

# State Legislation on Palliative Care: Convergent and Divergent Points

## Legislações estaduais sobre cuidados paliativos: pontos convergentes e divergentes

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### ABSTRACT

**Background:** Palliative care (PC) is justified and supported by the Brazilian Federal Constitution of 1988. However, Brazil remains on the list of countries that do not have specific state or federal laws and policies regulating PC in a nationwide context.

**Objective:** To analyzing the legislation on palliative care already available in Brazilian states with a view to comparing them and determining their convergent and divergent points.

**Methods:** A documentary research was carried out on websites and official journals of Brazilian states in search of state laws on PC. A thematic content analysis was performed following the stages of 1) pre-analysis, 2) material exploration and 3) treatment of results, inference and interpretation. Our findings were presented in a table and discussed in terms of convergent and divergent points in state laws on PC.

**Results:** The documentary research identified only seven state laws on PC enacted between the years 2017 to 2021 in the following states: Goiás (GO), Rio Grande do Sul (RS), Rio de Janeiro (RJ), Maranhão (MA), Paraná (PR), São Paulo (SP) and Minas Gerais (MG), respectively.

**Conclusion:** The goal of ensuring early access to PC by patients and their families was the main point of convergence. Guidelines for using the service, profile of professionals, and forms of financing were among the main divergent points.

**Keywords:** Palliative Care; State Legislation; Health Policy.

### RESUMO

**Antecedentes:** Os cuidados paliativos (CP) são justificados e amparados pela Constituição Federal Brasileira de 1988. No entanto, o Brasil permanece na lista de países que não possuem leis e políticas estaduais ou federais específicas que regulem os CP em âmbito nacional.

**Objetivo:** O presente estudo teve o objetivo de analisar as legislações estaduais sobre cuidados paliativos no Brasil comparando-as quanto aos seus pontos convergentes e divergentes.

**Métodos:** Foi realizada uma pesquisa documental em sites e diários oficiais dos estados em busca de leis estaduais sobre cuidados paliativos no Brasil. Os documentos passaram por análise de conteúdo, na modalidade temática, dividida em três etapas: 1) pré-análise, 2) exploração do material e 3) tratamento dos resultados a partir das inferências e interpretação. Os resultados foram apresentados em um quadro e discutidos quanto aos pontos convergentes e divergentes nas leis estaduais sobre cuidados paliativos.

**Resultados:** A pesquisa documental identificou apenas sete leis estaduais sobre cuidados paliativos no país oriundas dos estados de Goiás (GO), Rio Grande do Sul (RS), Rio de Janeiro (RJ), Maranhão (MA), Paraná (PR), São Paulo (SP) e Minas Gerais (MG) e publicadas entre os anos de 2017 a 2021.

**Conclusão:** O objetivo de garantir precocemente o acesso a cuidados paliativos a pacientes e suas famílias foi o principal ponto convergente. As diretrizes para a utilização do serviço, o perfil dos profissionais e as formas de financiamento estão entre os principais pontos divergentes.

**Palavras-Chave:** Cuidados Paliativos; Legislação como Assunto; Política de Saúde.

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**Authors' contributions:** TBM, PPMB, TSPC, AAO: conception of the work; TBM, PPMB, TSPC, AAO: acquisition and analysis of data for the work; TBM, PPMB, TSPC, AAO, RSS; drafting of the manuscript; ABAV, RNSOB, RSS: critical revision of the manuscript. All authors have approved the final version of the manuscript and agree to be accountable for all aspects of the work.

**Conflict of interest:** There is no conflicts of interest to declare.

**Received** on July 19, 2022; **Accepted** on March 20, 2023; **Published** on June 28, 2023

**Editor-in-chief:** João Batista Santos Garcia

## BACKGROUND

Palliative Care (PC) is a care approach provided in a holistic and active way to people of all ages who experience intense suffering from a serious illness, especially those who are at the end of life, with the objective of improving the quality of life of patients, family members and caregivers<sup>1</sup>.

