinary and palliative care team, also involving patients and family members”*. Some residents (18%) also described that a good physician-patient relationship could help to improve communication and the decision-making process about goals of care.

DISCUSSION

The frequent barriers to goals of care’ discussion present in the literature included lack of time, discomfort with difficult discussions, fear of affecting patients’ hope and emotional coping and lack of training in communication strategies about end-of-life^{5,11,12}. In the present study, the barriers most perceived were related to patients and their family, such as the difficulty for patients to

understand and accept their prognosis. These findings corroborate those of the *Decide*-study⁷ and *Decide-Oncology* study⁴, in which health-care professionals on general medical wards and physicians in oncology ambulatory identified patient and family related factors as the most important barriers to goals of care discussion. Some external factors such as the lack of time for these discussions was also considered a significant barrier in the present study, in agreement with the aforementioned authors^{4,7}.

However, the physicians' perception about the patient's difficulty to understand and accept his/her prognosis may reflect, at least in part, on the doctors' difficulty in predicting prognosis - a well-reported barrier in this study - and even with the well-established prognosis, they may have difficulties on communicating this prognosis in an objective and clear way⁷. It is important to consider that this study involved exclusively medical residents - who spend at least one month at oncology and/or palliative care services- unlike the DECIDE oncology study⁴, which included mostly oncologists, possibly with more experience than medical residents.

When comparing groups of residents by years of medical residency, 3rd and 4th year residents (generally on oncology, geriatric, hematology or palliative medicine residency) considered the most important barriers the patients' expectations regarding the benefits of therapy and the lack of time to have this conversation. In the field of oncology, communication skills are paramount, as the life-threatening or life-limiting nature of the conditions encountered in this field create multiple challenges for practitioners, both those in training and seasoned oncologists. The ability to communicate about a new diagnosis, poor prognosis, relapse, imminent death, or death itself is not innate, nor is it commonly taught at

any level of training.¹³ According to Perron et al¹⁴ the clinical experience alone is not enough; such skills should be taught and trained. It could reflect the needs of continuous education in medical communication skills at postgraduate.

Physicians who deal with patients with serious illnesses need to have great communication's skills. Clarifying cancer treatment goals and aligning expectations are essential to engage patients in timely and meaningful ACP¹⁵. It requires good illness understanding and realistic expectations about prognosis, so that patients can express their values and make decisions in a timely manner¹⁶. Granek et al¹² explored oncologists' views on end-of-life care discussions and revealed various physician-related barriers to ACP, including personal discomfort with death and dying, reluctance to communicate painful information, perception of other physicians' failure, focusing too much on a cure or treatment, along with a lack of experience with breaking bad news, especially in end-of-life care and lack of mentorship on training end-of-life communication strategies, which were also found in the present study.

Regarding the discontinuation of directed cancer therapies, this study also found the discordance with other specialists in estimating prognosis/length of survival, followed by difficulty on estimating patient prognosis and uncertainty of the benefits of further active cancer therapy as important barriers. It is known that earlier follow-up by palliative care team could improve the communication with patients with incurable disease in helping them to prepare for the end of life, through shared decision-making among patients, their families, and healthcare providers¹⁷.

Detering K et al² identified trained facilitators, patient centered discussions and systematic education of doctors, among other elements, as crucial to

successful advance care planning. They also found that patients welcome ACP and expect health professionals to initiate this kind of discussion. Another recent systematic review found that healthcare professionals' training in ACP had positive effects on their knowledge, attitude and skills about communication in end-of-life care¹⁸. The use of decision aids and advanced technology, such as audio-visual material and online tutorials; workshops using role play, training content focused on ACP communication skills and the needs and experience of patients in decision-make processes, contributing to ACP training programs effectiveness^{19,20}. There are only few studies about communication skills designed for medical residents evaluated for their effectiveness²¹. They are not specific about advance care planning skills, although many of them provide the basis for this discussion¹⁸. Some authors demonstrated that communication skills training programs may improve residents' breaking bad news skills with a positive change in their emotional reactions after training and minimizing insecurity to talk about challenging issues like prognosis^{18,21,22}. In the present study, most of the residents self-reported an average skill level to discuss goals of care with their patients and also ranked it as high priority to learn those skills, although most of them already had a formal training regarding communication and goals of care discussion, which they classified as a moderately high-quality training. It is probably because most of the residents are already at the third or fourth year of residency, in oncology-hematology or palliative care services at university hospitals, and deal with patients with advanced diseases frequently in their clinical practice.

Different tools may be effective for clinicians with varying expertise and competency in end-of-life communication skills. Myers et al¹ demonstrated in a

systematic review the instruments that could facilitate the ACP process, like *Respecting Choices*²³ a program with trained facilitators, and the *Physician Orders for Life Sustaining Treatment* (POLST) that is a standardized form containing medical orders that reflect a patient's treatment preferences²⁴. They demonstrated that exposure to these tools, and others, if compared to controls, could result in an increased advance directive completion; increased appointment of a surrogate; more involvement in end-of-life decisions; better consistency between patient wishes and medical interventions undertaken at end-of-life¹. Most studies still present data from the point of view of healthcare providers and more research from the patients' perspective is still needed^{1,18}. Barriers related to patients and family members were the most reported in the present study, as well as in previous studies involving only health care professionals^{4,7}.

In Brazil, a competency framework of palliative medicine for geriatricians' residents was developed to guide the teaching of essential skills of palliative care in geriatrics settings²⁵. It includes communication's skills such as: to explore the elderly patient and family's understanding of illnesses, concerns, goals and values and planning treatment that fits these priorities (advance care planning), and adequately communicating on how to perform advance directives, based on bioethical and legal principles²⁵. In other areas such as oncology, a competency framework would certainly help to standardize the skills and competencies of resident physicians. In the present study, a great majority of residents described continuing education in palliative care and communication skills training as suggestions for improving shared decision-making about goals of care.

Given the lack of studies that address barriers to discussing goals of care in Brazilian reality, evaluating the difficulties from the perspectives of medical

residents and their relative importance to discussing this topic are the strengths of this study, besides the validation of a questionnaire to access it. This study is the first step for the adaptation and validation of the *Decide-oncology* questionnaire⁴ to the Brazilian-Portuguese language. Nonetheless some limitations included a small sample, because it involved only medical residents from three university hospitals. Furthermore, a positive response bias among those who did participate is possible, with potential for higher response rates among those most engaged in palliative and end-of-life care.

Conclusion

This study aimed to explore barriers to goals of care and advance care planning discussion in patients with cancer from the perspective of Brazilian medical residents. Patients' barriers such as the difficulty in understanding and accepting the diagnostic and the prognosis, and the patients' desire to receive full active treatment and the lack of an advance directive were the most barriers described by medical residents. The physician and external factors such as lack of training and lack of time to have these conversations were also described as very important barriers. In addition, the willingness to initiate and lead ACP and goals of care discussions were demonstrated by most residents in this study, who consequently indicated the need for training in this area as a priority. These challenges may be overcome with improved education about end-of-life communication. The identification of barriers that limit the discussion of ACP and early palliative care referrals could help to prioritize the next steps for future studies aimed at improving advanced care planning and goals of care discussion.

Ethics approval and consent to participate

Ethical approval was waived by the University Hospital of João de Barros Barreto University Hospital (Nº 4.376.747). Informed consent was obtained from all subjects. All methods were carried out in accordance with relevant guidelines and regulations.

Competing interests

The authors declare that they have no competing interests.

Authors' Contributions

LD, FR designed the study and survey, collected the data, analyzed, and interpreted the data, prepared the initial manuscript as well as revised it. MF, MB, WB collected the data and helped in revising the manuscript. LC did the statistical analysis, interpreted the data and revised the manuscript. All authors read and approved final manuscript.

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2. ADVANCE CARE PLANNING AND GOALS OF CARE DISCUSSION: THE PERSPECTIVE OF BRAZILIAN ONCOLOGISTS

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RESEARCH

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Advance care planning and goals of care discussion: the perspectives of Brazilian oncologists

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Abstract

Background: Advance care planning (ACP) and goals of care discussions are important instruments that enable respect for patient autonomy, especially in patients with a life-threatening disease, such as cancer. Despite their well-established benefits, ACP and goals of care discussions are still not frequently performed in clinical oncology practice. Understanding the barriers to this topic is the first step toward developing future interventions that are more likely to improve professional practice and patient satisfaction with care.

Aim: To explore Brazilian oncologists' barriers to discuss goals of care and advance care planning.

Methods: A cross-sectional study was developed to identify Brazilian oncologists' barriers to discussing goals of care and ACP. The *Decide-Oncology* questionnaire was used to identify the importance of these barriers according to oncologists' perceptions. Participants were asked to rank the importance of various barriers to discussing goals of care, ranging from 1 (extremely unimportant) to 7 (extremely important). A quantitative analysis using descriptive statistics was used, including median and interquartile intervals and a qualitative analysis based on Bardin content analysis of the two open questions.

Results: Sixty-six oncologists participated in this study. Most of them perceived the patient and family's related barriers as the most important, such as patients' difficulty in understanding their diagnosis and accepting their prognosis. Physician and external related factors, such as lack of training and lack of time for this conversation, were also described as important barriers. Participants with formal training regarding goals of care communication and with experience in palliative care perceived the lack of patients' advanced directives as a significant barrier and manifested more willingness to participate in decision-making about goals of care. The lack of access and of support for referral to palliative care was also considered a significant barrier for ACP and goals of care discussion.

Conclusion: The identification of barriers that limit the discussion of ACP and early palliative care referrals can certainly help to prioritise the next steps for future studies aimed at improving ACP and helping clinicians to better support patients through shared decision-making based on the patient's values and experiences.

Keywords: Personal autonomy, Oncology, Advance care planning

Introduction

Evidence shows that most patients want to discuss end of life plans with their doctors, despite this still being an uncommon practice [1]. Communicating about the end of life has been reported as one of the most difficult

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and stressful parts of the oncological practice, given that oncologists receive little training in this area. As a result, many do not communicate these issues effectively with their patients [2]. Many patients with advanced cancer spend their last month of life in the hospital, with 6% percent receiving chemotherapy up to 2 weeks before death [3].

One of the principles of good care is respect for patients' wishes and values; thus, it is important to understand patients' perspectives about cancer treatment [4]. Furthermore, evidence suggests that unwanted treatment at the end of life is associated with negative outcomes, such as reduced quality of life and low satisfaction with care [4, 5].

In this context, advance care planning (ACP) and goals of care discussion are justified as instruments that enable respect for the patient's autonomy [6]. They involve the exploration of a person's values, beliefs, and what is most important to each person: to ensure concordance between the received clinical care and the patient's wishes [5, 7]. It is important to note that ACP conversations focus on preparing for future healthcare decisions, whereas goals of care discussion focus on current healthcare decisions. Thus, goals of care discussions are also an important part of the ACP process [5, 7, 8, 9, 10].

ACP is associated with a wide variety of benefits, such as less moral distress of health care professionals; higher rates of patient advanced directives (AD); reduced hospitalisation and intensive and futile treatment at the end of life; greater probability of the patient dying at the chosen place; greater satisfaction with the quality of care; and less risk of stress and depression in family members during bereavement [5, 11]. But even in the face of its benefits, ACP is still very little performed in clinical practice [9]. To know the barriers to goals of care discussion enables the development of tailored interventions that are more likely to improve professional practice and training programs [12, 13]. Considering the scarcity of studies about the difficulties of Brazilian oncologists in discussing ACP and goals of care, this study aims to identify these barriers.

Aim

To explore Brazilian oncologists' perceived barriers to discuss goals of care and advance care planning with the patient.

