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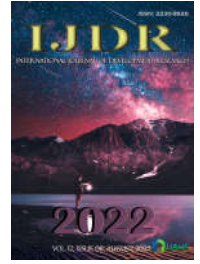
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## STIGMAS AND BARRIERS TO PALLIATIVE CARE AND IMPLICATIONS FOR CANCER PATIENTS: A SYSTEMATIC REVIEW

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### ABSTRACT

**Introduction:** Although the literature recognizes the benefits of Palliative Care (PC) integrated with standard cancer treatment, access to PC is limited by barriers and stigmas and ends up directly influencing the care and support of cancer patients and their family caregivers. **Objective:** To analyze the implications of stigmas and barriers related to palliative care in the care of cancer patients. **Methods:** Systematic review study using Medline, SciELO, and LILACS databases to search for studies published from 2017 to 2022. The search was conducted considering the terms “stigmas”, “barriers”, “palliative care” and “cancer”. The quality of articles was assessed using the Study Quality Assessment Tool from the Department of Health and Human Services. **Results:** A total of 63 studies were identified; 8 studies were eligible and included. North America and Europe were the countries with the highest number of studies included (n=3, n=2, respectively). The stigmas and barriers related to PC identified were administrative, economic, institutional (n=3), cultural (n=2), knowledge (n=6), communication (n=3), geographic (n=1) and social (n=1). Inaccessibility to PC or late referral as a result of PC-related stigma and/or barriers was identified in all studies. Patients with the maintenance of the expectation of healing, receiving futile care at the end of life (n=1), impact on the desires for end-of-life care, autonomy and dignity (n=1), unmanaged psychological and spiritual suffering (n=1), purchase of drugs for analgesia with own resources (n=1); non-shared decision-making (n=1) and worsening of the mental health of professionals in pediatric oncology (n=1). **Conclusion:** The barriers and stigmas related to PC can influence the care received by patients, especially in end-of-life care, due to lack of access to PC or late access. Heterogeneity regarding study design and results, and low methodological quality are challenges when reaching conclusions.

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## INTRODUCTION

Estimates indicate that by 2021 approximately 40 million people will need Palliative Care (PC) (World Health Organization, 2014). To guarantee access to Palliative Care (PC) for all patients who need it, the 2014 World Health Assembly Resolution on Palliative Care requested all countries to include PC in their health systems (World Health Organization, 2021). In this scenario, cancer patients represent a large part of the indications for PC, since cancer is a serious chronic disease (World Health Organization, 2021) and for a considerable number of patients the initial diagnosis is advanced, which requires receiving specialized and individualized care such as that of the PC (Hui, 2015). Patients with cancer present physical and neuropsychological symptoms from diagnosis and during the

evolutionary process (Zimmermann, 2014). These symptoms are a result of the disease and treatment, evolve progressively, and in a complex way impair the quality of life of patients (Nickolich, 2016). PC prevents and treats these symptoms early, as well as their complications, relieves suffering, promotes quality of life regardless of survival time, provides support to family members, and attention to religiosity and spirituality (Brown, 2019; World Health Organization, 2017). PC integrated with standard cancer care has been considered the most appropriate model today, as it provides satisfactory benefits in oncological outcomes by complementing clinical practice and improving patient care (Brown, 2019; Smith, 2012). Symptom control, reduction of aggressive care, less anxiety and depression, greater patient and family satisfaction with the care received, improved quality of life, and efficiently used health resources, among

others, include the benefits of PC (Kaasa, 2018) integration. Despite the global recognition of PC as an essential part of health services in human care (World Health Organization, 2014; World Health Organization, 2021) and the evidence of its benefits (World Health Organization, 2017; Smith, 2012; Kaasa, 2018), PC is often not recognized as a treatment modality and, therefore, referral to PC occurs more and more each time. later or not is a reality for everyone who needs it (Santos, 2021). Barriers and stigmas associated with patients, family members, and health professionals concerning PC are factors that can contribute to this reality in the field of oncology (Santos, 2021) and directly interfere in the care of cancer patients<sup>11</sup>. Little or no knowledge about PC, limited ability and ability to manage symptoms, and communication with patients and families regarding care and decision-making are the main barriers associated with health professionals (Santos, 2021). As for patients and family members, barriers are often associated with beliefs, unrealistic hope about the prognosis of the disease where survival occupied the greatest importance, and disagreement between patient and family regarding treatment. In addition, there is the stereotype of PC associated with death and the end of life, or when all therapeutic options have failed and there is nothing left to be done (Santos, 2021; Uribe, 2019). Although barriers and stigmas make PC access and integration difficult for cancer patients (Santos, 2021; Zhi, 2015), these can be modified when there is professional qualification and training, reaffirmation of PC principles, and effective communication between patients, family members, and professionals (Zhi, 2015; Yin, 2017). Consequently, the impact will be positive through the benefits of patient health care (Yin, 2017). In this sense, understanding the stigmas and barriers related to palliative care is essential to achieving individualized care for the biopsychosocial needs of cancer patients. Thus, the objective of this study was to analyze the implications of the stigmas and barriers related to PCs in the care of cancer patients.