According to the World Health Organization (WHO) and the Worldwide Hospice Palliative Care Alliance (WHPCA), approximately 56.8 million people in the world currently need palliative care<sup>2</sup>. However, there are few countries around the world that have health and education policies that include palliative care<sup>3</sup>. In the United States, the prevalence of hospital PC services has increased by 26% in the last decade, and national standards have been evolving to accompany this process<sup>4-7</sup>.

In Brazil, some laws deal with the subject although not specifically. For example, the federal law that has created the National Policy for the Prevention and Control of Cancer in the Health Care Network for People with Chronic Diseases within the Unified Health System (SUS) mentions PC as part of comprehensive care and recommends the provision of palliative care on an outpatient and inpatient basis<sup>8</sup>. Although the Resolution No. 41, of October 31, 2018, establishes a set of guidelines for PC management in light of integrated continuous care, within the scope of our Unified Health System (SUS), Brazil remains on the list of countries that do not have specific PC federal laws and policies, that is, specific legislation in a nationwide context<sup>9</sup>.

PC is justified and supported by our Federal Constitution of 1988 insofar as it addresses citizens' fundamental rights and affirms the guarantee of human dignity and that no one should be subjected to torture or inhuman or degrading treatment<sup>10</sup>. In addition, some Brazilian states have state laws that deal with the provision of PC in the context of public health.

## OBJECTIVE

To analyzing the legislation on palliative care already available in Brazilian states with a view to comparing them and determining their convergent and divergent points.

## METHODS

A documentary research was carried out. This is a type of research that has certain similarities with bibliographical research, and is developed from already existing material<sup>11</sup>, whose search for information occurs in documents that have not received scientific treatment<sup>12</sup>. It is a relevant research modality in the context of qualitative research, and

the procedures comprise the collection, understanding and analysis of documents<sup>13</sup>.

In the present study, the search for state laws related to PC in all Brazilian states was carried out in June 2022, on state's websites and official gazettes by two authors independently. The official documents identified were downloaded from the websites and organized. In the following step, the qualitative data from the documents were subjected to content analysis according to the technique proposed by Bardin<sup>14</sup>, divided into three stages: pre-analysis, material exploration and treatment of results, inference and interpretation. A floating reading of the laws was carried out aiming at building the study corpus, which was explored, organized and completed by the other authors.

Subsequently, documents found were organized and grouped into thematic units, and the results were submitted to inferences and interpretations according to the purpose of the study. Following identification, apprehension and analysis of the documents, results were presented in a table and discussed with respect to their convergent and divergent points.

## RESULTS

Our documentary research identified only seven state laws on PC in the country, all published between 2017 and 2021 in the states of Goiás (GO), Rio Grande do Sul (RS), Rio de Janeiro (RJ), Maranhão (MA), Paraná (PR), São Paulo (SP) and Minas Gerais (MG), respectively. The state laws are listed below as well as the main contents addressed in each of them (Table 1).

## DISCUSSION

The qualitative content analysis of state laws on PC was carried out considering the following aspects: concept of PC, scope, objectives, and guidelines of the laws, mechanisms for implementing PC, profile of law beneficiaries, integration of PC into the Network of Health Care (RAS), planning of PC actions in the territory, financing of PC actions, training of health teams to work in PC, respect for the will of patients and their legal representatives and, finally, best practices for pain relief.

As for the scope of the state laws<sup>15-21</sup>, our study pointed out that state PC policies<sup>15-16,20</sup> have been established in the states of Goiás, Rio Grande do Sul and São Paulo based on these laws. In Rio de Janeiro the state legislation establishes the state PC program<sup>17</sup>. In the states of Maranhão, Paraná and Minas Gerais, respectively, the state legislation establishes general guidelines for implementing PC<sup>18</sup>, precepts and foundations of PC<sup>19</sup>, and the principles, guidelines and objectives of palliative care actions to be developed at state level<sup>21</sup>.