Methods

Type and questionnaire study

A cross-sectional study with a quantitative and qualitative approach was developed to identify Brazilian oncologists' barriers to discussing goals of care and ACP. A sociodemographic questionnaire was included

(age, gender, ethnicity, religion and years of experience in oncology). The instrument "*Decide-Oncology*" [14] was used to identify the importance of these barriers according to the perception of physicians who assist cancer patients. The *DECIDE (DECISION-making about goals of care for hospitalized meDical patiEnts)* questionnaire was originally developed to identify barriers and facilitators to improve EOL communication and decision-making with critically ill hospitalized medical patients with advanced chronic illness. In 2017, Ethier et al. [14], adapted and validated the DECIDE questionnaire to the oncology context, in a Canadian multicentric survey involving only oncologists. This instrument is based on three pillars: (1) barriers to the discussion about goals of care; (2) barriers to the approach of interrupting active cancer therapies (for example, chemotherapy, radiation therapy); and (3) barriers to referring to palliative care teams. These difficulties were further stratified into barriers related to patients, doctors, and/or related to the health system or external factors. Each session comprises statements about the difficulties in discussing advance care planning in a Likert-type response scale classified from 1 to 7 points, where 1 is the extremely unimportant difficulty; 2, very unimportant; 3, little unimportant; 4, neither important nor unimportant; 5, little important; 6, very important; and 7, extremely important [14].

Questions about participants' degree of formal training on ACP and discussing goals of care and their perception of its importance, as well as participants' suggestions to improve decision-making about goals of care in clinical practice, to better qualitatively evaluate such strategies, were comprised to meet a sequential explanatory design.

The "*Decide-Oncology*" questionnaire underwent a translation process to Portuguese—Brazil, followed by a cross-cultural adaptation by experts in the area to content validity and the translation's adequacy [15]. A Content Validity Coefficient > 0.80 was considered [15, 16]. Further details of the cross-cultural adaptation process are described in the pilot study already submitted for review for publication [10].

The questionnaire was adapted into an electronic version (Google forms) and sent via e-mail to the Brazilian oncologists via the Brazilian Society of Clinical Oncology.

Study population

Sixty-six oncologists from all Brazilian regions responded to the questionnaire (out of approximately 700 Brazilian oncologists) after two rounds of electronic survey via e-mail with an interval of two weeks (39 answered in the first round and 27 in the second round).

Statistical analysis

The results of the paper and electronic surveys were pooled and compiled using descriptive statistics, including median and interquartile intervals [1st Q; 3rd Q] for quantitative variables and counts and proportions for categorical variables. Survey responses were presented by median scores. The distribution of scores was compared between groups of participants who had formal training on communication about goals of care and those who had no training, as well as between groups who had already worked at palliative care services at some point and those who had not worked, using Mann–Whitney's non-parametric test. Data analysis was performed using SPSS® Statistics (version 26.0; SPSS Inc., Chicago, IL, USA). In all tests, values of $p < 0.05$ were considered significant.

Qualitative analysis

A content analysis based on Bardin [17] was conducted, and two categories, namely intrinsic and extrinsic factors, were developed based on the content found in the answers to the two open questions: 1- *“Reflecting on the barriers which you rated as very important or extremely important in Sect. 1, what specific suggestions do you have about ways to overcome these barriers and make it easier for healthcare providers to talk with patients and their family members about goals of care?”* 2- *“What is currently working well to promote communication and decision-making about goals of care between healthcare providers and patients and their family members?”*

As these questions were related to the unique issue *“Suggestions to improve communication and decision-making about goals of care”*, we condensed the answers according to the content analysis. A system of categories was developed to analyse the contents following three phases: pre-analysis (contact with the material to be analysed, detailed reading of the content); exploration of the material (choice of coding units, classification, grouping of words by meaning); and treatment of results – inference and interpretation (identification of the latent content, the meaning behind the apprehended content) [17]. This process was conducted by two authors independently, and they then reached a consensus about the categories.

Results

Quantitative analysis

Participants

Sixty-six oncologists from all Brazilian regions answered the electronic surveys between April and September 2021. Most participants were female ($n = 38$; 57.6%), with a median age of 40 years old (minimum of 28 years and maximum of 68 years of age).

Considering the five regions of Brazil, most participants ($n = 27$; 40.9%) act in the Southeast region, followed by the North region ($n = 17$; 25.7%). The participants have a median of 11.5 years in oncology practice. Half of the participants have already worked in palliative care settings. Respondent demographics are outlined in Table 1.

A) Barriers to discussing ACP and goals of care

Most oncologists perceived the patient and family's related barriers as the most important, such as patients' difficulty in understanding their diagnosis and accepting their prognosis, patients' desire to receive full active treatment, and lack of an advance directive (Fig. 1).

Uncertainty in estimating prognosis/length of survival and lack of training were the main physician-related barriers, despite most of the participants already having had formal training regarding communication. And the main external factor indicated was a lack of time to have a conversation (Fig. 1).

Table 1 Sociodemographic profile of the 66 oncologists in the sample

Variable	Descriptive
Age, median [1 ^o Q; 3 ^o Q], min–max	40 [36; 45], 28–68
Sex, n (%)	
Female	38 (57.6)
Male	28 (42.4)
Ethnicity, n (%)	
White	43 (65.2)
Black/Pardo	21 (31.8)
Asian	1 (1.5)
Other	1 (1.5)
Religion, n (%)	
Catholic	42 (63.6)
Agnostic	12 (18.2)
Evangelic	6 (9.1)
Spiritualism	5 (7.6)
Cristian	1 (1.5)
Years in oncology, median [1 ^o Q; 3 ^o Q], min–max	11.5 [8; 15], 2–39
Regions of medical service, n (%)	
Southeast	27 (40.9)
North	17 (25.7)
Northeast	10 (15.1)
Midwest	06 (9.1)
South	06 (9.1)
Work at palliative care services at some point, n (%)	
No	33 (50)
Yes	33 (50)



Fig. 1 Barriers of patient, physician, and external factors to initiating goals of care discussions (A), interrupting cancer-directed therapies (B), and referring to palliative care (C) (median scores)

B) Barriers to discussing the discontinuation of cancer-directed therapies

Patient and family's related barriers were also considered the most important, namely patients' and families' poor appreciation of prognosis or denial of likely survival duration as well as patients' inflated expectation

of the benefits from further cancer-directed therapy (Fig. 1).

Regarding the physicians' related barriers, the most selected was the difficulty in estimating patient prognosis/length of survival, the uncertainty of the benefits of further active cancer therapy, and patient age (whereby

had more difficulty suspending active treatment in younger patients) (Fig. 1).

The lack of guidelines for discontinuing cancer-directed therapy was also ranked as an important external barrier (Fig. 1).

III) Barriers to early palliative care referrals.

The most described barriers were lack of access to palliative care services, lack of allied health support team (social workers, nurse practitioners, etc.) to aid in the patient referral process to palliative care, and the patient or family refusal of referral (Fig. 1).

Most of the oncologists self-reported an average level of skills in goals of care communication ($n = 34$; 51.5%) and indicated learning communication skills as a high priority ($n = 39$; 59.1%). Nevertheless, most already had formal training regarding this topic ($n = 38$; 57.6%) and considered the quality of the training had moderately high ($n = 19$; 50%).

Comparing the two groups: participants who had formal training on communication about goals of care and those who did not have any training, some statistically significant differences were found. Patients' lack of use of advanced directives ($p = 0.007$) was found to be a more significant barrier in discussing advance care planning and goals of care by the group with training on communication about goals of care, as well as the lack of decision aids and guidelines for discontinuing

cancer-directed therapy ($p = 0.023$; $p < 0.001$). Participants with formal training ranked the lack of access to palliative care services within the hospital as a more important obstacle to referral to early palliative care ($p = 0.012$). Furthermore, they revealed more willingness to participate in decision-making about goals of care ($p = 0.006$) (Table 2).

When comparing the group of participants who have already worked in palliative care services with those who have not, the group with experience in palliative care also considered the lack of patients' advanced directives ($p = 0.007$) as an important barrier to goals of care discussion and stated more willingness to participate in decision-making about goals of care ($p = 0.001$; $p = 0.01$). Particularly, the group with palliative care experience was perceived as a significant barrier to patients' difficulty in understanding their prognosis/length of survival ($p = 0.018$) and patients' inflated expectation of the benefits from further cancer-directed therapy ($p = 0.004$), as well as the lack of sufficient allied health support (social workers, nurse practitioners, etc.) to aid in patient support/referral process to palliative care ($p = 0.012$), compared to the group of participants without experience in palliative care (Table 3).

Table 2 Barriers scoring differences according to the report on formal training regarding communication with patients and families about goals of care ($N = 66$)

BARRIERS	Formal training regarding communication with patients and families about goals of care		
	No ($n = 28$) Med [1 st Q; 3 rd Q]	Yes ($n = 38$) Med [1 st Q; 3 rd Q]	Mann-Whitney's p -value
A) Barriers to Discuss ACP and goals of care			
Barriers Related to the Patient/Family			
Patient does not have an advance directive	6 [5; 6.5]	6 [6; 7]	0.014*
B) Barriers to Discontinuation of Cancer Therapies			
External barriers			
Lack of decision aids for discontinuing cancer-directed therapy	5 [3; 6]	6 [5; 6]	0.045*
Lack of guidelines for discontinuing cancer-directed therapy	4 [2; 6]	6 [5; 6]	< 0.001*
C) Timing of Palliative Care Referral			
Lack of access to palliative care services within the hospital	5 [3.5; 7]	6.5 [5; 7]	0.024*
D) Willingness to Participate in Communication and Decision-Making About Goals of Care			
Rate your willingness to initiate the discussion (bring up the subject) about goals of care with patients such as these and their families	6 [6; 7]	7 [6; 7]	0.006*
Rate your willingness to lead the discussion with patients such as these and their families. This includes exchanging information (disclosing diagnosis, prognosis, and eliciting values) and being a decision coach (clarifying values, assisting with weighing options for care, etc.)	6 [6; 7]	7 [6; 7]	0.013*

* $p < 0.05$, Med Median, Q Quartile

Table 3 Barriers scoring differences according to the report of palliative care experience (work at palliative care services at some point) regarding communication with patients and families about goals of care ($N=66$)

BARRIERS	Work at palliative care services at some point		
	No ($n=33$) Med [1 st Q; 3 rd Q]	Yes ($n=33$) Med [1 st Q; 3 rd Q]	Mann–Whitney's p -value
A) Barriers to Discuss ACP and goals of care			
Barriers Related to the Patient/Family			
Patient does not have an advance directive	6 [5; 6]	7 [6; 7]	0.014*
Patients' difficulty understanding their prognosis/length of survival	6 [6; 7]	7 [6; 7]	0.037*
B) Barriers to Discontinuation of Cancer-Directed Therapies			
Patient and family barriers'			
Patient's inflated expectation of the benefits from further cancer-directed therapy	6 [5; 6]	6 [6; 7]	0.008*
C) Timing of Palliative Care Referral			
Lack of sufficient allied health support (social workers, nurse practitioners, etc.) to aid in the patient support/referral process	6 [5; 6]	6 [5; 7]	0.023*
D) Willingness to Participate in Communication and Decision-Making About Goals of Care			
Rate your willingness to initiate the discussion (bring up the subject) about goals of care with patients such as these and their families	6 [6; 7]	7 [6; 7]	0.003*
Rate your willingness to lead the discussion with patients such as these and their families. This includes exchanging information (disclosing diagnosis, prognosis, and eliciting values) and being a decision coach (clarifying values, assisting with weighing options for care, etc.)	6 [6; 7]	7 [6; 7]	0.02*

* $p < 0.05$, Med Median, Q Quartile**Table 4** Strategies and suggestions to improve decision-making about goals of care in clinical practice ($N=39$)

Intrinsic factors (Strategies related to the doctor)	n (%)
Early conversation about prognosis	15 (38.5)
Emotional aspects	11 (28.2)
Education in communication skills and palliative care	11 (28.2)
A good physician–patient relationship	08 (20.5)
Others	06 (15.3)
Extrinsic factors (Strategies Related to the system)	n (%)
Access to palliative care and interdisciplinary teams	10 (25.6)
Availability to discuss goals of care	08 (20.5)

Qualitative analysis

Strategies and suggestions to improve decision-making about goals of care in clinical practice

Two categories of responses were identified: Intrinsic factors (related to the physician) and extrinsic factors (related to the health system) (Table 4).

