Shared decision-making in clinical cancer guidelines

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Abstract

Shared decision-making is a collaborative process that includes patient preferences in the care planning process. This study aimed to analyze how the shared decision-making is considered in the cancer guidelines of the Brazilian Unified Health System through a research of documents about patients' participation on the databases of the National Cancer Institute and National Commission for the Incorporation of Technologies. We analyzed 29 documents, and 10 of them presented an approach for shared decision-making or ideas related to the topic. These documents addressed the possibility of screening some types of cancer and established criteria for interrupting the treatment. The results show the great challenges that still exist to promote autonomy, and to respect individual values and partnership in clinical settings.

Keywords: Clinical protocols. Decision making. Neoplasms. Evidence-based medicine. Bioethics.

Resumo

Análise documental sobre decisão compartilhada nas diretrizes clínicas de câncer

A decisão compartilhada é processo colaborativo que inclui preferências individuais na elaboração do plano de cuidados. Este estudo examina como esse tipo de decisão é contemplado nas diretrizes terapêuticas para o câncer do Sistema Único de Saúde, buscando nos sites do Instituto Nacional de Câncer e da Comissão Nacional de Incorporação de Tecnologias documentos que citassem a participação do paciente. Foram analisados 29 documentos e, dentre eles, dez abordavam decisão compartilhada ou ideias relacionadas. Esses textos tratavam da possibilidade de rastrear alguns tipos de câncer e estabeleciam critérios para a interrupção do tratamento. Os resultados revelaram que ainda há grandes desafios para promover a autonomia, o respeito a valores individuais e a parceria em ambientes clínicos.

Palavras-chave: Protocolos clínicos. Tomada de decisões. Neoplasias. Medicina baseada em evidências. Bioética.

Resumen

Análisis documental sobre la toma de decisiones compartida en las directrices clínicas para el cáncer

La toma de decisiones compartida es un proceso colaborativo que incluye preferencias individuales en la elaboración del plan de cuidados. Este estudio buscó examinar la manera en que este tipo de decisión es contemplado en las directrices terapéuticas para el cáncer del Sistema Único de Salud de Brasil, buscando, en los sitios electrónicos del Instituto Nacional del Cáncer y de la Comisión Nacional de Incorporación de Tecnologías, documentos que mencionaran la participación del paciente. Se analizaron 29 documentos y, entre ellos, diez abordaban la toma de decisiones compartida o ideas relacionadas. Estos textos abordaban la posibilidad de rastrear algunos tipos de cáncer y establecían criterios para la interrupción del tratamiento. Los resultados revelaron que aún hay grandes desafíos para promover la autonomía, el respeto por los valores individuales y la coparticipación en entornos clínicos.

Palabras clave: Protocolos clínicos. Toma de decisiones. Neoplasias. Medicina basada en la evidencia. Bioética.

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In search of the best conduct for individuals under their care, health professionals use their skills, experience and scientific knowledge [1,2]. Regarding the decision-making process, the literature presents three models: the paternalistic, informed decision-making and shared decision-making.

In paternalism, based on the premise of not causing harm, the professional advises the individual and decides on the conduct he believes to be the most appropriate [3]. In this approach – the most usual –, the doctor indicates the intervention and the patient only accepts it, in a passive way. There is no joint resolution, and the patient's opinion is not properly considered [4]. In the second model, informed decision-making, the individual is informed about his situation but not necessarily included in the deliberative process [5].

The third approach, shared decision-making, aims to break the asymmetry of power to ensure that the individual preferences are respected. This model proposes a collaborative and consensual relationship in health care, with greater patient's participation [3]. Shared decision-making recommends the active participation of professionals and patients, and may also involve other actors such as family and the social network [6]. The model implies agreement between the parties, who together decide the best option, considering scientific factors and individual values [7].

The patient's participation is based on person-centered clinical methods idealized in the 1980s and strengthened in the 1990s, when shared decision-making was described for the first time [8]. The proposal seeks to confront the hegemonic biomedical model by valuing the individual's autonomy, recognizing his participation as essential for establishing the care plan. The objective is to ensure that values and preferences are respected, including broader principles such as autonomy, equal power in the clinical relationship, and control over decisions that affect well-being [4,5].

