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Article

COVID-19, Bioethics, and Palliative Care: Dialogues between Health, Technology, and Human Dignity in Brazil

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ABSTRACT
The inclusion of Palliative Care (PC) in strategies for assisting patients with COVID-19 is necessary not only because of the urgent need to optimize resources, but also because of the right to dignity and comfort in the face of a life-threatening illness. Aiming to discuss the effects of the COVID-19 pandemic on the practice of PC in Brazil and its adequacy to the principled bioethical model in the context of social distancing, a systematic review of the literature was conducted, including six articles. The effects of the pandemic on palliative care practice have highlighted pre-existing weaknesses in the Brazilian healthcare system. Although the complexity inherent in dealing with humanitarian crises is recognized, it is precisely this scenario that reinforces the need for critical reflection on the bioethical parameters that guide professional practice in health emergency contexts. Questions that arose regarding the allocation of scarce resources, relief of suffering, and respect for patient autonomy brought to light the need for greater preparation on the part of health professionals when faced with dilemmatic situations. This study highlights that low government investment in the training and capacity building of CP teams became evident during the COVID-19 pandemic, as well as the importance of this practice in promoting the physical, mental, and spiritual well-being of patients hospitalized under isolation. The resilience and empathy of healthcare professionals were fundamental during the pandemic, when they used new technologies to provide emotional encounters between patients and family members and alleviate their suffering.

Keywords: palliative care; bioethics; COVID-19; healthcare professionals.

Introduction

The first definition of Palliative Care (PC) was published by the World Health Organization (WHO) in 1990. In 2002, it was revised and replaced by the current concept, in which Palliative Care is defined as an approach that aims to promote the quality of life of both patients and their families in the context of coping with life-threatening illnesses through the prevention and relief of suffering (WHO, 2022). PC is therefore understood not as a series of protocols, but as principles to be practiced in the face of life-threatening illnesses.

The principles of PC aim to: (i) promote the relief of pain and other unpleasant symptoms; (ii) reaffirm life and face death as a natural process of life in conditions of irreversible illness; (iii) neither hasten nor postpone death, that is, neither cause euthanasia nor dysthanasia; (iv) integrate psychological and spiritual aspects into patient care; (v) provide a system that allows the patient to live as actively as possible until their death; (vi) provide support to family members so that they know how to deal with the patient's illness and cope with grief; (vii) develop a multidisciplinary approach focused on the needs, desires, and values of the patient and their family members, including grief counseling; and (viii) begin as early as possible, along with other therapeutic measures aimed at improving quality of life and positively impacting the course of the disease (Carvalho; Parsons 2012).

Coined by Dame Cicely Saunders in 1967, the concept of "total pain" interprets pain as more than a purely physical phenomenon, but also considers its connection to the emotional, social, and spiritual dimensions of human beings. Suggested by this concept, the CP Manual characterizes the consideration of psychosocial and

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spiritual aspects as the "total symptom" to be treated in conjunction with non-pharmacological measures and drug prescription (ANCP, 2012).

In the challenging times of a humanitarian crisis, as exemplified by the COVID-19 pandemic, PC has emerged as a widely accepted and vital approach in the field of medical treatment. By recognizing the growing demand from patients for more holistic care focused on quality of life, Palliative Care has established itself as a fundamental guideline in strategies for assisting patients during such crises. Despite its widespread acceptance, PC is at the heart of ethical and bioethical discussions that emphasize such care in a context of shared choices, thus considering the principle of autonomy (Paulo Neto *et al.*, 2022).

Ethical guidelines in PC include its implementation as a healthcare practice capable of transcending both technique and the use of medication in controlling the patient's symptoms and pain. It is therefore essential that the completeness of the patient's life be achieved through ethical actions; that said, the meaning attributed to life by the patient, their spirituality, experiences, and cultural practices must be taken into account by healthcare (Mount *et al.*, 2006).