A total of 39 participants (59%) answered the open-ended question about the strategies and suggestions to improve decision-making about goals of care in their clinical practice. Intrinsic factors that could positively impact in goals of care discussion, such as the capacity to talk about the prognostic earlier in the course of the disease, were one of the most described strategies ($n=15$;

38.5%), like this participant cited: “Initial explanation about diagnosis/prognosis and available therapeutic lines and outcome expectations” (P8). This was followed by emotional aspects ($n=11$; 28.2%), as described: “Be honest and transparent with the patient and family, without taking away their hope” (P48). Continuous education in communication skills and palliative care ($n=11$; 28.2%) was also frequently described: “Increased staff awareness of the importance of palliative care from the outset in the patient with metastatic disease” (P48), “Training on this since graduation and medical residency could facilitate this approach” (P59). Various participants ($n=8$; 20.5%) also describe that a good physician–patient relationship could help to improve communication and the decision-making process about goals of care, for instance: “get to know the patient well, their values, their experiences. Have a good relationship with patient and family” (P60) (Table 4).

Also, ten participants (25.6%) described extrinsic factors such as access to palliative care and interdisciplinary teams: “Joint follow-up with the palliative care team earlier” (P19, P49). Another extrinsic factor observed frequently was to have enough time to discuss goals of care ($n=8$; 20.5%): “Have enough time for bonding, since low ability to understand patients and family members and a culture of denial of the finitude process, especially in young patients is common.” (P36); “Good relationship

with patient and family and to have time for patient and family education" (P46) (Additional file 1).

Discussion

In this study, the barriers to goals of care discussion and ACP most perceived by Brazilian oncologists were those mainly related to patients' and families' factors, such as the difficulty for patients and their families to understand and accept their prognosis and lack of an advanced directive. These findings were similar to the results from two Canadian multicenter studies [12, 14] that applied the *Decide-Oncology* instrument with the aim to perceive these barriers from the perspectives of physicians who assist cancer patients and also found patients and families' difficulty accepting their prognosis/length of survival as the main difficulties to start the conversation about goals of care. A systematic review of ACP from the patients' perspective showed that some of them reported initial resistance to participating in an ACP conversation because they fear being confronted with the life-threatening nature of their disease. Despite the initial resistance, most of the patients who completed the conversation were satisfied [18].

The results showed that physician-related barriers were the least frequently described as important. It is necessary to reflect on the perception of physicians about the most important barriers being patient-related, such as the difficulty of patients to understand and accept their prognosis, which can be related, at least in part, to the physicians' difficulty in predicting and/or in communicating this prognosis in an assertive and clear way [2, 14, 19] since these physicians' difficulties were also frequently described by oncologists in this study. Evidence also shows that feeling discomfort with goals of care discussion, fear of affecting patients' hope and emotional coping and lack of training in communication strategies about end-of-life are some frequent difficulties reported by physicians, as well as lack of time to have the conversations [2, 11, 19, 20], which were also found in this study.

Regarding the discontinuation of directed cancer therapies, the patients' barriers were also perceived as the most important by oncologists, in accordance with the findings of the Canadian studies [12, 14]. The desire of patients and their families to maintain all kinds of therapies, even those considered futile, could be related to the notion that ongoing cancer treatment is often connected with hope [12, 21]. This may reflect gaps in patient knowledge regarding the limitations and potential harms of cancer therapies at the end of life, as well as deficiencies in physicians' ability to effectively communicate about prognostics [14]. It is known that early follow-up by palliative care could improve the

communication with patients with advanced diseases in helping them to prepare for the end of life through shared decision-making among patients, their families and healthcare providers [22].

The lack of palliative care and multidisciplinary teams aligned with the care of cancer patients are common difficulties perceived by the participants who had formal training on goals of care and who had worked at palliative care services. The insufficient health support (social workers, nurse practitioners, psychologists, etc.) integrating teams to aid in the patient referral process to palliative care is still a common reality in hospitals, especially those without specialised palliative care services, which hinders these patients' access to the necessary integrated care [23]. Also, the lack of patients' advanced directives was one of the main barriers denoted by the aforementioned groups. In Brazil, there are still low rates of advanced directive records, and it is still very little discussed by healthcare professionals since many are unaware of this instrument and that it could facilitate the decision-making process about goals of care at the end of life [24, 25, 26, 27]. Professionals who work in palliative care teams tend to perform more advance directives with their patients, and therefore, they may be more sensitive to the importance of this instrument for decision-making and the impact of the lack of patient advance directives. A systematic review shows that structured communication tools may increase the frequency of discussions about and completion of advanced directives and the consistency between the care desired and the care being provided to patients with advanced disease [28]. Training health professionals through communication skills courses is a promising approach to changing communication behaviour and attitudes [29]. Continuous education about this issue from medical graduation until the course of medical practice is likely to improve this scenario [5, 29, 30].

In this study, the oncologists were asked about strategies that, in their experience, could facilitate the discussion with patients about goals of care. The intrinsic factors were the most underlined in this qualitative analysis, like to know how to talk about prognostics earlier to deal with emotional aspects while discussing goals of care and ACP with their patients, and having continuous education in communication skills and palliative care. Granek et al. (31), in a Canadian qualitative study about communication in end of life, found some similar oncologists' strategies, such: being open and honest with patient; having ongoing, early conversations; communicating about modifying treatment goals; and balancing hope and reality. Schulman-Green et al. [19] explored American oncologists' perceptions about goals of care communication in a qualitative study and described

as important facilitators for the discussion of goals of care the oncologist's practice experience and a supportive practice environment. In our study, the oncologists reported a median of 11.5 years in practice. Furthermore, most participants had received training on goals of care communication, which had a significant positive impact on the willingness to participate in the decision-making process about goals of care, compared with those who did not have this training, even though most of the participants did not consider their level of training high on this topic, which could contribute to the perception of the difficulties even among those with training.

There is a lack of studies that address barriers to discussing goals of care and ACP, especially in the Brazilian reality. Given the current challenges society is facing, such as the growing ageing population and the increase in chronic diseases, the implementation of ACP and the discussion of goals of care are imperative for humanised care [7, 19, 23]. This study allows understanding of the difficulties perceived by the oncologists in discussing ACP and goals of care with their patients from both a quantitative and qualitative perspective, enabling the future development of strategies to surpass them.

Limitations of this study include a small sample – there was a reduced response rate. Given that data collection occurred during the pandemic period by a coronavirus, most healthcare professionals were mentally and physically overwhelmed and overburdened. Further issue that may have contributed to the lower response rate was the vulnerable nature of this topic. This may be related to a selection bias, since not everyone feels comfortable talking about this issue. Another limitation was that not all participants answered the open questions considered for qualitative analysis. This may reflect the difficulty/interest of the participants in describing strategies to minimize barriers to discussing goals of care. Nevertheless, this study comprises oncologists from all regions of Brazil, which allow us to have an overview of the national reality. Moreover, differently from the previous studies, the results have been further analyzed according to the presence of any formal communication training or working experience at the palliative care, instead of comparing only according to years of medical experience.

Conclusion

Barriers to the engagement of oncologists with patients with advanced cancer in Advance Care Planning and goals of care conversations were assigned specially to patients' and families' related difficulties. Nevertheless, physician-related difficulties, such as estimating patient prognosis/length of survival, constraints in the clinical practice environment, lack of time and lack of access/support for referral to palliative care, were also described.

The continuous education regarding goals of care communication has been suggested as a strategy that can minimise these barriers. Although some findings apparently reflect structural issues, such as the lack of a well-integrated palliative care structure in the Brazilian health system, some barriers also considered important should be overcome with continuous education about communication in end-of-life care.

The present study also elucidates the importance of recognising different characteristics and values of the patient and family and highlights the necessity of adapting the training of oncologists to correctly identify the indicators and approaches to initiating goals of care and advance care planning discussion. Moreover, the identification of barriers that limit the discussion of ACP and early palliative care referrals could help to prioritise the next steps for future studies aimed at improving advance care planning, helping clinicians to better support patients and families through shared decision-making based on the patient's values.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12904-022-01052-w>.

Additional file 1.

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Authors' contributions

LD and FR designed the study, collected the data and prepared the initial manuscript. MB and WB collected the data and helped in revising the manuscript. LC conducted the statistical analysis, and LD and AC the qualitative analyses. LD, LC, AC, and FR interpreted the data and revised the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate

Ethical approval was waived by the Ethics Committee of João de Barros Barreto University Hospital (N° 4.376.747). Informed consent was obtained from all subjects. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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3. ADVANCE CARE PLANNING: A PRACTICAL GUIDE

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Prezada autora Laiane Moraes Dias,

É com satisfação que comunicamos que o artigo "Planejamento antecipado de cuidados: um guia prático", foi aceito para publicação na Revista Bioética e será publicado em momento oportuno.

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Planejamento antecipado de cuidados: um guia prático

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Resumo

Planejamento Antecipado de Cuidados é um processo de discussões entre profissionais de saúde e pacientes que permite a tomada de decisão compartilhada quanto aos objetivos de cuidados de saúde, atuais e/ou futuros, baseados nos desejos e valores do paciente e em questões técnicas do cuidado. É considerado fundamental na prestação de cuidados de excelência em fim de vida, permitindo que profissionais de saúde alinhem os cuidados prestados com o que é mais importante para o paciente. Apesar de seus benefícios, ainda é muito pouco realizada na prática clínica, especialmente no Brasil. Considerando a necessidade de guias práticos de planejamento antecipado de cuidados adaptados à realidade brasileira, pautados em estratégias de comunicação empática, este estudo é uma proposta de guia baseada em revisão integrativa da literatura (Pubmed e Scielo), com recomendações de evidências atuais, incluindo instrumentos validados para o português (Brasil), para facilitar sua implementação na prática clínica.

Palavras-chave: Planejamento antecipado de cuidados. Tomada de decisão compartilhada. Comunicação. Cuidados de fim de vida.

Resumen

La Planificación Anticipada de Decisiones es un proceso de discusiones entre profesionales de la salud y pacientes que permite la toma de decisiones compartidas con respecto a las metas de atención médica actuales y/o futuras, con base en los deseos y valores del paciente y en cuestiones técnicas de atención. Se considera fundamental para brindar una excelente atención al final de la vida, lo que permite a los profesionales de la salud alinear la atención brindada con lo que es más importante para el paciente. A pesar de sus beneficios, aún es poco frecuente en la práctica clínica, especialmente en Brasil. Considerando la necesidad de guías prácticas para la planificación anticipada del cuidado adaptadas a la realidad brasileña, con base en estrategias de comunicación empática, este estudio es una propuesta de guía basada en una revisión integrativa de la literatura (Pubmed y Scielo), con recomendaciones de evidencia actual, incluyendo instrumentos validados para portugués (Brasil), para facilitar su implementación en la práctica clínica.

Palabras-clave: Planificación Anticipada de Atención. Toma de decisiones conjunta. Comunicación. Cuidado Terminal.

Abstract

Advance Care Planning (PAC) is a process of discussions between health professionals and patients that allows shared decision-making regarding current and/or future health care, based on the patient's desires and values and on technical issues of care. It is considered fundamental in providing excellent end-of-life care, allowing healthcare professionals to align the care provided with what is most important to the patient. Despite its benefits, it is still little performed in clinical practice, especially in Brazil. Considering the need for practical guides for advance care planning adapted to the Brazilian reality, based on empathic communication strategies, this study is a proposal for a guide based on an integrative literature review (Pubmed and Scielo), with recommendations of current evidence, including instruments validated for Portuguese (Brazil), to facilitate their implementation in clinical practice.