In Brazil, clinical protocols and therapeutic guidelines (CPTG) support decision-making based on the main available evidence, indicating the most suitable action according to effectiveness, safety and cost [9]. Law 12,401/2011 [10] provides for the incorporation of technology in the Unified Health System (SUS) and determines the use of CPTG to standardize conduct.

Evidence-based medicine uses probabilistic methods to point out the most appropriate intervention in each situation, weighing pros and cons. However, individual preferences vary according to previous experiences, values, fears and beliefs [11]. To combine scientific knowledge with the particularities of each person, shared decision-making seeks to include the patient in clinical deliberation, to achieve the most adequate option for their context of life [12].

In the case of diseases such as cancer, which directly affect the individual's lifestyle, this approach is especially relevant, for different options influence physical and psychological well-being differently. In 2019, Brazil had more than 600,000 new cases of cancer, and the trend is for this number to grow, given the population aging caused by the increase in life expectancy [13].

Recognizing the magnitude of this health problem, this study analyzes how documents that guide medical practice consider the need to incorporate patient preferences in decision making. More specifically, we analyze how the shared decision-making is addressed in cancer-related CPTG within SUS.

Method

We analyzed the documents [14] about cancer-related CPTG on the websites of the National Commission for the Incorporation of Technologies in SUS (Conitec) and the Brazilian National Cancer Institute (Inca). The Conitec website was selected because this institution is responsible for receiving and evaluating guidelines and protocols to be incorporated into SUS [15]. Inca, on the other hand, was selected because it is the Ministry of Health (MS) body specializing in the disease, and also responsible for assisting in the development and conduct of protocols and guidelines on the topic [16].

We included all documents that addressed the conduct of professionals in any stage of cancer-related care. The last search was carried out in April 2019, with no time limit as a filter, given the intention of gathering the largest possible data set – in addition, the main database used (Conitec) was created recently, in 2011, so there would be no risk of excess of texts for our analysis. We selected all cancer-related protocols and guidelines available in the Conitec, while on the Inca website it was necessary to evaluate the purpose of each document.

To collect the data, we used an extraction form including year, source, characteristics, and whether the text considers shared decision-making or not. For the analysis, the following attributes were evaluated: presence of guidelines/indications on shared decision-making; attention to the patient's preferences, values, wishes or opinions at the time of the clinical decision; and respect for the individual's decision to maintain or stop any health action [17,18].

The selected documents were compared with the model described by Elwyn and collaborators [19] in 2012 and updated in 2017 [20], the most used in the literature today. The authors propose three principles for the actions of professionals, here referred to as "choice talk," "option talk" and "decision talk." The first principle comprises joint work between professional and patient, clarifying care options and expected results. During option talk, the alternatives are discussed, highlighting the main risks and benefits of one and comparing possible outcomes according to the corresponding risks. Finally, in the third step, decision talk, the preferences are clarified according to the options presented, indicating the most appropriate decision.

In this study, the documents were read in full and analyzed by a first researcher following these steps [14]: context assessment, data source, nature of the text, interests and key concepts related to the shared decision-making. Doubts regarding the presence or absence of some attributes were resolved by consensus, after the analysis of a second researcher.

Documents considered relevant after this were read by two evaluators and further categorized according to the conceptual model adopted. At this stage, the documents were discussed by the researchers until consensus was reached. The subjectivity of the researchers' views stands out as a limitation of this study. However, with the standardization and description of the criteria adopted, we tried to minimize this bias.

Results

We found 30 documents on the databases. One of them was excluded for presenting only the dosage of a medicine, with 29 remaining within the inclusion criteria – 24 from Conitec and five from Inca. As for the topic addressed, 24 were about diagnosis or treatment and five about early detection.

The characteristics of each of the 29 documents are detailed in Chart 1. The publication date ranged from 2012 to 2019, with the highest volume in 2014. Twenty-three texts have recommendations for adults, and six for children and adolescents (this category considers individuals under 19 years of age). Concerning the type of tumor, nine are related to hematological cancer and the rest to specific organs.

