Revista Bioética
Print version ISSN 1983-8042 | On-line version ISSN 1983-8034

Rev. Bioét. vol.34 Brasília 2026

Decision support tools and autonomy of oncology patients

Maria Jayne Lira de Araújo [1], *Millena Maria Maciel Pinto* [1], *Késsia Karina Alves de Oliveira* [1], *Francimar Alves de Oliveira Neto* [1], *Karina Amorim* [2], *Claudio Emmanuel Gonçalves da Silva Filho* [2,3]

1. Pesquisadora autônoma, João Pessoa/PB, Brasil. **2.** Faculdade de Medicina Nova Esperança, João Pessoa/PB, Brasil. **3.** Faculdade de Medicina da Universidade do Porto, Porto, Portugal.

Abstract

When facing a life-threatening illness, patients and their families are often confronted with complex decisions. Decision aids have gained prominence as effective strategies to facilitate shared decision-making among patients, families, and healthcare professionals. In this context, this study aims to analyze the impact of such tools on oncology patients who are in a terminal phase or receiving palliative care. A systematic review was conducted following the PRISMA Protocol, using online databases. The study population totaled over 1,200 patients, and the methods included programs, videos, structured interviews, and booklets. These resources helped enhance patients' and caregivers' understanding and involvement in decisions regarding palliative care, promoting more effective communication. Therefore, shared decision-making represents a patient-centered approach, which requires tools that humanize communication—especially in the context of limited prognoses.

Keywords: Palliative care. Decision making, shared. Medical oncology. Patient-centered care.

Resumo

Instrumentos de apoio à decisão e autonomia de pacientes oncológicos

Pacientes em final de vida e seus cuidadores/familiares frequentemente enfrentam decisões complexas. As ajudas decisionais têm ganhado destaque como estratégias para facilitar a tomada de decisão compartilhada entre pacientes, familiares e profissionais da saúde. Este estudo visou analisar o impacto delas em pacientes oncológicos em fase terminal ou sob cuidados paliativos. Foi realizada revisão sistemática, conforme o protocolo PRISMA, de literatura obtida em bases de dados on-line. A população estudada totalizou mais de 1.200 pacientes, e os recursos analisados incluíram programas, vídeos, entrevistas estruturadas e livretos. Eles ajudaram a aumentar o entendimento e a participação de pacientes e cuidadores nas decisões sobre cuidados paliativos. Conclui-se que a tomada de decisão compartilhada é centrada no paciente, o que demanda instrumentos para humanizar a comunicação, especialmente diante de prognósticos limitados.

Palavras-chave: Cuidados paliativos. Tomada de decisão compartilhada. Oncologia. Assistência centrada no paciente.

Resumen

Instrumentos de apoyo a la toma de decisiones y autonomía de pacientes oncológicos

Al enfrentar una enfermedad potencialmente mortal, los pacientes y sus familias suelen encontrarse ante decisiones complejas. Las herramientas de apoyo para la toma de decisiones han ganado protagonismo como estrategias eficaces para facilitar la toma de decisiones compartida entre pacientes, familiares y profesionales de la salud. En este contexto, el presente estudio tiene como objetivo analizar el impacto de dichas herramientas en pacientes oncológicos en fase terminal o en cuidados paliativos. Se realizó una revisión sistemática siguiendo el Protocolo PRISMA, a partir de bases de datos en línea. La población estudiada totalizó más de 1.200 pacientes, y los métodos incluyeron programas, videos, entrevistas estructuradas y folletos. Estos recursos contribuyeron a aumentar la comprensión y participación de pacientes y cuidadores en las decisiones sobre cuidados paliativos, favoreciendo una comunicación más efectiva. Así, la toma de decisiones compartida representa un enfoque centrado en el paciente, que requiere instrumentos que humanicen la comunicación, especialmente ante pronósticos limitados.

Palabras clave: Cuidados paliativos. Toma de decisiones conjunta. Oncología médica. Atención dirigida al paciente.

The authors declare no conflict of interest.
Prospero registration CRD420251031120

Research

As the world population ages, mortality patterns change, and with the growing number of individuals with incurable health conditions and terminal illnesses, end-of-life care and the associated complex decision-making processes have become a focus of attention for society and healthcare professionals. End-of-life care comprises medical and psychosocial support provided during the days, weeks, or months preceding death, with the objective of providing comfort, dignity, and quality of life [1].

Communicating prognosis and care goals at this stage can constitute a major challenge both for the healthcare team and for patients and families, especially in the face of intense emotions, uncertainties, and differences in values [2]. In this context, shared decision-making is defined as an approach in which healthcare professionals and patients collaboratively discuss, considering individual values, preferences, and goals, the best available scientific evidence to build the care plan [3]. This practice has been widely described as one of the pillars of person-centered care, as it has contributed toward more conscious and personalized decisions [4].