Keywords: Advance care planning. Decision making, shared. Communication. Terminal care.

Declaram não haver conflito de interesse.

Introdução

Poucas pessoas conversam com seus familiares, amigos e/ou profissionais de saúde sobre suas preferências de cuidados futuros, caso apresentem doença grave e avançada. Embora a grande maioria de indivíduos deseje cuidados que priorizem qualidade de vida e alívio do sofrimento no final de suas vidas, o sistema de saúde tende a oferecer intervenções para manutenção da vida, muitas vezes sem melhora da qualidade de vida. Na ausência de conversas sobre prognóstico, objetivos e expectativas do tratamento, os pacientes não têm a oportunidade de expressar seus valores e preferências, levando médicos a decidirem por intervenções adicionais, muitas vezes incompatíveis com as prioridades e desejos dos pacientes ^{1,2}.

A maioria das pessoas acha que é muito importante e deseja discutir com seus médicos sobre suas condições de saúde e as opções de cuidado que melhor se adaptam aos seus desejos e valores pessoais, mas essas discussões ainda são pouco frequentes em nossa prática clínica ³.

Planejamento antecipado de cuidados (PAC) é um processo de discussões entre profissionais de saúde e pacientes que permite a tomada de decisão compartilhada quanto aos objetivos de cuidados de saúde, atuais e/ou futuros, baseados nos desejos e valores do paciente e em questões técnicas do cuidado. Para os pacientes, as discussões sobre os objetivos de cuidados, opções de tratamento e prognóstico são importantes e a maioria deseja ter esse tipo de conversa com seus médicos. Embora muitos médicos concordem com a importância dessa discussão, menos de 20% relatam discutir rotineiramente com seus pacientes sobre isso ^{4,5}.

Assim, o PAC se justifica como um instrumento que possibilita o respeito à autonomia do paciente ^{6,7}. É um processo contínuo e dinâmico, onde as preferências e metas de cuidados devem ser revisadas e discutidas ao longo da evolução da doença, como nas intercorrências ou a cada internação, tal qual como o prognóstico, que deve ser discutido sempre que houver mudança no curso clínico da doença. Seu conteúdo pode ser alterado e outros aspectos podem ser acrescentados a qualquer momento ^{3,6}. Fazem parte do espectro do planejamento antecipado de cuidados ⁸:

1. A compreensão do diagnóstico e prognóstico pelo paciente;
2. Identificação de seus desejos, preferências, prioridades e preocupações;
3. Discussão das melhores opções de tratamento disponíveis adequadas às necessidades e valores do paciente;
4. Elaboração de uma diretiva antecipada de vontade (DAV) na forma de testamento vital ou de nomeação de um procurador de cuidados de saúde.

As decisões de tratamento discutidas no PAC podem incluir o seu registro em uma diretiva antecipada de vontade, que faz parte do planejamento de cuidados, nem sempre obrigatório apesar do seu grande valor. O testamento vital é o registro por escrito, de paciente com capacidade decisória preservada, sobre as decisões de tratamento e/ou cuidados que deseja ou não ser submetido, em caso de doença avançada e irreversível, a ser utilizado quando o paciente perder sua capacidade de decisão e de comunicação ⁹.

O processo de tomada de decisão pode ser mais difícil quando a doença avança e o paciente perde a capacidade de se expressar. Nesses casos, o procurador de cuidados de saúde (geralmente familiares) deve intervir para tomar decisões que consideram como as do melhor interesse do paciente no âmbito dos valores que este expressou previamente. O PAC também tem o papel de orientar a escolha de substitutos, caso o paciente prefira, para lhe representar quando não puder mais decidir e se expressar, e preparar este substituto para a tomada de decisão em nome do paciente. Isso pode minimizar a dificuldade dos familiares tomarem decisões durante intercorrências, pois estes estão muitas vezes emocionalmente vulneráveis e sem condições adequadas para responder por seu ente. Por isso se justifica que o PAC seja realizado o quanto antes, quando o paciente ainda tenha capacidade cognitiva preservada para determinar o que é importante para si. Vale lembrar que qualquer pessoa, mesmo sem doença crônica ou grave, pode compartilhar com seus médicos ou pessoas mais próximas, suas preferências e prioridades relacionadas ao fim de sua vida ^{7,10}.

Além de garantir que os pacientes recebam tratamentos consistentes com suas preferências, de reduzir o ônus decisório da família, e da sobrecarga emocional importante sobre decisões envolvendo cuidados de fim de vida de seu familiar, estudos apontam outros benefícios do PAC, como: menor sofrimento moral dos profissionais de saúde; maiores taxas de DAV; maior probabilidade de médicos e familiares entenderem e cumprirem os desejos do paciente; redução de tratamentos extraordinários no final da vida com maior acompanhamento por equipes de cuidados paliativos; maior probabilidade do paciente morrer no local preferido; maior satisfação com a qualidade do atendimento; menor risco de ansiedade e depressão em familiares durante o luto ¹¹⁻¹⁵.

Apesar das inúmeras evidências dos benefícios do PAC, este importante recurso que visa garantir a autonomia do paciente até o fim da sua vida, ainda é pouco realizado na prática clínica no Brasil. Por isso, este guia tem como objetivo traçar estratégias de comunicação para estimular, iniciar e melhor conduzir o planejamento antecipado de cuidados.

Quando fazer?

Ainda é muito comum que conversas sobre objetivos de cuidados aconteçam tarde demais, nos momentos de maior criticidade (exacerbação da doença de base, por exemplo), que demandam uma tomada de decisão mais urgente relacionada a tratamento, e quando, muitas vezes, o paciente não tem mais condições de decidir. Nessas circunstâncias, equipe de saúde e familiares acabam tomando decisões, que nem sempre representam os valores e prioridades do paciente. Por isso, a conversa sobre objetivos de cuidados deve ser iniciada de forma gradativa e o mais precocemente possível, a partir da definição prognóstica ^{4,14,16}.

Esse planejamento é um processo complexo, não deve ser realizado em uma única conversa. É preciso tempo para estabelecer uma relação médico-paciente de confiança que permita explorar as informações sobre o que é mais importante para o paciente. Essa discussão pode ser iniciada a qualquer momento, ao longo da trajetória da doença, mas idealmente com paciente clinicamente e emocionalmente estável, para que possa refletir e expressar plenamente suas preferências. O conteúdo

do planejamento pode variar conforme a condição de saúde do paciente, desde um contexto de ausência de sintomas, fase inicial da doença e até uma situação de terminalidade. E deve ser revisado regularmente, principalmente quando há mudança no quadro clínico (após a admissão do paciente no hospital, por exemplo), para constatar se houve mudanças nas preferências de cuidados ou para acrescentar alguma nova informação ^{6,17}.

Algumas características relacionadas ao prognóstico indicam a necessidade de discussão sobre objetivos de cuidados, dentre elas ^{18,19}:

- Questão surpresa: “Você ficaria surpreso se esse paciente morresse no próximo ano?”;
- Declínio funcional pela doença de base (Palliative Performance Scale (PPS) ou
- Karnofsky Performance Scale (KPS) ≤ 50);
- Falta de resposta ao tratamento inicial ou incerteza quanto a resposta terapêutica;
- Quimioterapia de segunda ou terceira linha;
- Admissões hospitalares recorrentes;
- Exacerbações de doenças, apesar do tratamento otimizado;
- Características relacionadas ao prognóstico da doença de base ²⁰.

Todos os pacientes com necessidades de cuidados paliativos devem ter seu planejamento antecipado de cuidados, atualmente reconhecido como um bom indicador de qualidade de cuidados paliativos de excelência ^{6,7}. Alguns pacientes podem ter mais dificuldades para essa conversa, principalmente se não tiverem bem-informados sobre seu diagnóstico e prognóstico. Evidências sugerem que algumas características demográficas como idade mais avançada e baixa escolaridade – o que é comum ainda no Brasil – podem influenciar na tomada de decisão sobre cuidados de saúde, sendo esses indivíduos mais propensos a confiarem aos seus médicos essas decisões. Nesses casos, cabe aos profissionais de saúde explorarem os valores e prioridades do paciente, considerando sua história de vida, para definir o cuidado baseado no melhor interesse do paciente ^{21,22}.

Como fazer?

Apesar do crescente interesse pelo tema e dos diversos estudos e guias propostos para a elaboração do PAC na literatura internacional, ainda não há uma sistematização sobre o conteúdo do PAC na literatura. Ele pode ser dividido em etapas ².

Preparação

Etapa que antecede a conversa com o paciente, inclui a revisão completa do histórico clínico do paciente, prognóstico e opções de tratamento. Além disso, informações sobre os aspectos psicossociais e dinâmica familiar podem ser acessados na discussão com outros membros da equipe de saúde.

Introdução

Etapa em que se esclarece o objetivo da conversa e é o momento para estabelecer uma relação de confiança entre o médico e paciente para a conversa mais efetiva.

Identificação da percepção do paciente

É a etapa em que se acessa as perspectivas do paciente, o enfrentamento da doença; aborda a finitude, as emoções (medos e preocupações, esperança) e questões práticas relacionadas ao fim da vida. É a parte central da conversa.

Ação

Nesta etapa é realizado o registro das informações da discussão, que pode ser através de:

- a) Registro do que foi discutido no prontuário (que é considerado um documento legal).
- b) Elaboração de uma diretiva antecipada de vontade, por exemplo através de um documento à parte em que o paciente descreve seus desejos e preferências de cuidados com a devida orientação do profissional de saúde que lhe conhece e acompanha.
- c) A designação de um procurador de cuidados de saúde do paciente quando ele não puder mais se expressar (mandato duradouro).
- d) Estratégias para que o paciente compartilhe o conteúdo do PAC com as pessoas próximas e de sua escolha, para que fiquem cientes das suas preferências de cuidados.
- e) Orientação sobre questões legais.

Abaixo seguem algumas recomendações práticas sobre cada uma dessas etapas da discussão do planejamento antecipado de cuidados, baseadas em *guidelines* atuais sobre o tema ^{2,4,7,23}.

Quadro 1. Etapas do planejamento antecipado de cuidados

Etapas	Objetivos	Exemplos
Preparação		
	Certificar-se dos detalhes do diagnóstico, prognóstico e opções de tratamento disponíveis antes da conversa com o paciente.	
Introdução		
Permissão/checar autonomia	O paciente deve ser questionado se ele quer ser envolvido na tomada de decisão ou se prefere que a equipe converse com um familiar.	<i>“Você gostaria de falar sobre isso sozinho, ou há outras pessoas que você gostaria que participasse da conversa?”</i>
Estabelecer vínculo com o paciente	Construir uma relação de confiança para que o paciente se sinta à vontade para conversar sobre os seus desejos e medos.	<i>“Apesar da sua condição, ainda há muitas coisas relacionadas aos cuidados que podemos fazer. Eu gostaria que você se sentisse à vontade para falar, e assim eu poder lhe ajudar. Não importa o que aconteça, você não estará sozinho.” “Como seu médico, quero ter certeza de que estou fazendo as coisas que podem lhe ajudar.”</i>
Convidar para a conversa e perceber as expectativas em relação ao futuro.	Convidar o paciente para discutir sua condição atual e desejos em relação a cuidados médicos futuros. Pacientes com sintomas descompensados devem ter a conversa após a melhora dos sintomas.	<i>“Você gostaria de falar sobre o que pode acontecer adiante e como podemos fazer para que suas preferências sejam respeitadas?” “Para alinhar as opções de tratamento às suas vontades e necessidades, precisamos conhecer suas preferências em relação a</i>