Bioethics, considered a field of "applied ethics," deals with the use and appropriate solutions to new technologies and moral dilemmas concerning medical science, respectively. Thus, ethical principles are associated with the problems inherent in medical care and enable the understanding and resolution of existing ethical conflicts, as well as allowing science, technology, individuals, and society to communicate (Clotet, 2003).

Four principles of bioethics are proposed: (i) non-maleficence; (ii) beneficence; (iii) justice; and (iv) respect for autonomy. Non-maleficence refers to the obligation not to cause harm intentionally; beneficence refers to the use of positive actions; justice establishes equity as an ethical obligation; and respect for autonomy recognizes the individual as capable of self-governance. These principles are considered equally important and, therefore, should permeate each other (Childress; Beauchamp, 2002).

Prevention and relief of suffering should be offered to anyone who suffers physically, psychologically, and/or socially, and not only to those who are at imminent health risk. In addition to adequate symptom control, which is a basic and fundamental human right to alleviate suffering, regardless of the chances of survival, spirituality must be taken into account, whose importance is recognized in the comfort and promotion of the well-being of patients and family members (Bajwah *et al.*, 2020).

The inclusion of CP in care strategies for patients with COVID-19 is necessary not only because of the urgent need to optimize resources, but also because of the right to dignity and comfort in the face of a life-threatening illness. The organization of health services should consider CP as a cross-cutting issue in all areas, as there is a need to balance ethics, comfort, and quality care (Bajwah *et al.*, 2020).

Strategies should be directed toward supporting patients and their families, considering principles such as alleviating symptoms, ensuring comfort in the dying process, offering patient-centered care, caring for patients and their families in relation to physical and spiritual aspects, and acting to offer support to teams on the front lines of combating the pandemic. This approach promotes a holistic view of the patient with respect to life and human dignity, contributing to humanized and respectful care, welcoming the preferences of patients and family members. The focus of care is on the person and not on the disease, centered on biography and respect for autonomy, emphasizing quality rather than quantity of days to be lived (Crepaldi *et al.*, 2020).

In light of the particularities concerning the care of patients infected with SARS-CoV-2, bioethical guidelines in PC have highlighted the growing need to establish a “bridge,” as proposed by Van Rensselaer Potter, between scientific knowledge and human values (Potter, 2016). This encounter between palliative care and bioethical issues allows for reflections on the relationship between the patient and the medical team; in this sense, the “capacity for moral judgment” is enhanced through bioethics and applied to PC based on an understanding of the patient’s ability to express their suffering (Moreira, 2021).

The PC team, therefore, together with the patient and their family, should seek to prioritize a shared decision-making approach in which pain management, mental health, and religious and spiritual needs are discussed, allowing the patient autonomy. In addition, it is essential to discuss with the patient issues such as living wills, legal documentation, and their burial preferences (Mount *et al.*, 2006). While palliative care has been considered positive and relevant in theory in the context of humanitarian crises and emergencies, its practical application was initially neglected as efforts focused on saving lives, as seen during the COVID-19 pandemic (ANCP, 2012).

However, even though the primary objective is to save lives, human dignity must be respected. Thus, despite the ethical and bioethical dilemmas and social distancing rules imposed by the WHO, PC teams have taken on a significant role in the lives of patients and their families by providing encouragement to infected individuals in isolation and their families through new technologies, where cameras, phone calls, and video calls were made between them (Galbadage *et al.*, 2020).

Given the specificities related to the treatment of people infected with COVID-19, CP and the bioethical issues involved in its practice have had a significant impact on its *modus operandi*. With the objective of reflecting on the effects of the COVID-19 pandemic on the practice of CP in Brazil and its adequacy to the principled bioethical model in the context of social distancing, this study also proposes to reflect on the changes that have occurred in search of adaptation to future humanitarian crisis situations.