This process is supported by emerging decision support tools, called decision aids (DA), whose purpose is to help patients understand possible healthcare interventions and, thus, analyze available alternatives and reflect on their potential benefits and risks [5]. The tools favor the understanding of healthcare information by presenting care options in an accessible and structured manner, thus promoting debate and providing inputs for informed individual choice [6].

This study aims to analyze the impact of DAs on shared decision-making among oncological patients under palliative care or end-of-life care, considering their effects on treatment understanding, decision quality, and care experience.

Method

This systematic review follows the recommendations of the Preferred Reporting Items For Systematic Reviews and Meta-Analyses (PRISMA 2020). The review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) under number CRD420251031120. The literature search used the online databases Scopus, Web of Science, and PubMed. The applied methodology had the following steps: 1) development of the research question and search strategy; 2) sampling from the online literature; 3) data collection; 4) critical analysis of the included studies; 5) discussion of the results.

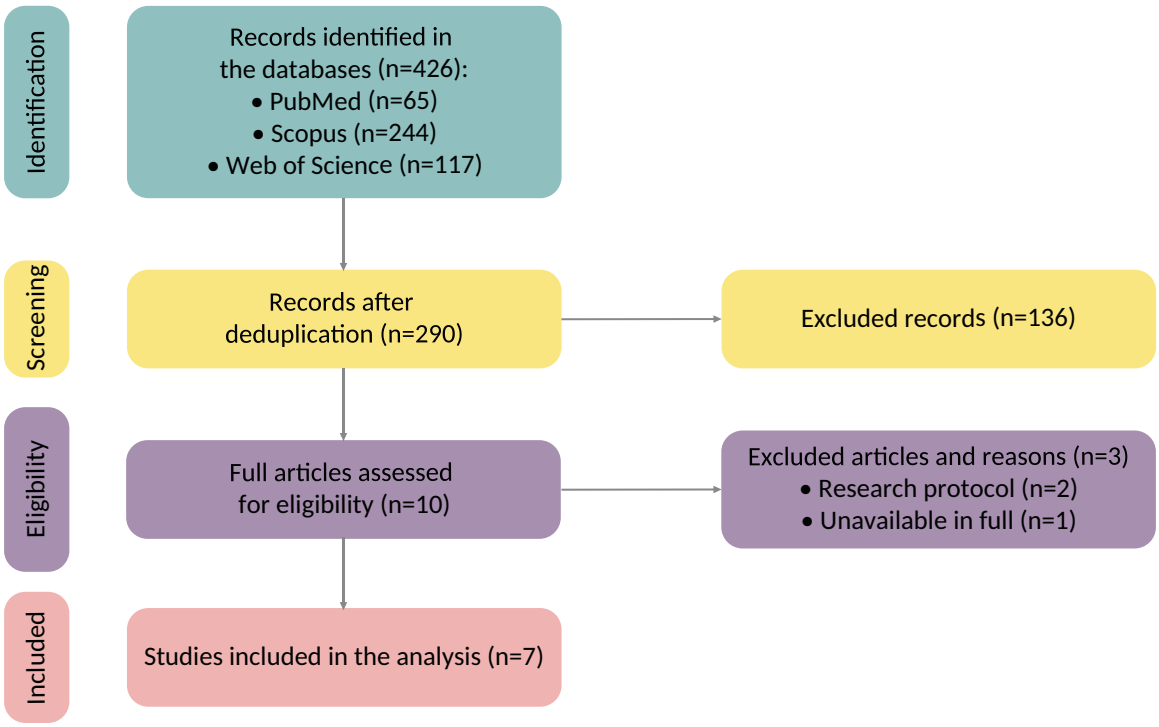
The guiding question was: what are the benefits of using shared decision-making support tools in oncological patients under palliative care? Based on such question, we formulated the following search strategy, in English: ("End of life" OR "Terminal care" OR "Palliative care" OR "Supportive care" OR "Palliative treatment" OR "Palliative therapy") AND ("decision support model" OR "Decision Support Technique" OR "Decision Analysis" OR "Decision Aid" OR "Decision Modeling") AND (Neoplasm OR tumor OR cancer).

To guide the review, we adopted the PICO strategy, in which: Population referred to oncological patients under palliative care or end-of-life care; Intervention referred to shared decision-making support tools or techniques; Comparison referred to absence or standard use (without specific tools); and Outcomes referred to improved communication, patient satisfaction, reduced anxiety and depression, improved quality of life, and decisions aligned with patient values.

The online platform search was conducted by an independent researcher on March 29, 2025, and resulted in 426 records; after deduplication using the Mendeley platform, 290 studies remained. Blind screening was conducted by three authors, between April and May 2025, by reading the titles and abstracts using the Rayyan platform. The inclusion criteria encompassed full-text articles of randomized clinical trials and observational studies with a population of cancer patients, published from 2010 onwards, available in full, in English, Portuguese, or Spanish. Articles without full text available, literature reviews, studies with non-oncological patients, and studies in languages other than the selected ones were not included.