		<i>alguns aspectos. Você deseja falar sobre isso agora?"</i> <i>"Você pensa muito no futuro? O que lhe preocupa? Quais são suas expectativas?"</i>
Identificação da percepção do paciente sobre a doença, seus valores e desejos		
Estabelecer o ponto de partida	Checar a compreensão do paciente e de seus familiares sobre o diagnóstico e prognóstico, e uniformizar as informações de maneira que todos entendam o momento atual.	<i>"O que você entende sobre a sua doença?"</i> <i>"O que seus médicos já disseram a você sobre a doença e os tratamentos possíveis?"</i>
Explorar valores e objetivos de vida	Entender o que é viver bem para o paciente e qual a expectativa dele em relação ao tratamento.	<i>"O que é mais importante para você agora?"</i> <i>"O que mais lhe preocupa sobre a sua situação?"</i> <i>"Como tem sido sua vida no último ano enfrentando a doença? O que você espera do tratamento?"</i> <i>Se a sua situação de saúde piorar, quais são os seus objetivos mais importantes?"</i>
Conversar sobre possíveis dilemas e as preferências de cuidados	Introduzir conversa sobre preferências de tratamentos, principalmente sobre os invasivos: questionar o paciente se ele já pensou em como gostaria de ser cuidado e quais tipos de tratamento não gostaria de ser submetido. Algumas pessoas têm experiências prévias de familiares ou conhecidos sobre reanimação e intubação e esta pode ser uma forma de introduzir o assunto. Explicar os riscos e benefícios das diferentes opções de tratamento. Esclarecer quando medidas invasivas e artificiais de suporte de vida são benéficas e quando deixam de ser tecnicamente benéficas e se tornam fúteis.	<i>"Alguém próximo a você já passou por situações e/ou, tratamentos durante o curso de uma doença grave e avançada, que lhe fez pensar sobre o seu fim de vida, no sentido de não querer ser submetido à determinadas intervenções, como respirar por aparelhos ou se alimentar por sondas? Esses procedimentos não tem como reverter a doença de base, mas há medidas de conforto para alívio da falta de ar ou outro sintoma, como alternativa."</i> <i>"Seria importante saber que tipos de cuidados gostaria de receber. Como e onde você imagina passando seus últimos dias, semanas e meses? Você poderia manifestar sua vontade sobre isso desde já. Pois numa intercorrência mais grave, você pode ser atendido no pronto-socorro por uma equipe que não lhe conhece bem e pode não saber detalhes da sua doença. Sua família, se não estiver bem informada sobre suas preferências de cuidados, terá mais dificuldades em decidir junto a equipe o que seria melhor pra você"</i>
Tomada de decisão e Plano de cuidados.	Traçar o plano de cuidados alinhando as opções terapêuticas disponíveis às preferências e prioridades do paciente.	<i>"Diante dos seus objetivos e prioridades e o que sabemos sobre sua doença neste momento, seria recomendado..."</i> <i>"Você disse que se sua doença agravar, prefere deixar a natureza seguir seu curso, sem o suporte de</i>

		<i>medidas invasivas como reanimação cardiopulmonar, ventilação mecânica, internação em unidade de terapia intensiva. Medidas de conforto para controle de sintomas serão prioridade. Estou afirmando corretamente suas preferências?”</i> <i>“Infelizmente o tratamento direcionado ao câncer não se mostrou mais benéfico. Prosseguir com mais quimioterapia neste momento pode lhe trazer mais riscos do que benefícios, não sendo indicado. Da mesma forma, outras medidas de suporte invasivo, como reanimação cardiopulmonar, não estão associadas a melhora da qualidade de vida numa condição de piora, com parada cardiorrespiratória. Recomendo que sejam priorizadas as medidas de conforto. O que você me diz sobre isso?”</i>
Ação/ Registro do PAC		
Documentar as decisões	Sempre registrar as preferências em prontuário para que toda a equipe responsável pelo paciente tenha acesso ao que foi discutido. Incentivar e orientar o paciente a redigir sua diretiva antecipada de vontade*	<i>Estas são decisões importantes sobre seus possíveis tratamentos no futuro. Devemos nos certificar, de preferência por escrito, para que não haja dúvidas.”</i>
Identificar um procurador de cuidados de saúde do paciente, se houver.	Se perceber que é apropriado, estimule o paciente a conversar com seus familiares sobre suas preferências de cuidado e escolher uma pessoa para representá-lo quando não puder se expressar. Se não quiser escolher um representante, deve-se incentivar que compartilhe suas preferências com pessoas próximas e de confiança. Nota: Se o paciente nomear várias pessoas, tente estabelecer um procurador principal	<i>Se você fosse incapaz de dizer aos seus médicos que tipo de tratamento você gostaria de receber, quem você indicaria para lhe representar, falando de suas vontades para ajudar na tomada de decisão junto a equipe de saúde?”</i> <i>“Seria importante que pessoas de sua confiança soubessem de seus desejos e vontades para o futuro.”</i>
Revisar o PAC	Momento para validar o que foi conversado e oferecer ao paciente a possibilidade de revisar a qualquer momento o plano de cuidados.	<i>“Você gostaria de revisar seu plano de cuidados? Alguma decisão mudou depois dessa última internação? Você pode acrescentar informações ou alterá-lo a qualquer momento.</i>

*Recomendações para elaboração das DAV ²⁴

A discussão sobre PAC pode incluir ordens de tratamento médico específicas e acionáveis (por exemplo, ordens de não reanimar ou de não passar sonda para dieta enteral), refletindo as preferências de tratamento do indivíduo e a condição médica atual. É importante que essas ordens de tratamento médico sejam escritas de forma apropriada e padronizadas para que sejam prontamente compreendidas por profissionais de saúde durante uma emergência ou em qualquer modalidade de assistência ⁷.

Instrumentos para o planejamento antecipado de cuidados e diretivas antecipadas de vontade.

Há vários instrumentos utilizados com o objetivo de facilitar a conversa sobre preferências de cuidados ao final de vida, e assim permitir a construção de uma diretiva antecipada de vontade, mas poucos já validados e adaptados à realidade brasileira – a grande maioria são instrumentos de outras línguas e culturas, principalmente norte-americana. É importante enfatizar que esses instrumentos não excluem, pelo contrário reforçam, o papel dos médicos na conversa sobre esses objetivos de cuidados. É essencial a orientação dos profissionais de saúde neste processo, incluindo a conversa sobre a doença e prognóstico.

Abaixo seguem alguns exemplos de instrumentos já validados para o português (Brasil), que podem ser usados como recursos na elaboração do PAC (Tabela 1).

Tabela 1. Instrumentos para auxiliar a elaboração do planejamento antecipado de cuidados

Instrumentos	Objetivos	Público-alvo
“Cartas na mesa” ²⁵ - Jogo de cartas	Estimular e facilitar a conversa sobre as suas preferências de cuidados, de uma forma simples e lúdica. Pode ser jogado em dupla com o seu procurador de cuidados de saúde.	Pacientes e familiares
Minhas Vontades ²⁶ – Aplicativo para smartphones	Refletir sobre as preferências de cuidados para então compartilhar com seu médico e pessoas de sua confiança. Considerar a escolha de um procurador de cuidados de saúde.	Pacientes
Physician Orders for Life-Sustaining Treatment (POLST) ²⁷	Traduzir os valores e as preferências de cuidado dos pacientes no fim da vida em uma prescrição médica de forma a facilitar a prestação de cuidados consistentes com tais valores e preferências.	Médicos
The conversation project ¹⁶	Guia de conversas iniciais com objetivo ajudar as pessoas a dialogarem sobre seus desejos de cuidados de fim de vida.	Paciente e familiares
Voicing my Choicestm ²⁸	Introduzir discussões sobre o PAC. Validado somente com adultos jovens com câncer	Pacientes

Aspectos legais

Cuidar de pacientes é uma tarefa desafiadora que requer não apenas uma visão holística do paciente, mas também a compreensão das circunstâncias familiares, sociais, legais, econômicas e institucionais que os cercam, especialmente à medida que se aproximam do fim da vida. Infelizmente,

existem muitos mitos e equívocos sobre o que pode ou não ser legal neste cenário. Nos EUA e alguns países da Europa (Portugal, França, Inglaterra, Espanha, por exemplo), as DAV já são consideradas documentos legais que orientam a tomada de decisão de tratamento. No Brasil, ainda não há legislação específica sobre as DAV, mas há a resolução do Conselho Federal de Medicina N. 1995/2012 ²⁹ que determina que todo médico deve levar em consideração as Diretivas Antecipadas de Vontade do paciente nas decisões sobre cuidados e tratamentos daqueles que se encontram incapazes de se comunicar ou expressar de maneira livre e independente seus desejos. Esta resolução também determina que o médico registrará em prontuário as Diretivas Antecipadas de Vontade que lhe forem comunicadas pelo paciente ^{7,29}. Esta resolução visa garantir que a autonomia do paciente seja respeitada, baseada na ortotanásia – sem qualquer relação com a eutanásia – reconhecendo o direito do paciente de recusar tratamento extraordinário, entendido como aquele que visa apenas prolongar a vida sem garantir qualidade de vida ou benefício na perspectiva do paciente. Assim, o que tiver sido determinado nas DAV prevalece sobre qualquer outra decisão de terceiros, desde que dentro dos preceitos ético-legais ²⁹.

Considerações finais

Alinhar os valores dos pacientes às melhores alternativas disponíveis de tratamento exige habilidades de comunicação para entender as necessidades e prioridades do paciente e estabelecer metas de cuidados com base no que foi compartilhado. Não existe um plano único para um cenário clínico específico e essa flexibilidade requer alguma prática. Este guia traz sugestões e recomendações de evidências atuais para facilitar o planejamento antecipado de cuidados na prática clínica, que deve ser pautado numa comunicação empática, desde a informação do diagnóstico e prognóstico – essencial para que o paciente identifique suas prioridades – passando por uma escuta ativa para explorar o que é importante para o paciente, até a tomada de decisão propriamente dita, e posterior compartilhamento das informações e registro do plano de cuidados.

Há evidência suficiente que justifica o PAC como um processo-chave para melhorar cuidados de fim de vida e, portanto, deve ser rotineiramente integrado à prática clínica por todos os médicos que assistem aos pacientes com doenças crônicas e potencialmente graves. Quanto antes iniciadas essas discussões, maiores as chances de o paciente receber tratamento consistente com seus desejos e valores, refletindo em melhor qualidade de vida, além de menor sobrecarga emocional para familiares e redução dos custos com intervenções desproporcionais.

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GENERAL DISCUSSION

The value of autonomy

Respect for patient autonomy is an essential element of modern medical ethics (84). In most Western societies, especially the developed ones, the paternalistic posture in the doctor-patient relationship has been replaced by a decision-making model that is progressively shared between healthcare professionals, the patient and their family (85). Individuals expect and are asked to be involved in healthcare decisions now more than ever. Over the past 40 years, various influences from ethical, legal, and social issues in healthcare have changed this profile (86).

Thus, the appreciation of the patient's informed autonomy is considered an expression of the dignity of the human person and, therefore, must be respected. These changes have been increasingly discussed, especially for the benefit of those who face a serious illness, from diagnosis to the end-of-life, to respect their wishes and needs. Therefore, an approach based on valuing and respecting each person's preferences and priorities should be part of essential end-of-life care, such as: information and care options that the patient wants or does not want to receive; which symptoms or problems resulting from the disease are of most concern; decision-making about healthcare and place of death (85,87). Nonetheless, a mismatch between patients preferred and actual roles in decision-making was commonly described. Most patients do not recognize the role they desire (85,87). This gap is considered key both in the clinical and research context, given the preliminary evidence that states that the perceived role of patients may predict decision satisfaction (88). Clinicians must provide patients with an open communication that enables them to achieve the appropriate shared decision-making, rather than a paternalistic attitude regarding this decision (88).

Concern for autonomy stems from people's interest in making significant decisions about their lives for themselves and according to their own values or perception of a good life (88). Singer et al. argues that patients do not make treatment decisions strictly on a self-regarding basis and are, rather, essentially influenced by the lives of others, particularly those close to them such as family members (89). The patient is too involved in a network of relations to others to be

properly singled out as a self-sufficient decision-maker. Thus, autonomy cannot imply a person's right to choose for him/herself based on personal interests alone, given that others' interests are necessarily a factor in the process of decision-making (89).