Chart 1. Characteristics, year and approach of shared decision-making in clinical protocols and therapeutic guidelines of the Ministry of Health (Brazil, 2019)

Identification	Guideline type	Guideline focus	Shared decision-making
Ordinance MS 602/2012. Approves the diagnostic and therapeutic guidelines for liver cancer in adults [21].	Diagnosis and treatment	Adult	No
Ordinance MS 599/2012. Approves the diagnostic and therapeutic guidelines for brain tumor in adults [22].	Diagnosis and treatment	Adult	Yes
Ordinance MS 114/2012. Approves diagnostic and therapeutic guidelines: treatment of chronic myeloid leukemia in children and adolescents with imatinib mesylate [23].	Diagnosis and treatment	Children and Adolescent	No
Ordinance MS 115/2012. Approves diagnostic and therapeutic guidelines: treatment of acute Philadelphia chromosome-positive lymphoblastic leukemia in children and adolescents with imatinib mesylate [24].	Diagnosis and treatment	Children and Adolescent	No
Ordinance MS 312/2013. Approves the treatment protocol for acute Philadelphia-positive lymphoblastic leukemia with imatinib mesylate in adults [25].	Treatment	Adult	No
Ordinance MS 357/2013. Approves the diagnostic and therapeutic guidelines for cutaneous malignant melanoma [26].	Diagnosis and treatment	Adult	No

continues...

Chart 1. Continuation

Identification	Guideline type	Guideline focus	Shared decision-making
Ordinance MS 1,219/2013. Approves the clinical protocol and therapeutic guidelines for adult chronic myeloid leukemia[27].	Diagnosis and treatment	Adult	No
Ordinance MS 1,440/2014. Approves the diagnostic and therapeutic guidelines for renal cell carcinoma[28].	Diagnosis and treatment	Adult	No
Ordinance MS 1,439/2014. Approves the diagnostic and therapeutic guidelines for esophageal carcinoma[29].	Diagnosis and treatment	Adult	Yes
Ordinance MS 958/2014. Approves the diagnostic and therapeutic guidelines for colon and rectal cancer[30].	Diagnosis and treatment	Adult	No
Ordinance MS 957/2014. Approves the diagnostic and therapeutic guidelines for lung cancer[31].	Diagnosis and treatment	Adult	Yes
Ordinance MS 705/2014. Approves the diagnostic and therapeutic guidelines for adult acute myeloid leukemia[32].	Diagnosis and treatment	Adult	No
Ordinance MS 840/2014. Approves the diagnostic and therapeutic guidelines for acute myeloid leukemia in children and adolescents[33].	Diagnosis and treatment	Children and Adolescent	No
Early diagnosis of cancer in children and adolescents; 2014[34].	Early detection	Children and Adolescent	No
Ordinance MS 956/2014. Approves the clinical protocol and therapeutic guidelines for diffuse large B cell lymphoma[35].	Diagnosis and treatment	Adult	No
Ordinance MS 7/2014. Approves the clinical protocol and therapeutic guidelines for differentiated thyroid carcinoma[36].	Diagnosis and treatment	Adult	No
Ordinance MS 1,051/2014. Approves the diagnostic and therapeutic guidelines for follicular lymphoma[37].	Diagnosis and treatment	Adult	Yes
Ordinance MS 494/2014. Approves the clinical protocol and therapeutic guidelines for gastrointestinal stromal tumor[38].	Diagnosis and treatment	Adult	No
Ordinance MS 516/2015. Approves the diagnostic and therapeutic guidelines for head and neck cancer[39].	Diagnosis and treatment	Adult	Yes
Ordinance MS 708/2015. Approves the diagnostic and therapeutic guidelines for multiple myeloma[40].	Diagnosis and treatment	Adult	No
Guidelines for the early detection of breast cancer in Brazil; 2015[41].	Early detection	Adult	Yes
Joint technical note MS/Inca 1/2015. Position of the Ministry of Health on the integrality of men's health in the context of Blue November[42].	Early detection	Adult	Yes
Brazilian guidelines for cervical cancer screening.	Early detection	Adult	Yes
Ordinance MS 498/2016. Approves the diagnostic and therapeutic guidelines for prostate adenocarcinoma[44].	Diagnosis and treatment	Adult	Yes
Protocol for early diagnosis of pediatric cancer; 2017[45].	Early detection and diagnosis	Children and Adolescent	No
Joint ordinance of the Secretariat of Health Care (SAS) and Secretariat of Science, Technology and Strategic Inputs (SCTIE) 6/2018. Approves the clinical protocol and therapeutic guidelines for infantile hemangioma[46].	Diagnosis and treatment	Adult	No
Joint Ordinance SAS/SCTIE 3/2018. Approves the diagnostic and therapeutic guidelines for stomach adenocarcinoma[47].	Diagnosis and treatment	Adult	Yes
Joint Ordinance SAS/SCTIE 19/2018. Approves the diagnostic and therapeutic guidelines for breast carcinoma[48].	Diagnosis and treatment	Adult	No
Joint Ordinance SAS/SCTIE 1/2019. Approves the diagnostic and therapeutic guidelines for ovarian epithelial malignancy[49].	Diagnosis and treatment	Adult	No