After applying the eligibility criteria, ten articles remained for full-text reading, of which three were excluded due to unavailability or because they were research protocols. Data extraction used an online spreadsheet and was carried out by the three reviewers simultaneously and independently. Next, a critical content review was performed, based on the following criteria: title, country of publication, objectives, study characteristics, studied population, intervention/exposure, outcomes analyzed, main results, and limitations. The summary of the study selection process is illustrated in Figure 1.

Figure 1. Bibliographic search and study selection flow diagram



Results

Of the 426 records identified in the databases, seven met the eligibility criteria. The intervention was applied to a population of over 700 participants, in four countries: the United States, Singapore, South Korea, and Norway. The methods included programs, videos, structured interviews, and booklets. The characteristics of these studies are summarized in Chart 1.

Chart 1. Summary of the included studies

Authors; year of publication	Design	Studied population	Intervention/exposure	Analyzed outcomes	Main results
Bakitas and collaborators; 2016 [7]	Mixed study	Patients aged over 18 years with advanced solid tumors or hematological malignancies (prognosis between 6 and 24 months) without dementia or active Axis I psychiatric disorders (such as schizophrenia and bipolar disorder) or substance abuse disorder, and their caregivers.	Before the third session, participants watched the program Looking Ahead PtDA, which addressed content on decision-making and advance care planning. coaching nurses used semi-structured interviews to obtain feedback from patients and caregivers approximately one week after they watched the program (booklet and DVD).	The semi-structured interview contained questions about how much they had seen of the program/booklet; time involved in the program; clarity of language; narrator voice; use/explanation of medical terms; satisfaction with the program; usefulness in clarifying values and decisions; usefulness in interactions with family, friends, and healthcare providers; and whether they would recommend it to others.	In total, 57 patients (mean age 64 years), 42% with lung cancer and 23% with gastrointestinal cancer, and 20 caregivers (mean age 59 years), 80% of whom were spouses, completed the PtDA assessment. Participants reported a high degree of satisfaction with the PtDA format, as well as with its length and clarity. They considered the format of using patient interviews "validating." The main themes were: 1) "the sooner, the better" for viewing the PtDA; 2) feeling empowered, aware of the different options; and 3) an urgency to participate in advance care planning.
Chong and collaborators; 2020 [8]	Mixed study (qualitative and quantitative)	Cancer patients who were at least 21 years old and were scheduled for chemotherapy but had not started it. They had to be able to read the PDA booklet and complete questionnaires in English, Chinese, or Malay. All types of cancer were included, and patients in concomitant therapeutic clinical trials were not excluded. Exclusion criteria included cognitive impairment and previous use of complementary and alternative medicine (CAM).	Booklet as a patient decision aid in English, Chinese, and Malay, containing information on chemotherapy and oral CAM, an impartial review of potential benefits and risks, and structured guidelines on decision-making.	Patient certainty and satisfaction with the decision on oral administration, regret over using oral CAM during chemotherapy, knowledge about CAM, absorption of oral CAM during chemotherapy, prevalence of communication between patients and their oncologists on the issue, and difference in quality of life between patients who used it and those who did not use it.	There was no difference in decisional conflict score and decisional regret score between the groups. There was a reduction in the chances of using CAM in the intervention group, but there was no difference in the discussion with oncologists about CAM use or in the quality of life of CAM and non-CAM users.

continues...

http://dx.doi.org/10.1590/1983-80342026424 3EN

Chart 1. Continuation

Authors; year of publication	Design	Studied population	Intervention/exposure	Analyzed outcomes	Main results
Nieder and collaborators; 2013 [9]	Retrospective analysis	124 patients treated with BSC, whole-brain radiotherapy (WBRT), or radiosurgery, all with adverse prognostic characteristics defined by scores such as the Diagnosis-Specific Graded Prognostic Assessment (DS-GPA).	Retrospective analysis of treatments received (BSC, WBRT, or radiosurgery) and development of a survival prediction model based on clinical and prognostic characteristics.	Overall survival; treatment adequacy (BSC *vs*. RT); usefulness of the survival prediction model in therapeutic decision-making.	Regardless of the score used, the DS-GPA, in isolation, was not a satisfactory parameter for treatment selection. A subgroup of 63 patients (51%) with short survival was identified, regardless of the therapeutic approach. For these patients, radiotherapy did not provide significant benefits, making BSC a reasonable choice.
Tate and collaborators; 2021 [10]	Methodological development study	Adults with illnesses and families, including caregivers and healthcare team members.	Development of an evidence-based decision support tool, which incorporated information on the prognosis, benefits, and limitations of palliative care, with the aim of facilitating informed discussions among patients, families, and healthcare professionals.	Understanding of patients and families regarding palliative care; satisfaction of patients and families with the decision support tool; intention to choose palliative care after using the tool; impact on communication among patients, families, and the healthcare team.	The decision support tool was well received by patients and families, with high satisfaction reported, fostering understanding of palliative care, and having the potential to be a tool used to support informed decision-making.
Volandes and collaborators; 2012 [11]	Pre- and post-intervention study	80 patients with advanced cancer treated in outpatient clinics at Memorial Sloan-Kettering Cancer Center.	The patients watched an educational video that explained the goals of care in advanced cancer: life-prolonging care, basic care, and comfort care.	Changes in patient preferences regarding goals of care; knowledge about goals of care; consistency between patient preferences and documented code status (do-not-resuscitate orders).	Patient preferences regarding care goals did not change significantly after watching the video. There was a significant increase in the number of patients who did not wish for cardiopulmonary resuscitation (71% after the video *vs*. 61% before; p=0.03) and mechanical ventilation (79% after the video *vs*. 67% before; p=0.008). Patient knowledge regarding care goals increased significantly after watching the video (p<0.001). Only 5% of patients who did not wish for cardiopulmonary resuscitation or mechanical ventilation had a do-not-resuscitate order documented in their medical records.