Decision-making and advance care planning discussions must also take account of the culture and relationship between patients and their family members. For some patients of minority ethnic groups, cultural values and family dynamics have greater influence on end-of-life decision-making (70).

Even with the increase in discussions about the benefits of shared decision-making in end-of-life care, the paternalistic attitude in health decision-making is still frequent (90). It means the decision of making medical interventions without considering the patient's opinion aiming at their benefit, as well as patients not understanding the true situation of their illness, defaulting the shared decision-making process (91). This attitude is still common in developing societies (92). Evidence suggests that it could be related to some demographic characteristics such as older age and lower socio-economic and educational level, which is still common in Brazil. These patients are more predisposed to trust entirely in their physicians and ask them to make the decisions related to end-of-life care (93). It is usual for patients to say to their doctors: "*Dr, you are the one who knows what is best for me. I trust you*". Whilst desiring to express their wishes, people with less formal education may lack appropriate knowledge to discuss potential medical, religious and spiritual care at the end-of-life (94). In these cases, the decision, however, must be based on what is best for the patient. It is up to healthcare professionals to identify and understand the patient's values and priorities, and to define care considering their history of life and based on the patient's best interest (85,87).

Patients may have more difficulties in advance care planning and shared decision-making if they are not well informed about their diagnosis and prognosis (56). They would be able to fully exercise their autonomy if they received appropriate information about their health condition and all available treatment alternatives. This is another factor that can contribute to a paternalistic attitude (95). Healthcare professionals must empower the patient to participate in the decision-making process, communicating clearly about the diagnosis and prognosis, and then, carry out an advance care planning (56,96).

England, a country with a strong libertarian tradition which values the individual preferences with a current legislation about advance directives, anticipated patients' wishes to refuse treatment, which were already binding under English common law (97). For many years, respect for patient's autonomy has been a dominant principle supported by English law, which is often placed over the doctor's duty to provide best medical care in order to save life (98). Although English physicians consider shared decision-making related to healthcare a very important task, they admitted difficulties in the implementation of advance directives, especially in the communication of poor prognosis and death (91). Both advance care planning and advance directives require facing and communicating bad prognosis. The rates of advance care planning are still low despite all the efforts to implement it in clinical practice (91). To better understand these physicians' efforts to implement values that are embedded in their culture and rights, it would be important to investigate further their practices, which could help to address problems related to the low rates of advance directives within a context where patient preferences are valued (98,99). Involving the community in end-of-life care is a priority for the United Kingdom. Taking a public health approach, there are models such as compassionate communities, fostering new networks and community resources to support those facing illness, dying, death and bereavement. Then, there is an increasing incentive for reflections on end-of-life preferences to still take place in the community, and not just in medical scenarios (94).

The United States, the first country to legalize advance directives and other questions related to the exercise of patient's autonomy, as well England, prioritizes autonomy and individual values. The 'Patient Self-Determination Act', established in 1990 to promote advance care planning, had great importance in increasing rates of advance care planning in clinical practice in that country (100). The 'Patient Self-Determination Act' requires Medicare and/or Medicaid certified healthcare institutions to ask their clients whether they have an advance directive, which is part of advance care planning, and inform them of their right to obtain it, with written information, at the time of enrolment (82,101).

By contrast, there are countries which consider a holistic approach and focus on collective and social aspects too, aligned with individual preferences, such as France. In this perspective, physicians should protect the vulnerable

person, representing and defending universal social values. Therefore, decisions can be made on behalf of the patient and according to the professional opinion relaying social values to patients' wishes and needs (99). Things begin to change, and it will be interesting to further observe how French physicians gradually integrate the new emphasis on patient autonomy in their practice. Further research is needed to explore whether advance directives can be useful in the French context where there are other forms of advance care planning focusing not only on patient wishes but also on physicians' responsibilities to advise vulnerable patients (98).

In Eastern countries, the value of the autonomy tends to be different from the Western societies. Regarding the decision-making process, Asian physicians tend to discuss the prognosis of their patients with relatives and, therefore, may not respect existing directives (102). In Japan, a recent study demonstrated a low engagement in advance care planning activities among physicians (28,7%) and nurses (27,6%) (103). Sittisombut et al., showed that 61.8% of Thai physicians never asked terminally ill patients if they wished to undergo cardiopulmonary resuscitation (CPR). However, 94.5% had discussed this issue with the patients' family members (104). Sprung et al., found that Protestant, Catholic or non-religious physicians refused advanced life support more often than Orthodox Greeks, Jews or Muslims. Decisions about end-of-life care were discussed with the families more often if the physician was Protestant, Catholic, or had no religious affiliation (105).

In Brazil, the preferences in end-of-life care are still poorly explored. A retrospective study with cancer patients demonstrates a low rate of advance directives (22.7%) and a gap between the preferences registered in advance directives and the treatment received. For example, for most of the patients who had expressed the desire to die at home, only 10% actually died at home. Another study with Brazilian elderly people, shows that most of them prefer to make their own decisions at the end of their lives, and in case of incapacity, they also would want their wishes to be respected, through a living will. When asked what is more relevant to their healthcare, the majority desired to improve the quality of life in the time they still had, instead of prolonging life (87).

Evidence shows that many physicians admit that fear of legal accountability may affect their decisions regarding a treatment decision, especially those in

countries without law on advance directives or advance care planning (106). In hypothetical scenarios of disagreement between family opinions and the patient's advance directive, most of them considered legal concerns to be important or very important in their decision (107,108). Similarly, Forte et al. (107), found that almost half of the physicians that participated in a retrospective study would change their behaviour if it were not for the fear of lawsuits and the opinion of society (108), and these dilemmas are frequently in situations involving therapeutic refusal. The topic of advance care planning is becoming frequently more challenging in clinical practice, especially when patients ask to limit treatments for diseases that are not so advanced or prognosis for which is not yet defined (97,99,109). Attention must be focused on making decisions based on ethical-legal precepts, especially in laws or resolutions on advance directives, in line with the best interests of the patient. This also signals the need to advance legislation on advance care planning/ advance directives, primarily in countries where they have not been legalized yet (27,75,109).

One of the studies that is part of this thesis is a systematic review assessing the factors associated with treatment refusal in older cancer patients, considering that refusal therapy and underuse of treatment are more common in older adults. Predictive factors of refusal treatment included female gender, unmarried status, non-white race, having government insurance or not having insurance, higher disease stage and poor performance status (20). Understanding these factors is important in clinical practice to improve treatment adherence, reduce errors, provide optimal care, and predict patients' attitudes towards decision-making in health and allow elaboration of an adequate care plan, considering the best interests and values of patients (110). These different characteristics influence the value of autonomy and of the decision-making process, both in refusal or in advance care planning. So, considering the different cultural and moral backgrounds helps to inform the kind of policy and ethical guidance that should be developed, in order to improve the implementation of advance care planning (70).

Although advance care planning is being increasingly discussed worldwide and its benefits are evident, it is still little practiced in the clinical routine (26,75). Strategies should be used to increase its implementation, especially in developing countries (93). It is paramount that physicians, especially those

dealing with chronic or critically ill patients, discuss and guide their patients to carry on advance care planning. Besides, in addition to the continuing education of healthcare professionals on this topic, it is necessary to make progress in the regulation of Advance Directives, primarily in countries where they have not been legalized yet, such as Brazil (108).

Challenges in Advance care Planning and Goals of Care Discussions in Clinical Practice

Although the great majority of physicians recognize the importance of advance care planning discussions for all its benefits, only a minority of them (21%) reported that they addressed frequently matters related to advance care planning or end-of-life care (111). For most clinicians, advance care planning and goals of care discussions are challenging and often avoided due to a variety of factors. Frequently cited barriers include lack of training, insufficient time to have a conversation on this topic, failure to recognize the need for discussion, discomfort with discussing prognosis or end-of-life issues, unease in responding to strong emotion, concerns about patients losing hope, and a desire to avoid conflict (33,36). Clinicians also hesitate due to their perception that patients and families often struggle to accept poor prognosis and have difficulty understanding the limitations of life-sustaining treatments; further, clinicians lack agreement among themselves regarding treatment decisions (32,33). These barriers lead to reluctance among clinicians to have these conversations or to initiate discussions about patients' goals and values (33,36,44).

The two studies developed within the scope of this thesis that aimed to explore the main perceived barriers of Brazilian oncologists and medical residents, in addressing advance care planning and goals of care discussion with cancer patients, found barriers that were categorized in 1) patients and families' barriers; 2) physicians' barriers; 3) external factors.

1) Patients and families' barriers to goals of care discussion and advance care planning.

These kinds of barriers were perceived by the oncologists and by medical residents as the most important in our studies. Patients' difficulty in understanding their diagnosis and accepting their prognosis, patients' desire to receive full active

treatment, and lack of an advance directive are the main barriers attributed to patients in the two studies.

- Difficulty in understanding and accepting the diagnosis and prognosis and emotional aspects

The difficulty in accepting the diagnosis and prognosis may be associated with an emotional response that impacts the comprehension of the situation. Anxiety and denial are critical patient-related factors that regularly contribute to challenges in discussing goals of care (27). All patients with a serious illness experience some anxiety; one-quarter to one-half of all patients with advanced cancer experience significant anxiety symptoms, and a small percentage develops anxiety disorders (112). Physicians fear that discussing end-of-life care increases the anxiety. Denial of the terminal illness is common and could be harmful since it impairs patients' ability to appreciate reality and engage in an informed manner with key decisions (31,82). It tends to increase in situations of high anxiety and crisis, such as hospitalization; in such situations, patients often lack cognitive and emotional resources to manage strong feelings and difficult decisions, such as those related to end-of-life care (82). Although guidelines recommend that initial discussions of goals of care and end-of-life preferences are best conducted when the patient is relatively stable, the majority of first discussions with cancer patients usually take place in the inpatient setting already at the time of a disease exacerbation or when the oncologist has indicated the suspension of active treatment (36,113).

In addition, the difficulty in understanding the prognosis may reflect the physician's difficulty in defining and communicating the prognosis (32), which was also an important barrier for the physician found as the study developed.

A systematic review of advance care planning from the patients' perspective showed that some of them reported initial resistance to participating in an advance care planning conversation because they feared being confronted with the life-threatening nature of their disease. Despite the initial resistance, most of the patients who completed the conversation were satisfied (75). The fact that the process of advance care planning in itself may help patients to discuss end-of-life issues more readily, might be related to aspects of the advance care planning process which patients experience as being meaningful to their specific

situation (114). Although advance care planning probably does not take away the stress of death and dying, participation in the decision-making process may reduce stress and anxiety, with new insights, a feeling of control, a comforting or trusting relationship with a relative or other experiences that are meaningful to them (75). Besides, being able to implement their decision about health is related to higher levels of wellbeing of the patient, namely physical, psychological and spiritual, as well as a better quality of life (115).

- Clinical and demographic aspects

Clinical and demographic variables of patients and families may also impact on goals of care and advance care planning discussions. In the study developed with Brazilian oncologists about their perception regarding goals of care discussion, the patient age - specifically difficulty suspending active treatment in younger patients, was a barrier frequently described to discussing the discontinuation of cancer-directed therapies (80). In a multicentric study, oncologists reported as barriers that may impact on advance care planning and goals of care conversation: younger patient or patients with young children, which makes conversations more emotionally challenging; lower educational level that makes it difficult for patients to their health condition and treatment options; high socioeconomic status, which could be accompanied by a sense of entitlement/power; religion may be a barrier when it was used to support denial about cancer progression or to support the need for futile interventions in the name of God or hope; and cultural issues that include discomfort in talking about death and dying attached to strong emotional responses, devaluing patient autonomy and valuing quantity over quality of life (116).