## METHODS

**Study Design:** A systematic literature review study registered in PROSPERO (National Institute for Health Research), the international database of systematic reviews in health and social care of the Center for Reviews and Dissemination at the University of York.

**Search Strategy:** Three online access databases were selected for the research: Pubmed/Medline, Scientific Electronic Library Online (SciELO), and Latin American and Caribbean Literature on Health Sciences (LILACS). With a controlled vocabulary in the search strategy in each of the bibliographic databases, Pubmed/Medline (MeSH terms), SciELO (DeCs terms), and LILACS (DeCs terms), the following terms were used: “stigmas”, “barriers”, “palliative care”, “cancer”, as well as their synonyms and combinations.

**Selection of Studies:** To carry out this research, the following question was asked: What is the impact of stigmas and barriers related to palliative care in the care of cancer patients? The study population included cancer patients as well as family caregivers and health professionals working in oncology. The intervention studied was the stigmas and barriers related to palliative care. A comparison group was not needed. The following outcome was necessary: some implication in the care of the cancer patient due to the stigmas and/or barriers related to PC. These results included both quantitative and qualitative results (Table 1). All studies identified through the initial database search were archived in a database prepared in Excel software (Version 16.4). The following eligibility criteria were adopted: (1) studies published in the last 5 years (2017 to April 2022); (2) studies without age, cancer type, and country of origin restrictions; (3) studies in English and Portuguese; (4) studies that included the evaluation of stigmas and barriers of cancer patients, family caregivers of cancer patients and/or health professionals in the oncology area concerning PC; (5) studies that analyzed at least one implication in the care of cancer patients due to the stigmas and/or barriers related to PCs; and (6) gray literature, case series, case studies, proceedings and conference abstracts, study protocols,

comment articles, letters to editors and policy briefs were excluded. At the end of this process, the full text of studies considered potentially relevant and independently selected by three study authors for inclusion or final exclusion based on pre-defined eligibility criteria was obtained. The Department of Health and Human Services (National Heart Lung, and Blood Institute, 2021) study quality assessment tools were used to assess the quality of the included articles.

### Step 1: identification of articles by searching electronic databases

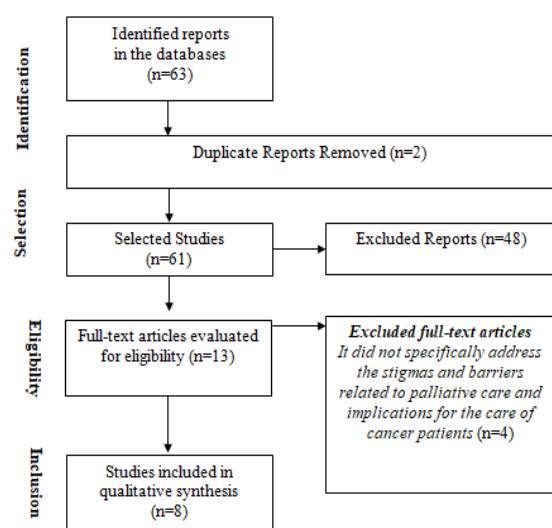
Electronic searches were performed by two independent reviewers. Subsequently, the titles and abstracts of the identified studies were independently evaluated for suitability for the research objective. Studies that did not address stigma and/or barriers related to PC in oncology were excluded. Disagreements were resolved by consensus between the two reviewers, or by a third reviewer when necessary. Duplicate studies were removed.

### Step 2: Eligibility assessment of full-text articles

Studies selected according to eligibility criteria were read in full. Throughout the selection process, uncertainties were discussed among the authors until a consensus was reached. In the different phases of the systematic review, a flow of information is originated. As for information related to eligibility, studies that did not specifically address possible implications for the care of cancer patients due to the stigmas and/or barriers related to PCs were excluded. The methodological quality assessment of the reviewed articles was performed using the quality assessment tools available at the US Department of Health and Human Services (National Heart Lung, and Blood Institute, 2021).