continues...

http://dx.doi.org/10.1590/1983-80342026424 3EN

Chart 1. Continuation

Authors; year of publication	Design	Studied population	Intervention/exposure	Analyzed outcomes	Main results
Yun and collaborators; 2011 [12]	Randomized clinical trial	Family caregivers of end-stage cancer patients.	Experimental group: received a video and manual explaining how to discuss terminal prognosis with the patient; control group: received a video and manual on cancer pain control.	Caregiver decision to discuss the terminal prognosis with the patient; caregiver anxiety and depression levels; satisfaction with communication.	Caregivers who used the decision-making tool experienced a reduction in decisional conflict. There was no significant increase in anxiety or depression levels among caregivers in the experimental group.
Yun and collaborators; 2019 [13]	Randomized clinical trial	204 patients with advanced cancer, recruited between August 2017 and February 2018.	Intervention group: received video and booklet on advance care planning; control group: received video and booklet on cancer pain control.	End-of-life care preferences (active treatment, life-prolonging treatment, or palliative care) in different life expectancy scenarios (within 1 year, several months, and a few weeks); assessment performed at baseline, immediately after the intervention, and after 7 weeks.	After the intervention, the group that received the decision-making tool showed a significant increase in preferences for palliative care across all life expectancy scenarios. The change in preferences was more pronounced immediately after the intervention and was maintained, to a lesser extent, after 7 weeks.

Note: PtDA: patient decision aid; DA: decision aid; DVD: digital versatile disc; CAM: complementary and alternative medicine; BSC: best supportive care; WBRT: whole-brain radiotherapy; DS-GPA: Diagnosis-Specific Graded Prognostic Assessment; RT: radiotherapy.

http://dx.doi.org/10.1590/1983-80342026424 3EN

Bakitas and collaborators [7] conducted a mixed study with 20 caregivers and 57 patients over 18 years of age with advanced solid tumors or hematological malignancies and a prognosis between 6 and 24 months, excluding patients with dementia, active psychiatric disorders, or substance abuse. The study evaluated the clarity and usefulness of the Looking Ahead PtDA program immediately after a cancer diagnosis. Most participants reported high satisfaction with the material, noting its clarity, usefulness for care planning, and value in initiating difficult conversations; furthermore, they felt more informed and prepared. The tool showed potential to support early care decisions in critically ill patients.

Chong and collaborators [8] also evaluated, in patients over 21 years old and at the beginning of chemotherapy, a booklet as a tool to aid the decision-making process on the use of complementary and alternative medicine (CAM) during chemotherapy and the communication with oncologists. The booklet reduced the chance of using CAM, but did not show an effect on physician-patient communication, quality of life, decisional regret, or decisional conflict. However, limitations such as the absence of a validated questionnaire on CAM, assessment of prior knowledge, and measurement of adherence, as well as a high dropout rate, were noted.

In a retrospective study in Norway, 124 patients with brain metastasis and limited prognosis were evaluated to support the development of a survival prediction model to aid in the choice between palliative care and radiotherapy [9]. The model, based on clinical and prognostic characteristics, showed that 51% of patients had short survival, without significant benefit from radiotherapy, proving appropriate. The Diagnosis-Specific Graded Prognostic Assessment (DS-GPA) score, alone, was not sufficient to guide therapeutic decision-making. Despite the lack of external validation and data on quality of life, the model can help avoid unnecessary aggressive treatments and prioritize patient-centered care.

Similarly, Tate and collaborators [10] developed a decision support tool, with clear information on benefits and limitations, to aid adult patients with serious illnesses and their families consider palliative care. The assessment of the tool provided indications of increased understanding of these cares and of potential to improve communication with healthcare professionals. Despite the limitations, the results indicate that the tool was well received and can serve as a model for promoting informed decisions in similar contexts.