Most protocols and guidelines are organized into topics that are repeated between documents. Among the topics, the one on clarification and responsibility has a standard text, emphasizing the importance of informing potential risks, benefits and adverse effects of the interventions. However, the text does not highlight the need to consider the patient's opinion when making a decision.

Six documents [23-25,27,38,46] also contained the topic "informed consent," which requires the signature of the patient or legal guardian declaring knowledge of the consequences of chemotherapy. This term is part of the bureaucratic process for dispensing the medication and, by itself, does not encourage the individual's participation in the choice of treatment.

Only ten documents [22,29,31,37,39,41-44,47] addressed shared decision-making, and all of them bring recommendations for adults (their characteristics and comparison with the adopted model are described in Chart 2). Four referred to early detection of cancer in adults (breast, prostate and cervix) and emphasize the need to discuss the risks of routine exams (screening) before making a decision [41-44]. The others involved the diagnosis and treatment of specific tumors – two on the digestive system (stomach [47] and esophagus [29]), for example, and brain tumor [22], lung cancer [31], follicular lymphoma [37] and head and neck cancer [39].

Another point, highlighted by three of these documents, was the limitation of scientific evidence concerning the individual scope, recommending the adequacy of interventions to the values and particularities of each person [41,43,47]. Individual preferences were valued in guidelines that presented treatment options for early or asymptomatic cancers [37,44] and addressed treatment interruption, valuing the individual's voluntary manifestation [22,31]. However, only one text, on early detection of breast cancer, presented the concept of shared decision-making [41].

In comparison with the theoretical model adopted [20], we observed that only two guidelines were in accordance with the three principles. Ideas related to the third principle (decision talk) were the most frequent, while the first (choice talk) was the least addressed.

Chart 2. Clinical protocols and therapeutic guidelines that addressed shared decision-making and comparison with the theoretical model

Identification	Text characteristics regarding shared decision-making	Compliance with the conceptual model of shared decision-making
Ordinance MS 599/2012. Approves the diagnostic and therapeutic guidelines for brain tumor in adults [22].	It recommends considering the patient's preferences when choosing treatment. Points to voluntary manifestation, after clarifying the risks and benefits, as a criterion for interrupting the treatment.	Partial compliance with the first and second principles (choice and option talk) by encouraging deliberation between the parties.
Ordinance MS 1,439/2014. Approves the diagnostic and therapeutic guidelines for esophageal carcinoma [29].	To define the most appropriate surgical technique, it is recommended to consider the patient's preferences, after he is duly informed about the expected results and consequences of the procedure.	Compliance with the second and third principles (option and decision talks).
Ordinance MS 957/2014. Approves the diagnostic and therapeutic guidelines for lung cancer [31].	It highlights the importance of considering the patient's preferences when choosing the treatment and recommends joint decision-making, with the patient's active participation. It deals with the interruption of treatment as the individual's option, after he is informed about the risks and benefits of the decision.	Compliance with the three principles.
Ordinance MS 1,051/2014. Approves the diagnostic and therapeutic guidelines for follicular lymphoma [37].	It presents options for treatment, one of which is the watchful waiting, which applies to asymptomatic individuals. For such treatment, it mentions the need to share the decision between physician, patient and family.	Compliance with the third principle (decision talk).

continues...