### Step 3: studies included in the qualitative synthesis

The number of articles identified, screened, assessed for eligibility, and included in this review were recorded, as were the reasons for exclusion. The characteristics (eg location, design, sample size, methods, results, and conclusions) of each study were recorded and summarized. The methodology of the studies and the measures of evaluation of the results were varied, therefore it was chosen to carry out a qualitative synthesis, instead of combining the data in a meta-analytical statistical approach. This systematic review was carried out based on the guidelines proposed by the Preferred Reporting Items for Systematic Reviews (PRISMA) (17). A flowchart with the different phases of a systematic review, and the description of information regarding the number of articles identified, included, and excluded and the reasons for exclusions originated in this review (Figure 1).



**Figure 1. Flowchart with the phases of the systematic review (PRISMA)**

## RESULTS

According to the electronic search, a total of 63 references were found: 57 (PubMed/Medline), 5 (SciELO), and 1 (LILACS). After excluding 2 duplicate references, 61 references were selected for eligibility assessment. After reading the titles and abstracts (n=61), a total of 48 studies were excluded for not meeting the pre-established criteria (Figure 1). The full text of the remaining 13 articles was evaluated for eligibility, and 3 articles were excluded for the following reasons: one study specifically addressed barriers to discussing psychotherapy in palliative care; a study aimed at the detailed description of the development of PC programs; absence of information capable of making it clear in the eligibility criteria and/or results that the participants selected and included in the study were cancer patients, caregivers or health professionals in oncology (one); directly analyzed the end-of-life experiences, needs and expectations of patients with serious illnesses (one). At the end of the entire process, 8 articles were selected for inclusion in this review (Figure 1).

**Table 1. PICOT eligibility criteria**

<i>PICOT question:</i>	<i>What is the impact of stigmas and barriers related to palliative care on cancer patient care?</i>
<i>Population</i>	Cancer patients, health professionals in the field of oncology, and family caregivers of cancer patients
<i>Intervention</i>	Stigma and barriers to palliative care
<i>Control</i>	-
<i>Outcome</i>	The study reported some implications in cancer patient care due to stigmas and barriers related to palliative care. These include quantitative and qualitative results.
<i>Type of study</i>	Experimental and observational

Table 2 presents the characteristics of the selected articles. These articles were analyzed regarding the objective, study design, the population studied, barriers and/or stigmas concerning palliative care, and its possible implications for the care of cancer patients. A total of 3 studies were of qualitative methodology (Pacurari, 2021; Purkey, 2019; Lee, 2019), 4 qualitative-quantitative and 1 quantitative of the observational type (Brickey). The studies were carried out more frequently in the countries of North America (n=3) (19,20,Brickey, 2022), Europe (n=2) (De Clercq, 2018), Asia (n=1) (Harding, 2019), Africa (n=1) and South America (n=1) respectively. The investigation of stigmas and barriers related to PCs in the studies was in greater proportion in oncology health professionals (Uribe, 2019,18,20-De Clercq, 2018), followed by cancer patients (Uribe, 2019,19,21, Harding, 2019; Brickey, 2022) and family caregivers (Harding, 2019). Among the studies with health professionals, 2 (two) were with professionals working in the field of pediatric oncology (De Clercq, 2018). The stigmas and barriers related to PC identified were administrative, economic, institutional (Tapera, 2020), cultural (Uribe, 2019,De Clercq, 2018), knowledge (Uribe, 2019; Pacurari, 2021 18, Tapera, 2020 -Brickey, 2022), communication (Uribe, 2019,20,Harding, 2019), geographic (Uribe, 2019) and social (Purkey, 2019). In general, the administrative and economic aspects were related to the country's public health policies (Uribe, 2019, Tapera, 2020) and the resources of health services (Purkey, 2019; Tapera, 2020). Perception of PC as a service that only manages pain, as a therapeutic option to be offered only when the treatment with a curative purpose ends (De Clercq, 2018), the lack of understanding and understanding of the concept and role of PC (Uribe, 2019; Pacurari, 2021; Tapera, 2020, Brickey, 2022), of the specialty oncology and cancer itself (Tapera, 2020), and the association of PC and cancer with death (Tapera, 2020) were the barriers to knowledge. Communicating the diagnosis of advanced cancer (Harding, 2019), the prognosis (Lee, 2019; Harding, 2019), and talking about death (Harding, 2019) with patients and family members were considered communication barriers and stigmas. Lack of knowledge about PC (Uribe, 2019; Tapera, 2020 -Brickey, 2022) together with the challenges of communication (Uribe, 2019; Harding, 2019) and limited qualification of health professionals (18) implied late referral to PC or lack of referral and access (Uribe, 2019,20, Harding, 2019),