In 2012, Volandes and collaborators [11] evaluated an educational video as a tool to aid patients with advanced cancer to better understand treatment options and its potential to influence their preferences on cardiopulmonary resuscitation (CPR). Eighty outpatients watched the educational video, whose content explained the goals of care, such as prolonging life and providing comfort. Regarding patient preferences, there was no significant change. However, there was a significant increase in the number of patients who did not wish for CPR. Furthermore, it was observed that only 5% of patients who did not wish for CPR had a documented order in their medical record.

In South Korea, Yun and collaborators [12] evaluated a tool, also composed of a video and a manual, aimed at aiding caregivers and family members to discuss the prognosis with end-stage cancer patients. The randomized clinical trial defined as intervention in the experimental group a video and a manual explaining how to discuss the terminal prognosis with the patient, and, in the control group, a video and a manual on cancer pain control. The caregivers in the experimental group had a reduction in decisional conflict, without a significant increase in anxiety or depression levels. The results suggest that the tool can facilitate difficult dialogues without emotionally overburdening caregivers.

Also in South Korea, Yun and collaborators [13] conducted a randomized clinical trial to evaluate a video and a booklet on end-of-life care preferences in 204 patients with advanced cancer. The experimental group received the aforementioned tool, and the control group received a video and a booklet on cancer pain management. There was a significant increase in the choice for palliative care after the use of the tool, with the effect maintained over time.

Discussion

The results of this review suggest that decision aids can improve specific components

of the decision-making process in oncology, especially by expansion of knowledge, preparation for conversations, clarification of values, and participation of patients and caregivers. However, their effects were not uniform: some interventions modified preferences or favored communication [7,10-13], while others did not produce differences in decisional conflict, regret, quality of life, or interaction with professionals [8]. Thus, the evidence more clearly supports the utility of these resources as facilitators of deliberation than as interventions capable, in isolation, of ensuring shared decisions or care aligned with patient values [14,15].

The interpretation of the results requires considering that the studies included interventions with distinct purposes and mechanisms. Videos, booklets, and programs for patients and caregivers seek to reduce unmet decisional needs, clarify values, and prepare communication [7,8,10-13]; prognostic models and clinical records, in turn, improve the estimation of benefits and the therapeutic proportionality from a professional perspective [9]. Although both can contribute toward more adequate decisions, clinical decision support and DA are not equivalent concepts. Gathering these interventions broadens the understanding of the phenomenon, but limits direct comparisons and prevents attributing to all of them similar effects on autonomy and participation [16].

The most consistent effects were concentrated on increasing participant understanding and preparation for deliberation. The program evaluated by Bakitas and collaborators was perceived as clear and empowering [7]; the video used by Volandes and collaborators expanded knowledge about care goals [11]; and the materials used by Yun and collaborators favored the approach to prognosis and reflection on palliative care [12]. These results are consistent with the 2024 Cochrane update, according to which DAs increase knowledge, adequate risk perception, clarity as to personal values, and active participation [14]. However, informing better does not necessarily mean producing a different choice: the ethical function of the instrument is to improve the quality of the decision, not to lead the patient to a specific alternative [11,14].

Not all interventions reduced uncertainty or decisional conflict [8]. In the study of Chong and collaborators, the booklet modified the probability of using complementary medicine, but did not reduce conflict or regret [8]. In the most recent evaluation of the hospice instrument developed by Tate, there was an improvement in self-efficacy, but not in knowledge or beliefs [17]. Similarly, the HELP trial, conducted with 138 patients with advanced lung cancer, found no difference in the primary outcome of clarity of values nor in decisional conflict, despite the majority considering the intervention useful for preparation [18]. In this study, 57.6% presented very high decisional conflict, especially due to insufficient information and uncertainty. These findings indicate that instruments can support the patient without eliminating the intrinsic ambiguity of decisions involving limited prognosis, multiple treatments, and uncertain benefits.

Another central aspect is the distance between forming a preference and transforming it into effectively received care. In the study of Volandes, the video increased knowledge and the proportion of patients who did not wish for resuscitation or ventilation, but only a small portion had these preferences documented [11]. Yun and collaborators also found a higher preference for palliative care, without demonstrating that the choices were subsequently implemented [13]. Recent evidence confirms this gap: an intervention combining videos and oncologist training moderately increased advance care planning documentation [19], and a 2026 meta-analysis found improvement for engagement and documentation, but not for completion of advance directives, satisfaction, or decisional conflict [15]. Thus, documentation constitutes a relevant outcome of the process, but it should not be considered in isolation as proof of care consistent with values.

The findings also indicate that the effectiveness depends less on the mere availability of material and more on its integration into the clinical meeting. The 2025 pragmatic trial combined patient-directed videos with communication training for oncologists and achieved increased documentation, although it was not possible to separate the effect of each component [19]. The review by Punnett and collaborators showed that interventions including education, modeling, training, and conditions that facilitate professional practice are more promising for increasing shared

decision-making behaviors [20]. Consequently, the implementation should involve patient preparation, team training, explicit opportunity for discussing values, and a mechanism for recording and reviewing the plan.