Materials and Methods

A systematic review was conducted of studies that addressed the practice of PC in the face of the COVID-19 pandemic and the bioethical aspects involved. The procedures for this review followed the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) 2020 guideline (Page *et al.*, 2021). The question that guided the investigation was: "What are the effects of the COVID-19 pandemic on the practice of palliative care, considering the bioethical aspects involved, in the context of social distancing in Brazil?"

We opted to conduct a systematic review. Galvão and Pereira (2014, p. 183) point out that this type of review, in relation to its construction, "should be comprehensive and unbiased in its preparation," therefore adopting "criteria (...) so that other researchers can repeat the procedure." Since it is an explicit scientific method for "presenting new results, systematic reviews are classified as original contributions in most journals" (Galvão; Pereira, 2014, p. 183).

Regarding the use of PRISMA, this guide presents a list containing 27 items responsible for guiding the specifics of the reports included in systematic reviews. Thus, this guide covers stages such as identification, selection, eligibility, and inclusion of studies (Page *et al.*, 2021).

For the data production strategy, a systematic electronic search was conducted for articles published up to the present year (2023) in the Virtual Health Library (VHL) and SciELO databases. To define the search terms, a strategy was developed in which the descriptors were combined in various ways (Table 1). The filtering of articles considered the following eligibility criteria: articles published between 2020 (the year in which COVID-19 was characterized by the WHO as a pandemic) (WHO, 2002) and 2023; full text available in Portuguese, Spanish, or English; focus on Brazil; focus on the practice of CP in individuals infected with SARS-CoV-2; and bioethical implications of the pandemic for this practice.

Table 1. Search strategy for the systematic review on palliative care and bioethics in the face of the COVID-19 pandemic.

Electronic database	Search strategy	Number of studies
Virtual Health Library (VHL) – https://bvsalud.org/	(palliative care) *AND* (COVID-19)	752
Virtual Health Library (VHL) – https://bvsalud.org/	(palliative care) *AND* (COVID-19) *AND* (health professionals)	59
Virtual Health Library (VHL) – https://bvsalud.org/	(palliative care) *AND* (COVID-19) *AND* (health professionals) *AND* (bioethics)	2
SciELO - https://scielo.org/	(palliative care) *AND* (COVID-19)	11

Source: prepared by the authors (2024).

The selected articles were investigated for initial collection of the following information: year, objective, location, and methodology, thus allowing the exclusion of articles initially identified as ineligible in relation to the objectives sought for this research. The following articles were excluded: publications outside the predefined time frame; without reference to patients infected with SARS-CoV-2; and referring to countries other than Brazil. Finally, the selected articles were evaluated according to the 22 STROBE criteria, so that the proportion of criteria met could be calculated (Von Elm *et al.*, 2008) (Table 2).

STROBE, *Strengthening the Reporting of Observational Studies in Epidemiology,* is characterized by presenting "recommendations for writing cross-sectional, case-control, and cohort studies, aggregating the similarities between these designs and specifying by study type when necessary" (Von Elm *et al.*, 2008, p. 430). Along with PRISMA, this guide is one of the most recommended by journals focused on epidemiology.

Table 2. Scores and quality percentages of articles based on STROBE criteria*.

Authors	Score	%
Neto *et al.*	21	95.45

Figueiredo *et al*.	21	95.45
Krautkenr, Cordeiro, and Campelo	21	95.45
Falcão *et al*.	20	90.91
Ranzani *et al*.	19	86.36
Tritany *et al*.	17	77.27

* The *Strengthening the Reporting of Observational Studies in Epidemiology* (STROBE) checklist consists of 14 items, some of which are stratified into sub-items, totaling 22 items. Each item added one point to the study proportionally considering the sub-items. Articles with a minimum score of 60% were included. Source: prepared by the authors (2024).

Results and Discussion

A total of 824 articles published between 2020 and 2023 were identified in the electronic databases. The complete flowchart of the selection process according to the PRISMA recommendation is shown in Figure 1. After removing 129 duplicate studies, 695 publications remained, of which 596 were excluded because they were not directly related to COVID-19, focused on children and adolescents, and/or addressed countries other than Brazil.