- Lack of advance directives

The lack of advance directives is also considered a barrier when discussing advance care planning and goals of care. Even in countries where there is legislation on advance directives, the rates of directives performed is low (at most 20% in some developed countries) (57,117,118). In Brazil, the challenge is still great. Although physicians recognize the importance of facilitating decision-making in health and the discussion of goals of care, in practice, few patients have been guided by their doctors on how to elaborate their advance directives

(93). These studies point to the need to implement these practices in the clinical context.

Patients, in general, expect their physicians to initiate discussions about end-of-life preferences. In this context, physicians' reluctance to broach these issues may prevent them from occurring at all, leaving physicians to make decisions about care without adequate information about patients' wishes (119).

2) Physicians' barriers to goals of care discussion and advance care planning

Uncertainty about prognosis and lack of training were the main physician-related barriers in our studies. Desire to maintain hope and not feeling comfortable having these conversations are also highlighted as important barriers for medical residents. These factors corroborate with studies on advance care planning barriers from other regions that show the physicians' same difficulties (31–33,44,120,121).

- Uncertainty about prognosis

While most patients want to discuss prognosis with physicians, many doctors hesitate to provide information because of uncertainty about prognostic accuracy and fear of harming the patient (122). Physicians tend to be overly optimistic and to overestimate prognosis in a favorable direction (123). These practices tend to influence patient decision-making. For instance, cancer patients who believe they have a survival period longer than 6 months tend to want more interventions, even potentially futile ones, compared with patients who thought that there was at least a 10% chance of death within 6 months (124). Another study showed that these optimistic patients did, indeed, tend to receive more life-sustaining treatments (54).

- Discomfort in discussing end-of-life issues

Discomfort in discussing end-of-life issues is also a physician-related barrier to advance care planning discussion. Lee et al. (31) explored oncologists' views on end-of-life care discussions and observed that personal discomfort with death and dying, reluctance to communicate painful information, perception of other physicians' failure, focusing too much on a cure or treatment, along with a lack of experience on breaking bad news, especially in end-of-life

care, were considered barriers to addressing advance care planning with patients (31). Talking about death and dying can be distressing to patients and physicians alike. Physicians report that they are reluctant to initiate end-of-life conversations and are uncomfortable with the process because these discussions trigger difficult emotions (125). Many of them also feel inadequate in managing the emotional and behavioural reactions of patients (126). As a consequence, therefore, physicians do not address patients' and families' psychosocial concerns, including those about dying (83).

Also, physicians tend to focus on the disease and treatments in discussions about end-of-life care. Whilst survival and treatment considerations are significant to patients, there is a broad range of psychosocial and spiritual concerns about the end-of-life for loved ones, about spiritual well-being, having the opportunity to say goodbye, for independence, sense of control and comfort, which are often inadequately understood and may be integrated poorly by physicians into the patient's overall treatment plan (127,128). Patients regularly bring up concerns related to dying with their physicians to which physicians often do not respond. Palliative care experts tend to explore these non-medical issues and to be more patient-centred in their discussions with patients about goals of care and end-of-life planning (83,129).

- Lack of training

Insufficient training is a barrier frequently cited in the present studies and in the international literature about advance care planning discussions. Many physicians feel poorly prepared to conduct end-of-life conversations (31,33,120,121,130). Although oncologists and other clinicians who deal with chronic and serious illnesses need to discuss end-of-life care with patients frequently (an average of 35 times a month for oncologists) and also express the desire for further training on communication strategies, few physicians reported actually receiving this kind of training in graduation or during their residency (50,78,131). An American multicentric survey showed that although 99% of participants agreed that it is important to have end-of-life conversations, only 29% reported having formal training on this topic. Those most likely to have training included younger physicians, and those who worked in hospital settings were more likely to report having a formal system in place for conversations than those

practicing in offices or clinic-based settings (111). In Brazil, teaching about palliative care is not yet mandatory in medical schools, and the issues related to the end-of-life discussion are still little addressed at graduation, including advance care planning. These are usually carried out more by those with experience in palliative care (78,81,132).

Physicians with the knowledge and access to a systematic approach to serious illness conversations also feel more comfortable with the content of these conversations and find the experience more rewarding (36). Clinicians should have training on goals of care conversations as part of their medical education and, likewise, expect that developing proficiency in communicating about serious illness goals requires training and practice to ensure quality and efficacy. (6,27,36). Communication frameworks, conversation guides and training programs should be available to clinicians and patients to promote health literacy and self-efficacy by enhancing their knowledge of palliative care and their role in advance care planning and goals of care conversations (6,36,133). In this sense and given the lack of these tools in the Brazilian reality, a practical guide to enhance and facilitate advance care planning and goals of care discussion was also elaborated as part of this thesis.

- Lack of access to palliative care services

The lack of palliative care services and multidisciplinary teams aligned with the care of cancer patients are common difficulties perceived by the physicians in the present studies. The insufficient health support (social workers, nurse practitioners, psychologists, etc.) integrating teams to aid in the patient referral process to palliative care is still a common reality in Brazilian hospitals, especially those without specialized palliative care services, which hinders these patients' access to the necessary integrated care (132). Professionals who work in palliative care teams tend to perform advance directives with their patients, and therefore, they may be more sensitive to the importance of this instrument for decision-making and an adequate care plan (81).

The progress of palliative care worldwide has been limited by additional human factors. Palliative care has come to be associated with end-of-life and dying (134). Psychologically, most people fear and avoid anything related to death. There is often a belief that even acknowledging the possibility that one

may die soon is harmful (71). Evidence suggests that palliative care improves quality of life and may actually improve patient survival, especially when introduced early during the illness process (134–136). However, efforts to engage the public and policy makers on the need for palliative care have met with limited success (71).

In 2020, The Global Atlas of Palliative Care updated data on palliative care development around the world. Brazil received the classification 3A, meaning that the development of palliative care is still sparse in scope and not well supported, that sources of funding are often heavily donor-dependent, that there is limited availability of morphine and that there is a small number of palliative care services in relation to the size of the population (71).

Having access to a well-structured and implemented palliative care service that encourages early discussions, supports symptom management, helps to align patients' and families' expectations, conducts family meetings, embraces appropriate communication and enables a multidisciplinary approach, is considered a key point in facilitating the discussion about advance care planning and goals of care (71,135). Oncologists who did not have the support of a palliative care team reported relying more on other team members to help with goals of care conversations. They perceived a benefit to partnering with others to support patients (116), and patients accept that goals of care discussions are initiated by multiple team members, including nurses, social workers, and care coordinators. Investing in interprofessional training in facilitating goals of care discussions can distribute the responsibility and offload any one member of the health care team (137,138).

3) External barriers to goals of care discussion and advance care planning

- Lack of Time

Lack of time is one of greatest and most often mentioned barrier to goals of care conversations, particularly in the ambulatory setting. Oncologists estimate goals of care conversations to take approximately 30 to 60 minutes, and mostly over the course of several appointments. They wanted more time to discuss several topics and to manage strong emotions in a discussion about goals of care and advance care planning. Oncologists felt the pressure of time, given the high number of daily patients. They reported that, if they took more time with one

patient, it would take away time from other patients, and they did not want to rush the goals of care conversation (139). This barrier may be minimized if these conversations begin early in the disease course and are continuous (121).

Physicians' attitudes appear to have considerable impact on whether and when these discussions occur, with physicians describing reluctance in initiating them when the patient appears well, does not have symptoms, or has not exhausted all treatment options (138). So, they tended to initiate end-of-life discussions late in the course of illness. In a large, population-based prospective cohort study of patients with metastatic lung and colorectal cancer, the first conversation about end-of-life care took place an average of 33 days before death (14). One of the consequences of this delay in discussions about end-of-life goals, including palliative care that is associated with superior quality care outcomes in those patients with advanced and irreversible disease, is that it occurs too late in patients' disease trajectory. Many are referred to palliative care only in their last week of life, so the benefits of this approach for patients and families are already very limited in this short period of survival (140). Earlier discussions about the realities of an advancing illness and the role of palliative care in meeting patient goals allows patients to choose the care trajectory that will best meet their wishes and goals of care (83).

In the United States of America, since 2016, fee-for-service Medicare began reimbursing physicians for advance care planning conversations during outpatient visits, recognizing, among all advance care planning's benefits, the reduction of unnecessary healthcare use and spending (40). This reimbursement may also incentive physicians to better organize their time to address advance care planning and goals of care during consultations and to prepare themselves better to perform it (12,40).

Bioethical Aspects

One of the greatest challenges during end-of-life care is to avoid overtreatment, which prolongs suffering, but at the same time to avoid premature decisions to withdraw treatment that can lead to potentially preventable deaths (141). This is a topic of advance care planning that we should talk about carefully with seriously ill patients, to set goals of care that make sense for the patient and

which try to lessen the burden of these dilemmas. In such circumstances, physicians may feel compelled, by reasons other than purely medical factors, to be more aggressive than their beliefs would have them be, tending to overtreatment (106,142). This ambivalence between attitudes and beliefs can be wider in countries such as Brazil, where there are still no laws about advance directives and withdrawal of life-sustaining therapies during the end-of-life, therefore is not consensual among jurists, often misinterpreted by the general public and by many healthcare professionals, and scarcely debated by society (62,108).

Deliberation on goals of care goes beyond simply asking patients what they want. This may not guarantee their autonomy if they do not have full understanding of their diagnosis and prognosis(106,108). The most complex decisions often take place within intensive care units or emergency rooms that require, most of the time, quick decision-making. Physicians sometimes avoid decision-making responsibilities and delegate them to patients and surrogates (143). It is not a real autonomy, and could inadvertently deprive the patient of the necessary health guidance for making decisions, especially in critical situations, as a- inappropriate- way of protecting oneself and promoting autonomy (92,143). Sometimes physicians see themselves in false dichotomies, as if they have to choose between autonomy or beneficence/ non-maleficence. The shared decision-making, in which the doctor clarifies prognosis and available treatment options, including the one he/she thinks is best for that condition, allows the patient or surrogate to participate in the decision about which care is best for them according to their principles and wishes, which is useful in minimizing doubts and conflicts, considering both beneficence and autonomy (56). An example would be the disagreement between the intensive care unit physician and the assistant oncology doctor regarding the referral to intensive care of a patient with advanced lung cancer with an acute condition (such as severe pneumonia). The intensivist, possibly focused on high mortality, does not indicate intensive care for this patient, and disagrees with the admission. Meanwhile, the oncologist, possibly worried about the patient's fear of death and focused on the characteristic and severity of the disease, recommends intensive support. Current ethical reasoning may approach this situation as an autonomy vs. beneficence/maleficence dilemma, where one principle may prevail. Alternatively, physicians could even

abstain from this difficult discussion and delegate the decision to the patient/surrogate, sometimes by simply asking “what would you like us to do?” despite the patient/surrogate’s lack of knowledge about the risks and benefits involving each choice. Such ethical dilemmas can arise in other contexts and other diseases (106,108). In most real-life scenarios, there are many uncertainties about risks and benefits of treatments, and about their impact on the patient’s core values, so the decision about goals of care would require a careful and deliberative dialogue.

Within the medical context, an essential first step is to assess the capacity of a patient or their surrogate to use information regarding a proposed treatment option to make a choice compatible with one’s own values (144). Although this can be a simple decision in the profoundly debilitated patient, the challenge becomes greater in a patient with the ability to communicate but an unclear ability to make medical decisions. An assessment of the decision-making capacity can be carried out by the clinician undertaking the advanced care planning with the patient and does not require any special psychiatric or legal expertise (27,36).

Capacity is defined around a specific medical decision; individuals may have capacity in one clinical context but not in another and vice versa. The law and ethics have settled on four decision-making abilities that constitute capacity, which according to Cook et al. (27) are:

1. Understanding: the patient (or their surrogate) must have the ability to understand the information being presented. This often comes down to a patient understanding their diagnosis and prognosis, as well as the risks and benefits associated with the treatment options.
2. Expressing a choice: the patient (or their surrogate) needs to be able to express a choice when presented with options. Although that choice can vary over time, frequent setbacks in the setting of an underlying neuropsychiatric condition may suggest an inability to reliably express a choice.
3. Appreciation: the patient (or their surrogate) must be able to appreciate how their medical condition and the implication of their choices are relevant to them, and express insight into their medical condition. If a person refuses to accept that they have a metastatic cancer, despite irrefutable evidence, it may indicate that they do not understand the nature of their diagnosis and may not have capacity.