In oncology, shared decision-making should be understood as a longitudinal process, not a one-time choice. Preferences can change with disease progression, response to treatment, onset of toxicities, functional decline, and new understanding of the prognosis. The review by Edwards and collaborators noted the need to offer time for preparation and opportunities for revisiting decisions [16], while the metasynthesis by Rabben demonstrated that the mode of participation varies according to the timing and nature of the decision [21]. Therefore, the instruments should support successive cycles of information, deliberation, recording, and reassessment.

The participation of caregivers requires a relational interpretation of autonomy [22,23]. The studies of Yun showed that materials geared toward family members can facilitate conversations about prognosis without increasing emotional distress and favor the consideration of palliative care [12,13]. Recent qualitative evidence indicates that patients often wish to involve their caregivers and reciprocally accommodate preferences due to trust, responsibility, and mutual concern [22]. This interdependence is not necessarily contrary to autonomy; it becomes problematic when the family withholds information, substitutes the voice of a capable patient, or directs decisions according to their own interests [23]. Tools aimed at the patient–family–team triad should clarify who wishes to participate, what values belong to the patient, and how any disagreements will be managed.

Shared decision-making in oncological palliative care also occurs in a context where the very perception of choice may be compromised. A 2024 meta-synthesis described a frequently experienced situation as "without choice," marked by urgency, fear, limited options, and life-or-death decisions [21]. Offering alternatives formally does not ensure autonomy when the patient does not understand that there exists a decision, feels unable to refuse treatment, or interprets the medical recommendation as the only legitimate possibility [18,21]. In this situation, respecting autonomy does not mean transferring all responsibility to the patient, but rather offering proportional professional recommendations, exploring values, and preserving real space for agreement, refusal, or review [24,25]

The incorporation of these resources should consider not only their availability but also their accessibility and real possibility of use by different patient groups. The systematic review of Ullrich and collaborators found favorable assessments of satisfaction, feasibility, and usability of web-based tools, but also sometimes low adherence, infrequent use, and high heterogeneity as to content, development, population, and outcomes assessed [26]. The realistic review of Edwards and collaborators showed that the effectiveness of aids depends on factors such as health literacy, balanced presentation of options, explanation of palliative terminology, provision of information in different formats, time for preparation, and opportunities for revisiting decisions [16]. These findings suggest that digital tools should not be used as the exclusive mode. In the Brazilian Unified Health System (SUS), their implementation should integrate printed, audiovisual, and digital materials, presented in understandable language and monitored by professionals capable of verifying comprehension, clarifying doubts, and supporting deliberation [16,26].

From a bioethical perspective, the instruments can strengthen autonomy by creating conditions for understanding, reflection, and expression of preferences, but they do not replace the professional responsibility for recommending clinically proportionate care [7,10-13,24,25]. Beneficence and non-maleficence require that information about benefits, risks, and prognosis be presented in a balanced manner, even when indicating a low probability of benefit from invasive treatments [9,14,24]. Truthfulness requires honest communication without abandonment of hope, while justice demands that decision support be accessible to different social groups [14,16]. In Brazil, this requirement is normatively supported by the National Policy on Palliative Care, established within the scope of the SUS [27], and by CFM Resolution 1,995/2012, which recognizes advance directives and reinforces shared care planning as a concrete expression of respect for autonomy [28].

The interpretation of these results should consider the heterogeneity of designs, populations, decisions, and outcomes, the presence of development studies and clinical supports, the small number of randomized trials, and the scarcity of Latin American evidence. Future research should evaluate instruments culturally adapted to Brazil, integrated into professional training and medical records, using as outcomes: knowledge, decisional conflict, agreement between values and decisions, documentation, care received, and patient and family experience.

Final considerations

The analyzed studies indicate that decision support tools can expand the knowledge, preparation, and participation of cancer patients and their caregivers in decision-making related to palliative care and end-of-life care. However, the effects on decisional conflict and regret, communication, quality of life, documentation of preferences and therapeutic choices were heterogeneous. These resources should be understood as components of a shared deliberative process, not as substitutes for clinical communication. Their ethical legitimacy depends on balanced and understandable information, presentation of uncertainties, clarification of values, accessibility, cultural adaptation, and integration into care. Given the small number and heterogeneity of the studies, there is a need for higher quality studies and instruments validated in the Brazilian context.