After this exclusion, 99 titles remained, of which, after reading the abstracts, 77 were excluded due to factors related to their methodology (articles with political and commercial bias) and because they could not be accessed free of charge. Next, 22 articles were read in full, 16 of which were excluded from this review because they focused on specificities that did not meet the established objectives (specific age group – children and adolescents or the elderly –; sociodemographic issues). Finally, six complete studies were included.

The included articles were published between 2020 and 2023. Table 3 presents a summary of the characteristics of the included articles. Three studies (Figueiredo *et al.*, 2021; Tritany *et al.*, 2021; Ranzani *et al.*, 2022) adopted qualitative and descriptive approaches. One article (Krautkenr; Cordeiro; Campelo, 2023) consisted of a bibliographic and exploratory investigation, one article consisted of a cross-sectional, descriptive, and quantitative study (Neto *et al.*, 2020), and one article (Falcão *et al.*, 2021) adopted an integrative review composed of five articles.

Table 3. Characteristics of the studies included in the systematic review.

Authors	**Year**	**Country**	**Methodology**
Neto *et al.*	2020	Brazil	Cross-sectional, descriptive, and quantitative study.
Figueiredo *et al.*	2021	Brazil	Study with a qualitative and descriptive approach.
Tritany *et al.*	2021	Brazil	Exploratory bibliographic research.
Falcão *et al.*	2021	Brazil	Integrative review.
Ranzani *et al.*	2022	Brazil	Scope review with qualitative synthesis.
Krautkenr; Cordeiro and Campelo	2023	Brazil	Study with a qualitative and descriptive approach with an interpretive paradigm.

Source: prepared by the authors (2024).