**Table 1.** State laws on PC published in Brazil between 2017 and 2021.

State	Law	Year	Introductory text	Content analyzed
Goiás (GO)	19.723	2017	Sets out the state palliative care policy and amends Law No. 16,140, of October 2, 2007.	Concept of PC is addressed; Purpose, objectives and guidelines; Profile of beneficiaries; Integration of PC into RAS; Territorial planning of actions; Financing; Training of teams; Best practices for pain relief.
Rio Grande do Sul (RS)	15.277	2019	Sets out the state palliative care policy, and makes other provisions.	Scope of the law, objectives and guidelines; Implementation mechanisms; Profile of beneficiaries; Integration of PC into RAS; Territorial planning of actions; Financing; Training of teams; Respect the will of patients.
Rio de Janeiro (RJ)	8.425	2019	Sets out the state palliative care program in the scope of public health in the state of Rio de Janeiro.	Concept of PC is addressed; Scope of the law, objectives and guidelines; Profile of beneficiaries; Integration of PC into RAS; Territorial planning of actions; Financing; Training of teams; Respect the will of patients.
Maranhão (MA)	11.123	2019	Sets out state guidelines for implementing palliative care for patients with life-threatening illnesses, and makes other provisions.	Concept of PC is addressed; Scope of the law, objectives and guidelines; Profile of beneficiaries; Integration of PC into RAS; Territorial planning of actions; Training of teams; Respect the will of patients; Best practices for pain relief.
Paraná (PR)	20.091	2019	Sets out precepts and fundamentals of palliative care in the state of Paraná.	Concept of PC is addressed; Scope of the law, objectives and guidelines; Implementation mechanisms; Profile of beneficiaries; Integration of PC into RAS; Territorial planning of actions; Training of teams; Respect the will of patients; Best practices for pain relief.
São Paulo (SP)	17.292	2020	Sets out the state palliative care policy, and makes other provisions.	Scope of the law, objectives and guidelines; Implementation mechanisms; Profile of beneficiaries; Integration of PC into RAS; Training of teams; Respect the will of patients;
Minas Gerais (MG)	23.938	2021	Sets out precepts, guidelines, and objectives for PC state's actions in the scope of public health.	Concept of PC is addressed; Scope of the law, objectives and guidelines; Implementation mechanisms; Profile of beneficiaries; Integration of PC into RAS; Training of teams; Respect the will of patients;

The concept of PC is explicit in five laws<sup>15,17-19,21</sup> that use the definition of the World Health Organization (WHO)<sup>22</sup>, and bring the notions of quality of life of patients and family members, pain treatment and other physical, psychosocial or spiritual issues as well. However, state laws in Rio Grande do Sul<sup>16</sup> and São Paulo<sup>20</sup> differ by not clearly addressing the concept of CP adopted.

Objectives are clearly defined in all seven state laws. The main points of convergence among them concerns guarantee of an early approach on PC, a search for improving the quality of life of patients and their families, detection,

prevention and relief of suffering and pain or other physical or psychological problems, and social factors involved<sup>15-21</sup>. In addition, it is noteworthy that state laws in Maranhão and Paraná address the organization of PC with emphasis on promoting the inclusion of disciplinary content on palliative care in technical, undergraduate and graduate training courses in the health area<sup>18-19</sup>.

Mechanisms for implementing PC are addressed in four state laws. The guidelines identified in the legislation of Rio Grande do Sul, Maranhão, São Paulo and Minas Gerais deal with the implementation of public policies related to

PC, intersectoral and multidisciplinary care, in addition to training professionals and promoting permanent education on the subject<sup>16,18, 20-21</sup>.

Those guidelines converge in terms of offering support so that each individual with a terminal illness can have the most active and autonomous life as possible<sup>15-20</sup>. Minas Gerais is the only divergent state, insofar as it does not address this point. Respect for patients cultural values, beliefs and religion<sup>15,17,21</sup> is another theme found in the guidelines of three state laws. Affirmation of death as a natural process of life appears as a guideline on five of the seven laws<sup>15,17-20</sup>. Approach to patient´s families in the context of PC is mentioned in all seven laws<sup>15-21</sup>, and, in this context, attention, counseling and support to the family during the process of mourning are explained in five laws<sup>15-16,18,20-21</sup>.