Chart 2. Continuation

Identification	Text characteristics regarding shared decision-making	Compliance with the conceptual model of shared decision-making
Ordinance MS 516/2015. Approves the diagnostic and therapeutic guidelines for head and neck cancer[39]**.**	It considers the patient's preferences when choosing laryngeal cancer treatment. For cancers with more than one therapeutic option, it is recommended to consider, in addition to clinical conditions, individual preferences. It is limited to one type of cancer of the anatomical complex addressed by the document.	Partial compliance with the third principle, without highlighting the consideration of the risks and benefits of the interventions.
Guidelines for the early detection of breast cancer in Brazil; 2015[41].	For moderate or low level evidence, it recommends the shared decision-making, presenting and valuing the concept. Even with the favorable recommendation for screening breast cancer in certain age groups, it includes the need to consider individual preferences and values.	It presents the concept, but does not describe any model. Compliance with the three principles (choice, option and decision talks).
Joint technical note MS/Inca 1/2015. Position of the Ministry of Health on the integrality of men's health in the context of Blue November[42].	Contraindicates screening for prostate cancer, considering that men who require this test must know the risks and benefits. The decision must be shared with the health professional.	Compliance with the second and third principles (option and decision talks).
Brazilian guidelines for the diagnosis of cervical cancer; 2016[43].	It presents the limits of generic recommendations, proposing that the patient's individual characteristics and values, as well as the professional's experience, should be considered. Weights the recommendations according to the level of certainty of evidence.	Compliance with the third principle (decision talk).
Ordinance MS 498/2016. Approves the diagnostic and therapeutic guidelines for prostate adenocarcinoma[44].	It presents the limits of diagnosis and highlights the importance of informing the risks and benefits for decision making regarding this procedure and considering the patient's opinion, discussing therapeutic options for low-risk tumors.	Compliance with the second and third principles (option and decision talks).
Joint Ordinance SAS/SCTIE 3/2018. Approves the diagnostic and therapeutic guidelines for stomach adenocarcinoma[47].	For the treatment, professionals should consider, among other aspects, the patient's preferences. The text also points out the limitations of scientific evidence to establish a standard method.	Compliance with the third principle (decision conversation).

Discussion

The results show that protocols and clinical guidelines for cancer diagnosis and treatment in Brazil recognize the importance of communicating the risks of interventions; however, they do not go much deeper into the need to incorporate individual values in decision making. When it appears, this concern is just mentioned in standardized texts that focus more on specific procedural risks and highlight informed consent terms.

These terms are bureaucratic tools that provide legal support to the professional, but do not necessarily encourage or facilitate interaction with the patient. The literature considers these documents to be essential for informed health decision-making[8], but such a model is based only on the transmission of information, which can cause anxiety in patients by placing all responsibility on them[5].

Based on the ethical premise of the participation of individuals, recent studies show the shared approach improves interpersonal relationships, decreases the chances of litigation for medical negligence and reduces financial costs for patients and the health system. With the discussion of pros and cons, the decision tends to be moderate, avoiding tests and treatments with more serious side effects and little benefit for the patient[50-52].

This point is especially relevant when it comes to indolent cancers, whose diagnosis or treatment can bring emotional and physical damage without providing real benefit. This concern is expressed in guidelines, as the application of tests in asymptomatic individuals can cause damage that directly affects the quality of life[53,54]. The main harms are false-positive and false-negative results, which lead to more unnecessary tests and therapies, and overdiagnosis and overtreatment, related to the identification and intervention of cancers that would not evolve to the point of threatening the person's life [53].

Some documents recommend weighing the decision with the patient before starting treatment for asymptomatic and low-risk cancers [37,44]. This guidance also appears in the criteria for discontinuing ongoing cancer therapy in adults with high mortality rates, such as lung and brain cancer [13,31].