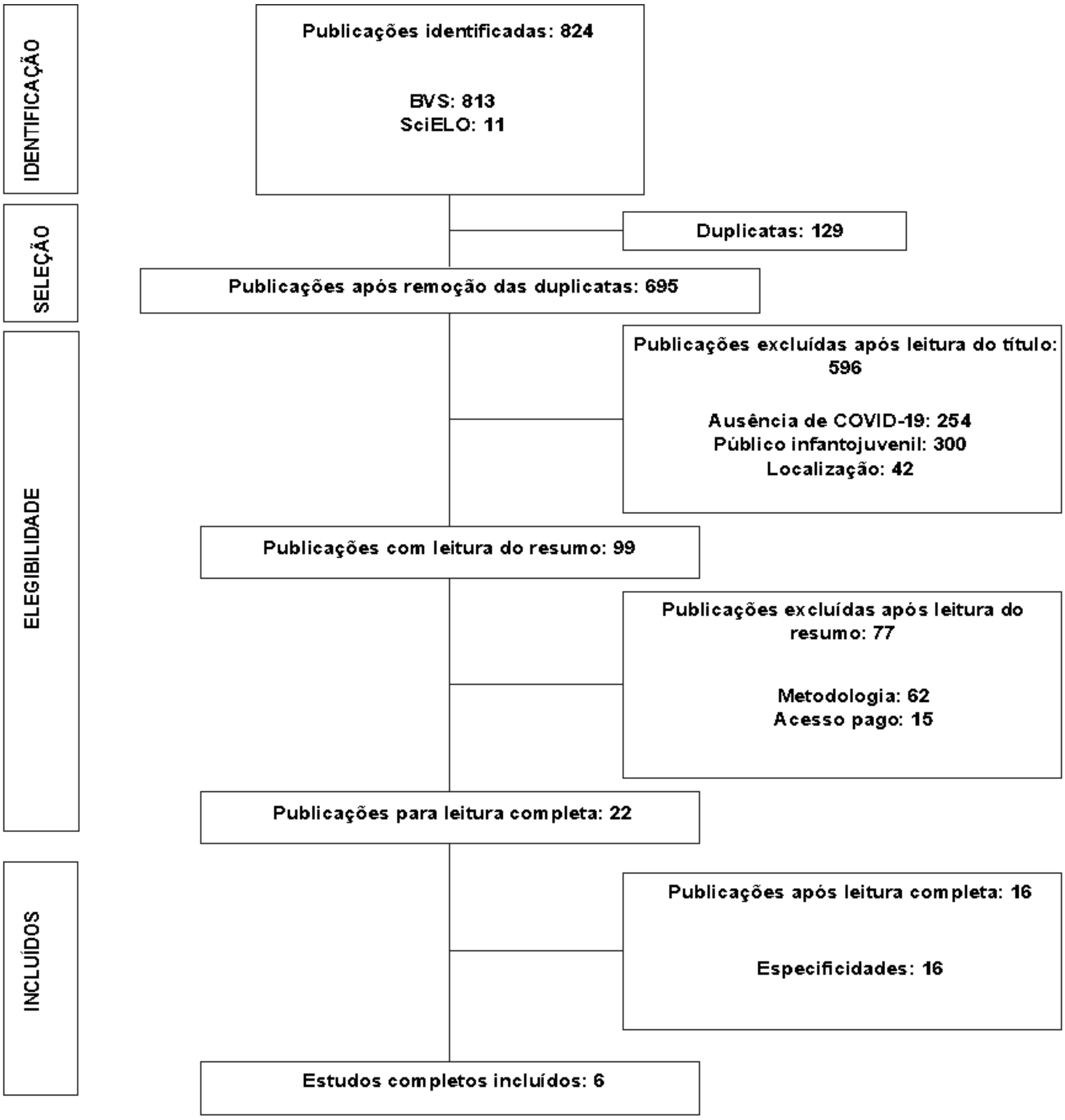

Figure 1. Flowchart of the selection of studies for the systematic review on palliative care and bioethics in the face of the COVID-19 pandemic. Source: prepared by the authors (2024)

The studies associated the effects of the COVID-19 pandemic on PC with the existing weaknesses in the Brazilian healthcare system. In this sense, the need to strengthen this practice was pointed out, also with the aim of attracting government funding to enable the necessary training for health professionals (Tritany *et al.*, 2021; Krautkenr; Cordeio; Campelo, 2023).

However, it was emphasized that the practice of CP during the COVID-19 pandemic needed and needs to be rethought, considering possible future humanitarian crises; This is because such practice requires consideration of the collective context of transmission in cases of viral infection and also the individual context of each patient, bearing in mind the social inequalities that make certain individuals more susceptible to contamination (Ranzani *et al.*, 2022).

The current reality of the Brazilian healthcare system is still far from ideal, especially when considering the bioethical aspects involved in the practice of PC. The perception of healthcare professionals who worked during the pandemic regarding the ethical problems related to Palliative Care proved to be insufficient. In a descriptive cross-sectional study with 190 health professionals working in a pediatric ICU in Porto Alegre/RS, 75.8% of respondents stated that they had sufficient knowledge of bioethics, however, the percentage of responses considered incorrect by the authors in relation to the decision to triage scarce resources reached 83.2% (Neto *et al.*, 2020). It is also necessary to consider that the questions formulated by the authors had answers considered correct based on the perceptions and interpretations of "ethical problems" by these same authors.

In this sense, the ethical and bioethical parameters of CP underwent new reflections concerning the *modus operandi* of the multidisciplinary teams involved in CP during the pandemic. Recommendations regarding social isolation (Krautkenr; Cordeiro; Campelo, 2023) required care teams to reinvent themselves and brought to light the even more poignant use of new technologies (mainly video calls between patients and family members and telecare) in search of relief from the mental suffering of hospitalized patients (Figueiredo *et al.*, 2021).