4. Reasoning: the patient (or their surrogate) must have the ability to compare options, drawing on the patient's values and beliefs. In practice, this is tested by being able to explain their rationale and that it is reasoned and reasonable. This does not mean that the physician needs to agree with their rationale, only that the patient can compare within the framework of their own belief system and that comparison is based in the reality of the medical situation.

Another important point is that healthcare professionals tend to conceptualize goals of care discussions in medical terms, and focus the discussion solely on medical interventions, if the patient's goals and preferences exist with a similar medical focus. It is likely that a patient's goals are far more individualized and less medically-oriented than most clinicians assume (124). Any discussion about goals of care and advanced care planning must consider a patient's desire to maintain and support relationships, to attend family events, and to avoid suffering. Balancing quality of life values along with quantity of life can help guide how the patient understands medical interventions (27). Best practices in discussing advance care planning and goals of care include not just withholding or withdrawing supportive treatments, but also sharing prognostic information, addressing decision-making preferences, understanding fears and goals, exploring views about trade-offs and impaired function (56,106).

Some criticisms are based on the fact that ethical hypotheses about patient autonomy embodied in academic literature and policy documents related to advance care planning are disconnected from the realities of clinical care (28,145). Medical norms and professional limits surrounding "good death" have a greater influence on care than patient preference. Advance care planning programmes, therefore, can be dismissed by healthcare professionals as irrelevant to care or may have the unintended consequence of limiting patient autonomy when used as a professional tool to encourage a "right" way to die, given that an exclusive focus on bureaucratic advance care planning programmes that reduce patient autonomy to a "checkbox" exercise may not improve end-of-life care (145).

CONCLUSION

Given the gap between what people want at the end-of-life and the care they actually receive, there is a need to build training tools and include advance care planning and goals of care discussion systematically into practice. Aligning patient values with the best available treatment alternatives requires communication skills to understand patient needs and priorities and set goals of care based on their values and wishes.

This doctoral thesis aimed to explore physicians' barriers to engaging patients with cancer in goals of care conversations and advance care planning. These barriers are grouped in physicians, patients and families, and external factors. This is the first Brazilian study on oncologists' barriers to advance care planning and the findings are in accordance with international literature, in which unrealistic patient or family expectations, lack of time, uncertainty about prognosis and lack of palliative care teams have been perceived as important barriers in discussing advance care planning and goals of care (31,33,121,146). It emphasizes that these challenges are universal across different cultures and countries to perform advance care planning, and even in countries in which there is already legislation on advance directives, there is a low rate of records about this subject. The studies also enhance the importance of identifying patients' values and highlights the urgent need to tailor oncologists' training to approach goals of care and advance care planning discussions. Initiatives may be implemented to support facilitators and address barriers, such as continuous education about this topic following medical graduation and the development of training tools. Based on the results, a proposal of a guide was prepared with suggestions and recommendations of current evidence to facilitate the advance planning of care in clinical practice in Brazil that should be based on empathic communication, following diagnosis and prognosis information, which is essential to identify patient's priorities, follow shared decision-making and registering the advance care planning (advance directives). This guide serves as a base for further studies to understand the adherence of medical doctors and its effectiveness around all regions of Brazil to better validate it for the Brazilian reality. Some strategies to improve advance care planning in practice include continuous education and training to health professionals, increasing population

health literacy about end-of-life care and their role in advance care planning, formal systems, and policies to promote its implementation.

Limitations of this study include a small sample for the empirical studies. Given that data collection occurred during the pandemic period of a coronavirus, most healthcare professionals were mentally and physically overwhelmed and overburdened. Another issue that may have contributed to the lower response rate was the vulnerable nature of this topic.

Advance care planning, including advance directives, need to be further studied from a clinical and legal perspectives. More prospective large-scale studies are needed, including experimental studies, especially in Brazil, which has few studies on this topic. Besides, most studies still present data from the point of view of healthcare providers and more research from the patients' perspective is still needed. The present thesis is the first to demonstrate the barriers to advance care planning and goals of care discussion with Brazilian oncologists. Exploring these barriers could help to prioritise the next steps for future studies aimed at improving advance care planning and helping clinicians to better support patients and families through shared decision-making based on the patient's values and self-identified goals.

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APPENDIX

1. Authorization for translation and cross-cultural adaptation of the DecideOncology questionnaire.

Friday, September 9, 2022 at 18:53:22 Brasilia Standard Time

Assunto: RE: DECIDE Oncology - license request for translation

Data: quarta-feira, 11 de novembro de 2020 16:52:56 Horário Padrão de Brasília

De: Ethier, Josee-Lyne

Para: Laiane Moraes Dias

CC: Sonal.Gandhi@sunnybrook.ca, Rob.Fowler@sunnybrook.ca

Dear Dr. Dias,

Thank you for contacting me.

I've reached out to Dr. Sonal Gandhi and Dr. Rob Fowler, lead investigators for the original DECIDE Oncology (copied on this email).

We would be pleased to allow the use and translation of the DECIDE Oncology questionnaire, if we could kindly ask that both the DECIDE Oncology and original DECIDE manuscripts (<https://nam10.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.ncbi.nlm.nih.gov%2Fpmc%2Farticles%2FPMC4544790%2F&data=04%7C01%7C%7C62b14e56878044f261de08d8867b612b%7C84df9e7fe9f640afb435aaaaaaaaaaaa%7C1%7C0%7C637407211752867417%7CUnknown%7CTWFpbGZsb3d8eyJWljiMC4wLjAwMDAiLCJQIjIjIjIuMzIiLCJBIjI6IjIhaWwlcjIjIjI6IjI0MD0%3D%7C1000&sd=CD1pnO0esQL03lgrhMIXD6vIRzqe01PFyGABmxKn0%3D&reserved=0>) be referenced as the platform for the proposed project in future publications or training materials.

Best of luck with your project!
Josee

--
Dr. Josee-Lyne Ethier, MD, MSc, FRCPC
Attending Medical Oncologist
Kingston Health Sciences Centre
Assistant Professor, Queen's University
Tel: (613) 549-6666 ext. 4505
Please note change of email: Josee-Lyne.Ethier@kingstonhsc.ca

From: Laiane Moraes Dias [laianemoraes@hotmail.com]
Sent: Wednesday, November 11, 2020 2:01 PM
To: Ethier, Josee-Lyne
Subject: FW: DECIDE Oncology - license request for translation

CAUTION: This email was sent from a user outside of KHSC. The KHSC Help Desk will never ask you to share or verify your user name and password. If you suspect this is a phishing or fraudulent email, please forward it to KHSC Help Desk<<mailto:KHSC%20HELP%20DESK%20%3cKHSC.HelpDesk@kingstonhsc.ca%3e>>.

De: Laiane Moraes Dias <laianemoraes@hotmail.com>
Data: quarta-feira, 4 de novembro de 2020 17:40
Para: "ethierjl@kgh.kari.net" <ethierjl@kgh.kari.net>
Assunto: DECIDE Oncology - license request

2. Ethics committee approvals

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ONCOLOGIA DA UNIVERSIDADE
FEDERAL DO PARÁ



PARECER CONSUBSTANCIADO DO CEP

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: Planejamento antecipado de cuidados em oncologia: os desafios na prática clínica.

Pesquisador: LAIANE MORAES DIAS

Área Temática:

Versão: 1

CAAE: 37544420.1.0000.5634

Instituição Proponente: Hospital Universitário João de Barros Barreto - UFPA

Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 4.376.747

Apresentação do Projeto:

Sem observações aplicáveis à fase do projeto.

Objetivo da Pesquisa:

O objetivo da pesquisa está bem esclarecido, quando externa a preocupação em estreitar o entendimento nos diversos âmbitos de comunicação, na assistência a pacientes em fase final da vida, quais sejam: A relação médico-paciente; relação médico-familiares/responsáveis; um enfoque jurídico e ético quanto ao dilema de condutas desproporcionais ou cessação de cuidados avançados.

Avaliação dos Riscos e Benefícios:

Os riscos são os inerentes a uma divulgação parcial ou total, indevida, dos dados coletados sobre os sujeitos da pesquisa, no entanto, os pesquisadores se comprometem quanto ao sigilo, assinam termo de responsabilidade e anunciam as medidas de tratamento desses dados mais sensíveis.

Comentários e Considerações sobre a Pesquisa:

Há um propósito bem relevante em que explicita um aspecto muito frágil na rotina de assistência a pacientes fora de possibilidades terapêuticas, cuja medida protocolar possa diminuir dúvidas, sofrimentos, falhas de comunicação e até o uso indevido de recursos. Óbvio que o envolvimento institucional é fundamental para adoção do proposto planejamento antecipado de cuidados oncológicos, este com alinhamento ético rigoroso.

Continuação do Parecer: 4.376.747

Muito boa pesquisa!

Considerações sobre os Termos de apresentação obrigatória:

Todos os termos padronizados para o tipo de pesquisa proposta estão de acordo, sem óbices para sua continuação.

Recomendações:

Há o emprego de um adjetivo constante na introdução "tratamentos fúteis" o qual vale uma reanálise de significação por parte do autor, uma vez que o adjetivo "fútil" significa leviano, podendo assim denotar uma mensagem pejorativa de infringência ética.

São observados pequenas falhas de concordância e erros de digitação ao longo do texto, sem comprometer a o projeto da obra. (-Este estuda objetiva; fase final de vida; luto[])

Conclusões ou Pendências e Lista de Inadequações:

Está citado o uso de um questionário "sem validação" (Decide- Oncology) apenas por uma questão idiomática, bem como as tratativas para esta situação, as quais este parecerista desconhece serem estas suficientes, assim apenas solicito a confirmação dos cuidados adotados, sem que isso influencie no status de aprovado ora registrado.

Considerações Finais a critério do CEP:

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Ar-quivo	Postagem	Autor	Situação
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_DO_PROJETO_1598039.pdf	09/09/2020 11:48:03		Aceito
Folha de Rosto	folha_de_rosto_PAC.pdf	09/09/2020 11:46:28	LAIANE MORAES DIAS	Aceito
Orçamento	ORcAMENTO.docx	16/08/2020 21:55:06	LAIANE MORAES DIAS	Aceito
Outros	DECLARACAO_DE_ISENCAO.pdf	16/08/2020 21:47:16	LAIANE MORAES DIAS	Aceito
Declaração de Pesquisadores	DECLARACAO_DE_RESPONSABILIDADE.pdf	16/08/2020 21:42:13	LAIANE MORAES DIAS	Aceito
Cronograma	Cronograma_de_Atividades_a_Developar.docx	16/08/2020 21:40:44	LAIANE MORAES DIAS	Aceito
Outros	APENDICE_QUESTIONARIO_Decide_oncology.docx	20/07/2020 22:57:21	LAIANE MORAES DIAS	Aceito
TCLE / Termos de	TCLE.docx	20/07/2020	LAIANE MORAES	Aceito

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EM ONCOLOGIA DA
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PARÁ**



Continuação do Parecer: 4.376.747

Assentimento / Justificativa de Ausência	TCLE.docx	22:53:40	DIAS	Aceito
Projeto Detalhado / Brochura Investigador	Projeto_Planejamento_Antecipado_Cuid ados_20_07.doc	20/07/2020 22:52:50	LAIANE MORAES DIAS	Aceito

Situação do Parecer:

Aprovado

Necessita Apreciação da CONEP:

Não

BELÉM-PA, 03 de Novembro de 2020

Bruna Cláudia Meireles Khayat.
Coordenadora.