Few documents, however, refer to the limitation of scientific evidence to standardize recommendations. Scientific knowledge, resulting from well-designed studies, is certainly one of the factors to consider in the complex decision-making process, but individual issues also influence the clinic routine. Depending on the context in which they are inserted, even when faced with the same information, people can make completely different choices [4].

There is a mismatch between the guidelines and the conceptual model of shared decision-making regarding the valuation of individual preferences. Elwyn and collaborators [20] present essential points to include the patient in the decision making process, with a smooth transition between the three steps. However, the researched documents emphasize the discussion of the risks and benefits of interventions and the decision itself, with little focus on choice talk and joint work. Only two texts followed the three principles, and the first of these (choice talk) was the least present.

Although it is the least recognized by the documents, the first step has the valuable intention of reducing the knowledge gap in the clinical relationship, proposing a wide discussion to identify the patient's values regarding his own health [20]. The research result, therefore, demonstrates the structural neglect of the individual's expectations and values in defining clinical outcomes.

Ideas related to the decision talk (third step) were the most present in the documents, which recognize the need to define interventions and treatments when there is more than one viable option. However, this step, in isolation, does not meet the complex task of incorporating the patient in the decision-making process, because when the partnership and understanding of what is important for the patient is neglected, the result is a care that does not agree with his life context [19].

The clinical relationship must be based on trust, synchrony and partnership between patients and professionals, who together seek to understand the problem and think about solutions. In this process, it is essential that the professional knows the patient, considering the multiple aspects that affect his perception of health, such as life history and influence of the social and family circle [55].

The expression "shared decision-making" – of relatively recent use in Brazil – was mentioned by only one document, which, although defining it, did not provide guidelines for putting it into practice [41]. Studies state that, in this type of decision, professionals should use their relational skills and be understand the patient's will and preferences [56,57], mentally changing his role from decision maker to partner [17]. None of the analyzed guidelines, however, shows how to include the individual in the decision making process.

In Brazil, autonomy is emphasized in national policies such as humanization policies [58], health promotion, primary care and even cancer prevention and control, in a more discreet way [59]. This approach, however, was absent from most of the documents analyzed here, which standardize the conduct for the care of cancer patients in SUS.

Authors who point out that shared decision-making is still little explored in Brazil identify as difficulties the resistance of health professionals and the little incentive to incorporate this practice [52,60]. On the other hand, studies that present actions that have already been consolidated in other countries attribute success to laws and policies that encourage patient participation [61]. Thus, in addition to building individual autonomy, favorable social conditions are needed, such as access to information, democratic laws, public policies, and a culture of active participation [61,62].

Final considerations

The study sought to find out how shared decision-making is treated in the protocols and guidelines on cancer in the country. However, we found that most of these documents reflect paternalistic practices, in which the physician assumes the role of sole decision maker, without considering the patient's beliefs and values when planning care. The few mentions to shared decision-making were restricted to the diagnosis – due to its risks –, to the treatment of indolent cancers and to the interruption of ongoing treatment.

Thus, we recommend that future research expand the debate on the individual's participation in the treatment, since this engagement is an ethical premise that, if fulfilled, can improve adherence and increase satisfaction with health services. In addition, we must break with the paternalistic model of care, which disregards individual expectations and preferences, neglecting the partnership between physician and patient. For such a cultural change, documents that guide the conduct of professionals must draw attention to the need for active participation of the individual in all stages of care.

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Participation of the authors

Renata Oliveira Maciel dos Santos conceived the project, researched and analyzed protocols and guidelines, wrote the article and carried out the final revision. Mirhelen Mendes de Abreu revised the content and wrote the sections "Discussion" and "Results." Elyne Montenegro Engstrom participated in the project conception, analyzed the protocols and guidelines and revised the article.

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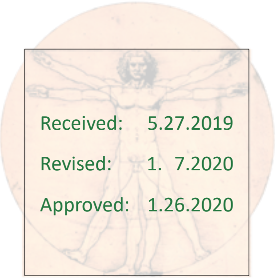

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