This systematic review evaluated the association between the COVID-19 pandemic and its effects on CP practice, as well as the bioethical issues involved in this scenario. All selected studies indicated that the pandemic directly impacted both PC teams and patients in distress who needed this type of care. Similarly, all articles emphasized the importance of bioethical reflection on PC in order to provide patients with multidimensional outcomes beyond the treatment of symptoms directly related to the disease.

The lower-than-expected percentages of correct answers from healthcare professionals regarding bioethical aspects (Neto *et al.,* 2020) revealed insufficient knowledge on the part of the professionals interviewed. However, this conclusion cannot be generalized since, despite its national scope, the research mainly covered the states of São Paulo and Mato Grosso do Sul. Thus, different realities are portrayed, along with their discrepancies.

Despite this, there is a clear need for readjustment, which CP teams had to undergo in order to act, especially in episodes of humanitarian crisis. It is necessary to educate these teams on bioethical aspects and new technologies that can help them deal with future crises (Tritany *et al.,* 2021). Furthermore, their priority should be to alleviate the suffering of patients and their families for as long as necessary (Ranzani *et al.,* 2022).

The possibility of including CP has proven to be positively relevant to the overall well-being of patients (Paulo Neto *et al.,* 2020; Falcão *et al.,* 2021; Figueiredo *et al.,* 2021; Tritany *et al.,* 2021), serving as an important point of contact between patients and the medical team. Considering the patient as an autonomous human being, the totality of their being is contemplated, and their decisions about themselves can be fully respected.

In contexts where the patient cannot respond for themselves and has not previously expressed their wishes on a particular issue, the decision is made after a discussion between the team and the patient's family or representatives; it is therefore essential that these professionals have extensive knowledge of the bioethical aspects that will guarantee the patient's dignity, whether in life or in death (Neto *et al.,* 2020).

The changes implemented by PC teams as a result of the pandemic mainly consisted of: (i) reassigning their members to specific COVID-19 sectors due to the need for a larger workforce; (ii) suspending patient visits; (iii) remote patient monitoring (, WhatsApp social media app, and phone calls); (iv) communication with family members by telephone; (v) support for other health professionals; and (vi) management of beds in order to promote human dignity, comfort, and quality of life (Figueiredo *et al.,* 2021).

The entire context presented is, therefore, a great opportunity not only for reflection on the bioethical implications of CP practice during the COVID-19 pandemic in Brazil, but above all an invitation to change the current context in search of new political and care choices that allow for the restructuring of the health care model currently employed in Brazil.

All studies included in this review converged on the perception that the pandemic had a direct and significant impact on CP teams and also on the patients under their care. However, this impact was not limited to the clinical management of the disease but, above all, required broader reflection on the bioethical dimensions involved, with an emphasis on the need to provide multidimensional results that transcend the treatment of disease symptoms.

The analysis of the articles indicated a significant gap in the knowledge of health professionals regarding bioethical aspects, evidenced by responses below expectations in relation to the metrics established by the authors regarding bioethical issues. This knowledge *deficit* highlights the importance of continuous and specific training for these professionals, especially considering the diverse realities represented in the research, which mainly covered the states of São Paulo and Mato Grosso do Sul. Although these regions offer a relevant overview, the diversity of regional realities in Brazil prevents the generalization of conclusions for the entire country.

The readjustment of PC teams during the pandemic was an inevitable and critical process, which, in turn, demonstrated the need for continuing education in bioethics and the incorporation of new technologies. The priority of these teams must remain the relief of the suffering of patients and their families in search of dignity throughout the care process. The inclusion of PC was identified as a crucial element for patient well-being, providing an essential point of contact between patients and the medical team. This aspect is particularly important in the context of respecting patient autonomy, who should be treated as a whole human being whose decisions must be respected.