There is a generalization of the profile of beneficiaries in the laws analyzed with regard to people who are experiencing life threatening diseases, or even situations identified as potentially fatal<sup>15-21</sup>. However, the only law that characterizes more precisely the profile of patients benefiting from PC is that of the state of Goiás, which points out some priority conditions and diseases for access to PC, such as cancer, dementia syndromes, progressive neurological diseases, Down Syndrome, Acquired Immunodeficiency (AIDS), congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), among others<sup>15</sup>.

Children and adolescents are only explicitly mentioned as beneficiaries of PC law in the states of Goiás<sup>15</sup> and Minas Gerais<sup>21</sup>. In the case of children, state legislation in Goiás includes in the profile of patients priority situations for access to PC, such as severe congenital malformations, cystic fibrosis, cerebral palsy, muscular dystrophies, cancer, AIDS, in addition to incurable and progressive diseases<sup>15</sup>. In the state of Minas Gerais, the guidelines to be observed in relation to children and adolescents in the process of terminal illness are indicated<sup>21</sup>.

The provision of PC integrated into SUS Health Care Network (RAS) as early as possible was a central point in the legislation, and its implementation is ensured throughout RAS<sup>15-21</sup>. Primary care appears as the ordering body of the Network and care coordinator<sup>18</sup>, and home care<sup>15,18-19,21</sup>, long-stay institutions and other healthcare facilities<sup>15,19</sup> are emphasized. Unlike other states, outpatient care, urgent and emergency services and hospital care, including university hospitals, high-complexity hospitals and oncology hospitals, are addressed in the state legislation in Goiás<sup>15</sup>, and integration with specialized services appears in the state legislation in Minas Gerais<sup>21</sup>.

In this regard, when observing the organization of RAS to support patients in need of PC<sup>23</sup> point out that the state of Paraná has been a place for several pioneering initiatives related to the application of this category of care in the public health system. However, there is a limitation of such an approach among the different services or levels of care, due to the fact that this PC practice has been neither institutionalized in the health system nor widespread in RAS yet.

With respect to territorial planning of PC actions, the legislation of the state of Goiás is the only one that provides for specific levels of differentiation, observing a growing degree of complexity as follows: palliative action, level I PC, level II PC and level III PC<sup>15</sup>. The states of Rio Grande do Sul, Rio de Janeiro and Maranhão indicate the possibility of partnerships and agreements for the development of actions and the creation of a PC network<sup>16-18</sup>. In contrast, Paraná legislation is the only one that explicitly includes private services in the context of PC<sup>19</sup>.

With regard to financing of PC actions, state laws in Goiás, Rio Grande do Sul and Rio de Janeiro explicitly determine that the expenses resulting from the execution of the law will have their own budget allocation<sup>15-17</sup>. Penalties related to non-compliance with the law appear only in the state legislation of Goiás, which provides for penalties such as warning, fine and disqualification of the service<sup>15</sup>.

With regard to PC team training, the legislation presumes a multidisciplinary or multiprofessional nature<sup>15-21</sup>. However, team modalities are described only in state laws in Goiás, Maranhão and Paraná<sup>15,18-19</sup>. Thus, despite recognizing the importance of including a multidisciplinary team, not all state laws indicate the obligation to have a multidisciplinary team composed of professionals from different areas, which is a divergence among them. In addition to what they refer to as a "minimum team", usually made up of doctors and nurses, the legislation in Rio de Janeiro and Minas Gerais predicts the presence and cooperation of a psychologist and a social worker, and the legislation of Paraná predicts a cooperation among nutritionist, occupational therapist, physiotherapist, pharmacist, dentist, speech therapist and spiritual assistant<sup>17,19,21</sup>.

According to WHO´s recommendations, assistance in PC must be multidisciplinary in order to permeate the entire process, ranging from diagnostic investigation, illness, finitude and even the period of mourning<sup>22</sup>. In this sense, the availability of information about the composition and performance of the team is important so that cohesive teams can be assembled and involved within the PC process. Da Cruz et al.<sup>24</sup> agree that it is necessary to have a multidimensional understanding of illness, so that comprehensive

and multiple professional actions can be provided, in which each profession, given their expertise, will present distinct, concatenated and centered attributions on the individual.