References

1. Lima MLF, Rego STA, Siqueira-Batista R. Processo de tomada de decisão nos cuidados de fim de vida. Rev. bioét. (Impr.) [Internet]. 2015 [acesso 1° dez 2025];23(1):31-9. DOI: 10.1590/1983-80422015231043
2. Santos ROM, Abreu MM, Engstrom EM. Análise documental sobre decisão compartilhada nas diretrizes clínicas de câncer. Rev. bioét. (Impr.) [Internet]. 2020 [acesso 25 nov 2025];28(2):265-75. DOI: 10.1590/1983-80422020282388
3. Hoque F. Shared decision-making in patient care: advantages, barriers and potential solutions. J Brown Hosp Med [Internet]. 2024 [acesso 2 abr 2026];3(4):e2024001. DOI: 10.56305/001c.122787
4. Rosca A, Karzig-Roduner I, Kasper J, Rogger N, Drewniak D, Krones T. Shared decision making and advance care planning: a systematic literature review and novel decision-making model. BMC Med Ethics [Internet]. 2023 [acesso 27 nov 2025];24(1):64. DOI: 10.1186/s12910-023-00944-7
5. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett C, Eden K *et al*. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev [Internet]. 2017 [acesso 28 nov 2025];4(4):CD001431. DOI: 10.1002/14651858.CD001431.pub5
6. Bonner C, Trevena LJ, Gaissmaier W, Han PKJ, Okan Y, Ozanne E *et al*. Current best practice for presenting probabilities in patient decision aids: fundamental principles. Med Decis Making [Internet]. 2021 [acesso 4 abr 2026];41(7):821-33. DOI: 10.1177/0272989X21996328
7. Bakitas M, Dionne-Odom JN, Jackson L, Frost J, Bishop MF, Li Z. "There were more decisions and more options than just yes or no": evaluating a decision aid for advanced cancer patients and their family caregivers. Palliat Support Care [Internet]. 2016 [acesso 26 nov 2025];15(1):44-56. DOI: 10.1017/S1478951516000596
8. Chong WQ, Mogro MJ, Arsad A, Tai BC, Lee SC. Use of decision aid to improve informed decision-making and communication with physicians on the use of oral complementary and alternative medicine among cancer patients on chemotherapy: randomized controlled trial. Support Care Cancer [Internet]. 2020 [acesso 22 nov 2025];29(7):3689-96. DOI: 10.1007/s00520-020-05872-5
9. Nieder C, Norum J, Dalhaug A, Aandahl G, Engljähringer K. Best supportive care in patients with brain metastases and adverse prognostic factors: development of improved decision aids. Support Care Cancer [Internet]. 2013 [acesso 26 nov 2025];21(10):2671-8. DOI: 10.1007/s00520-013-1840-5

10. Tate CE, Venechuk G, Pierce K, Khazanie P, Ingle MP, Morris MA *et al*. Development of a decision aid for patients and families considering hospice. J Palliat Med [Internet]. 2021 [acesso 16 nov 2025];24(4):505-13. DOI: 10.1089/jpm.2020.0250

11. Volandes AE, Levin TT, Slovin S, Carvajal RD, O'Reilly EM, Keohan ML *et al*. Augmenting advance care planning in poor prognosis cancer with a video decision aid: a preintervention-postintervention study. Cancer [Internet]. 2012 [acesso 22 nov 2025];118(17):4331-8. DOI: 10.1002/cncr.27423

12. Yun YH, Lee MK, Park S, Lee JL, Park J, Choi YS *et al*. Use of a decision aid to help caregivers discuss terminal disease status with a family member with cancer: randomized controlled trial. J Clin Oncol [Internet]. 2011 [acesso 26 nov 2025];29(36):4811-9. DOI: 10.1200/JCO.2011.35.3870

13. Yun YH, Kang E, Park S, Koh SJ, Oh HS, Keam B *et al*. Efficacy of a decision aid consisting of a video and booklet on advance care planning for advanced cancer patients: randomized controlled trial. J Pain Symptom Manage [Internet]. 2019 [acesso 22 nov 2025];58(6):940-48. DOI: 10.1016/j.jpainsymman.2019.07.032

14. Stacey D, Lewis KB, Smith M, Carley M, Volk R, Douglas EE *et al*. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev [Internet]. 2024 [acesso 26 nov 2025];1(1):CD001431. DOI: 10.1002/14651858.CD001431.pub6.

15. Han Z, Fang Y, Yang J, Jiang S, Ma G, Ma X. Effects of online advance care planning decision aid programmes on adults with cancer: a systematic review and meta-analysis. BMC Palliat Care [Internet]. 2026 [acesso 5 ago 2026]. DOI: 10.1186/s12904-026-02184-z

16. Edwards M, Holland-Hart D, Mann M, Seddon K, Buckle P, Longo M *et al*. Understanding how shared decision-making approaches and patient aids influence patients with advanced cancer when deciding on palliative treatments and care: a realist review. Health Expect [Internet]. 2023 [acesso 26 nov 2025];26(6):2109-26. DOI: 10.1111/hex.13822.

17. Tate CE, Mami G, McNulty M, Rinehart DJ, Yasui R, Rondinelli N *et al*. Evaluation of a novel hospice-specific patient decision aid. Am J Hosp Palliat Care [Internet]. 2024 [acesso 26 nov 2025];41(4):414-23. DOI: 10.1177/10499091231190776.

18. Villalobos M, Unsöld L, Deis N, Behnisch R, Siegle A, Thomas M. The Heidelberg Decision Aid for Patients With Lung Cancer (HELP): findings of a randomized controlled trial. Dtsch Arztebl Int [Internet]. 2024 [acesso 26 nov 2025];121(26):861-7. DOI: 10.3238/arztebl.m2024.0228.