In the scenario described, bioethical knowledge proved essential to ensure that decisions respected the dignity of patients, both in life and in the process of dying. The pandemic scenario presented a unique opportunity for in-depth reflection on PC practices and their bioethical implications. This historic moment calls for a review of current public policies and care practices, encouraging the restructuring of the healthcare model in Brazil. However, the evaluation of the studies reviewed also reveals the existence of important limitations, such as the lack of uniformity in the application of bioethical concepts between different regions and the variability in the responses of healthcare teams. Furthermore, the risks of bias in the studies include geographical limitations and the possible influence of external factors that were not completely controlled, pointing to the need for future investigations that explore these issues more broadly and systematically.

Final Considerations

The COVID-19 pandemic has highlighted the urgent need to rethink palliative care in Brazil, not only as a medical specialty, but as a fundamental right to human dignity. The challenges faced during the health crisis have revealed structural flaws ranging from unequal access to a shortage of qualified professionals in various regions of the country. It is essential that this debate goes beyond academic circles and translates into concrete actions, with the implementation of robust public policies that guarantee continuing education for health professionals and equitable access to quality care at all levels of the system.

Brazil faces alarming regional disparities in the provision of palliative care, with specialized services concentrated in the South and Southeast, while the North and Northeast have a critical shortage of beds and essential medications. This inequality is exacerbated when we consider that most patients depend exclusively on the SUS, a system that has not yet fully incorporated palliative care as an integral part of health care. The creation of a National Palliative Care Program (PNCP), with tripartite funding and progressive coverage targets, could represent a significant step forward in reducing these asymmetries. At the same time, it is essential to revise RENAME to include long-acting opioids and other essential drugs, which are currently unavailable in most Brazilian municipalities.

The experience accumulated during the pandemic has demonstrated the potential of technology as an ally in overcoming geographical barriers and humanizing care. Projects such as “Paliativo Digital” (Digital Palliative Care), developed in Paraná, have shown that telemedicine can reduce unnecessary hospitalizations and improve communication between patients, family members, and healthcare teams. However, for these initiatives to be expanded, it is essential to invest in basic technological infrastructure in all UBSs, create specific telehealth protocols, and establish partnerships with educational institutions to develop solutions adapted to the national reality. When used properly, technology can be a powerful tool for democratizing access to quality PC, especially in remote regions.

Professional training emerges as another critical issue that demands immediate attention. The curriculum of health courses still treats CP as a peripheral topic, resulting in professionals who are unprepared to deal with complex situations involving the end of life. Recent data reveal that most students graduate without having had any practical contact with the field, which contributes to the perpetuation of outdated care models. There is an urgent need to create a Center of Excellence in PC, linked to the Ministry of Education, responsible for developing national curriculum guidelines, certifying residency programs, and promoting applied research in partnership with health services.

In addition to technical and structural aspects, we cannot neglect the cultural dimension of palliative care in a country as diverse as Brazil. The traditions of indigenous, *quilombola*, and riverine communities, as well as the particularities of large urban centers, require care models that are sensitive to cultural differences. Experiences such as the “Care Circles,” which integrate traditional knowledge and professional practices, have shown excellent results in places where access to specialized services is limited. These initiatives show that it is possible to build innovative approaches that respect the multiple ways of living and dying present in our country.

Given this complex scenario, we propose the creation of a Permanent National Forum on PC, bringing together public managers, health professionals, representatives of civil society, academics, patients, and family members. The main objective of this pluralistic space should be to develop a Ten-Year Plan for PC in Brazil, with clear goals, measurable indicators, and defined sources of funding. The pandemic has taught us that death is an inescapable reality, but how we deal with it reflects our values as a society.

Looking ahead, new research should investigate the economic impact of palliative care in reducing hospital costs, innovative financing models, the effectiveness of community interventions in different contexts, and the potential of artificial intelligence in predicting palliative needs. Building a robust and equitable palliative care system goes far beyond a clinical necessity—it represents an ethical imperative and a demonstration of our commitment to the most fundamental values of civilization. May we transform the painful lessons of the pandemic into the foundation for a future in which no Brazilian has to face the end of life without the comfort, relief, and dignity that every human being deserves.

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