Mental health of professionals who deal with PC patients is dealt with only by the state laws in Goiás. It is worth noting that this legislation encourages the participation of volunteers and spiritual assistants at all levels of care<sup>15</sup>. Only state laws in Maranhão and Paraná deal with professionals specializing in PC, playing the role of reference and potential matrix supporters of other services across the health network, which can be carried out *in loco* or using remote communication technologies<sup>18-19</sup>.

Training and continuing education are essential for a satisfactory performance. In this context, training professionals and promoting permanent education on the subject are emphasized only in state laws found in Rio Grande do Sul<sup>16</sup>, Maranhão<sup>18</sup> and Minas Gerais<sup>21</sup>. Accordingly, every health professional can adopt palliative actions, including general practitioners and primary care professionals, grounded on basic knowledge to offer support to patients with specific needs and according to their clinical complexity<sup>23</sup>.

Respect for the will of patients and their legal representatives has been referred to in the state legislation in Rio Grande do Sul<sup>16</sup>, Rio de Janeiro<sup>17</sup>, Maranhão<sup>18</sup>, Paraná<sup>19</sup>, São Paulo<sup>20</sup> and Minas Gerais<sup>21</sup>, but only the state of Maranhão describes as a guideline the free manifestation of preference for medical treatment through an advance directive<sup>18</sup>. Advance directives constitute a means of expression of will for medical treatment. The two most common types of advance directives are the living will and the durable power of attorney for medical care. Both are legal instruments concerning patients' wishes that guide the decisions of medical teams and/or a patient's appointed attorney, and clearly specify which values are the basis of their life and what they would want or not<sup>25</sup>.

State laws found in the states of Minas Gerais and São Paulo guarantee patients the right to information about their health status. Based on this information, patients are assured the right to express their preferred medical treatment for a life-threatening illness, being able to accept, refuse or interrupt any treatment<sup>15,21</sup>. Bearing in mind that the guidelines translate into orientations that explain how PC actions should be established and developed, this is very important data, since a patient's autonomy and independence are essential objectives when it comes to assistance in PC<sup>26</sup>.

The central point in caring comprises the recognition and response to the needs of a patient and family members from a transdisciplinary and broad perspective<sup>27</sup>. At this point, considering the need to recognize and respect the

will of patients and their legal representatives, the situation may require the establishment of good practice guidelines that observe not only the rights of choice of a person in need of PC, but also ethical principles and deontology of professional categories.

Commitment to best practices for pain relief appears as an objective, principle or action specified in all state legislation on PC; however, access to pain relief medications<sup>15,18-19</sup> is addressed only by the states of Goiás, Maranhão and Paraná. While state laws in Paraná address only the supply of medications that promote the control of the symptoms of sick people<sup>19</sup>, state laws in Goiás and Maranhão provide for access to medications used in the treatment of symptoms that are typical of the context of PC, pointing to the use of opioids, notably morphine<sup>15,18</sup>. Legislation in Maranhão also explains that the use of opioids will follow current health standards and the existing agreements in the scope of SUS management instances<sup>18</sup>.

Finally, our findings suggest that state laws dealing with PC in Brazil are scarce. Our survey identified only seven state laws on PC in the country from a total comprising 26 states and the Federal District. Thus, although debates had been intensified around PC issues within the Federal Government since 2017, due to Ordinance No. 2, of September 28 of the same year, which deals with the consolidation of norms and policies concerning national health services (SUS)<sup>28</sup>, the enactment of a federal law on PC in Brazil is advocated, which expands the points of convergence among state legislation and helps to reduce their divergences, therefore leading to an alignment of essential elements of our legislation nationwide.

## CONCLUSION

The above data suggest that Brazil suffers from a scarcity of state laws dealing with PC. The documentary research identified only seven state laws on PC across the country. The existing state legislation on PC presents convergent and divergent points. Guaranteeing early access to PC for patients and their families is the main point of convergence observed. Guidelines for using the service, profile of professionals and forms of financing are among the main divergent points. Those divergent points in the texts of legal documents are important gaps to be dealt with from the perspective of developing a nationwide PC policy.

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