19. Volandes AE, Chang Y, Lakin JR, Paasche-Orlow MK, Lindvall C, Zupanc SN *et al*. An intervention to increase advance care planning among older adults with advanced cancer: a randomized clinical trial. JAMA Netw Open [Internet]. 2025 [acesso 26 nov 2025];8(5):e259150. DOI: 10.1001/jamanetworkopen.2025.9150.

20. Punnett G, Eastwood C, Green L, Yorke J. A systematic review of the effectiveness of decision making interventions on increasing perceptions of shared decision making occurring in advanced cancer consultations. Patient Educ Couns [Internet]. 2024 [acesso 26 nov 2025];123:108235. DOI: 10.1016/j.pec.2024.108235.

21. Rabben J, Vivat B, Fossum M, Rohde GE. Shared decision-making in palliative cancer care: a systematic review and metasynthesis. Palliat Med [Internet]. 2024 [acesso 26 nov 2025];38(4):406-22. DOI: 10.1177/02692163241238384.

22. Foley G, McCauley R, McQuillan R, Ryan K. How do patients with advanced cancer and family caregivers accommodate one another in decision-making? Findings from a qualitative study in specialist palliative care. Am J Hosp Palliat Care [Internet]. 2025 [acesso 26 nov 2025];42(5):452-8. DOI: 10.1177/10499091241255117.

23. Rabben J, Rohde GE, Fossum M, Vivat B. Experiences and perceptions of people with advanced cancer and their family caregivers of shared decision-making in palliative cancer care. J Adv Nurs [Internet]. 2025 [acesso 26 nov 2025];81(8):4976-88. DOI: 10.1111/jan.16705.

24. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A *et al*. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ [Internet]. 2006 [acesso 22 nov 2025];333(7565):417. DOI: 10.1136/bmj.38926.629329.AE

25. Stacey D, Légaré F, Boland L, Lewis KB, Loiselle MC, Hoefel L *et al*. 20th anniversary Ottawa decision support framework: part 3 overview of systematic reviews and updated framework. Med Decis Making [Internet]. 2020 [acesso 26 nov 2025];40(3):379-98. DOI: 10.1177/0272989X20911870

26. Ullrich P, Voß H, Unsöld L, Thomas M, Villalobos M. Web-based educational tools and decision aids for patients with advanced cancer: a systematic review. Patient Educ Couns [Internet]. 2025 [acesso 26 nov 2025];134:108706. DOI: 10.1016/j.pec.2025.108706.

27. Brasil. Ministério da Saúde. Portaria GM/MS nº 3.681, de 7 de maio de 2024. Institui a Política Nacional de Cuidados Paliativos no âmbito do Sistema Único de Saúde. Diário Oficial da União [Internet]. Brasília, 22 maio 2024 [acesso 5 ago 2026]. Seção 1. Disponível: https://bit.ly/3SZO7yz

28. Conselho Federal de Medicina. Resolução CFM nº 1.995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. Diário Oficial da União [Internet]. Brasília, p. 269-70, 31 ago 2012 [acesso 5 ago 2026]. Seção 1. Disponível: https://bit.ly/4zGKNJl

Maria Jayne Lira de Araújo – Graduate – jayne.lira22@gmail.com
0009-0002-3529-2122

Millena Maria Maciel Pinto – Graduate – millenamaciel9@hotmail.com
0009-0006-4479-0464

Késsia Karina Alves de Oliveira – Graduate – kessiakarina1@gmail.com
0009-0002-0955-415X

Francimar Alves de Oliveira Neto – Graduate – francimar_90@hotmail.com
0000-0002-5593-3292

Karina Amorim – Graduate (specialist) – karinapaliativista@gmail.com
0000-0003-1805-259X

Claudio Emmanuel Gonçalves da Silva Filho – PhD student – cegsilvafilho@gmail.com
0000-0002-5519-5023

Correspondence
Maria Jayne Lira de Araújo – Av. Frei Galvão, 12, Gramame, CEP 58067-695. João Pessoa/PB, Brasil.

Contribution of the authors
Maria Jayne Lira de Araújo: data curation; research; writing – original draft; writing – review & editing. Millena Maria Maciel Pinto: data curation; research; writing – original draft; writing – review & editing. Késsia Karina Alves de Oliveira: data curation; research; writing – original draft; writing – review & editing. Francimar Alves de Oliveira Neto: data curation; research; writing – original draft; writing – review & editing. Karina Amorim: research; writing – review & editing. Claudio Emmanuel Gonçalves da Silva Filho: conceptualization; methodology; writing – review & editing.

Data availability: All data used or generated in this study are described and presented in full in the body of the article.

Editor-in-charge: Dilza Teresinha Ambrós Ribeiro

Received: 12.5.2025
Revised: 3.6.2026
Approved: 4.9.2026

Research