an expectation of cure and acceptance of futile care at the end of life, absence of decision-making about their care (Uribe, 2019), high expenses with care (Harding, 2019), psychological and spiritual suffering. In addition, the term "palliative care" was considered a language barrier making it difficult to approach patients and family caregivers in clinical practice (De Clercq, 2018). Regarding the social barrier, 1 (one) study showed the inaccessibility to PC due to the absence of a home, since the population studied was homeless. The implications were for end-of-life care (19). The geographic barrier was evidenced in 1 (one) study that highlighted the limited access to PC and comprehensive support for rural residents (Uribe, 2019). All studies reinforced that barriers and stigmas can prevent access to PC or referral to be delayed (Uribe, 2019,18-Brickey, 2022). All included studies were analyzed using the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (U.S. Department of Health & Human Services) (Table 3). According to the characteristics of the eight articles included, the barriers and stigmas related to PC evidenced in the studies were lack of knowledge, communication, cultural, administrative, economic, institutional, geographic, and social. These were identified by health professionals, patients, and family members. Limited access to PC due to non-referral or late referral performed by health professionals was the main implication in care. A study inferred that patients maintain an expectation of a cure concerning advanced cancer and accept futile care at the end of life, underuse the PC service and psychological and spiritual suffering are not managed. One study concluded that inaccessibility to PC impacted the fulfillment of desires related to end-of-life care, dignity, and non-prioritized autonomy, and in one study, obtaining analgesics was obtained with the patient's resources or that of their caregivers. The need for care for the mental health of professionals working in the field of pediatric oncology was the finding of a study.

According to Brighton *et al.* (Lee, 2019), it is necessary to know the barriers that hinder and often prevent access to PC, and to understand how these barriers were evaluated in the world literature to develop strategies in the context of organizational and institutional public policies. capable of overcoming them and enabling professionals to offer better quality care to patients. In our study, the barriers and stigmas related to PC were consistent with the literature and are included in the recent findings by Neto *et al.* (Santos Neto, 2021). Through a bibliometric analysis, the authors identified 19 barriers to accessing PCs for cancer patients and grouped them into 9 classes: Barriers related to the health system; symptom control; knowledge; acceptance of death and loss; education and conducting research; religiosity and spirituality; barriers related to empathy and the patient, informal caregiver or family. In this study, we identified that the main implications of barriers and stigmas to PC in the care of cancer patients were associated with non-referral of PC or a late referral provided by health professionals (Uribe, 2019,18-Brickey, 2022). Consequently, cancer patients often do not benefit from the care offered by PC, or when access is late, the goals of this treatment modality do not have enough time to promote care capable of achieving its full purpose. In the study by Harding *et al.* (Harding, 2019) and Tapera *et al.* (Tapera, 2020), the lack of communication regarding the diagnosis of advanced cancer and prognosis, as well as the understanding of the disease, future perspectives, and approaches capable of promoting the dissociation of death with PC in addition to of limiting access to PC (Tapera, 2020, Harding, 2019) impacted the acceptance of futile care at the end of life, that is, receiving aggressive measures, unmanaged psychological and spiritual suffering (Harding, 2019) and own resources for the use of analgesics (Tapera, 2020). Purkey *et al.* (2019), when addressing the association of the social context of homeless people and the lack of access to PC, showed that at the end of life, desires regarding care were not met, and dignity and autonomy were not prioritized (Purkey, 2019). The integration of PC, especially if early, reduces the need for aggressive measures at the end of life, controls symptoms, and promotes quality of life. Another prominent result found in this review consisted of a specific approach to health professionals in pediatric oncology (18, De Clercq, 2018). Both studies demonstrated the implications related to the knowledge barrier (De Clercq, 2018).

Table 2. Characteristics of the studies included in the systematic review

Studies	Country	Sample Size	Barriers and Stigma to Palliative Care	Implications in care
Uribe et al. (2019) [12]	Colombia	Participants (n=56): gastric cancer patients (n=14), caregivers (n=24) and physicians (n=18)	Administrative; economic; cultural, lack of knowledge; Communication; institutional; geographic.	Limited understanding of the disease, treatment, and prognosis makes it impossible to make joint decisions; deficit of medical resources to guarantee access and comprehensive care and support measures.
Pacurari et al. (2021) [18]	Romania	Health professionals in pediatric oncology (n=25)	Emotional overload related to the profession and area of activity; lack of staff due to financial resources; persistent culture about the concept and incorrect understanding of PC and oncology; professional qualification.	Unhealthy work-life balance; attention to the mental health care of health professionals working in this area of pediatric oncology.
Purkey et al. (2019) [19]	Canada	Homeless patients with cancer and other comorbidities (n=31)	Social: inaccessibility to the PC due to the absence of a place to live.	Fulfillment of wishes concerning end-of-life care; dignity and autonomy are not prioritized.
Lee et al. (2019) [20]	USA	Surgery resident physicians (n=18)	Challenges in predicting patient prognosis; difficulties in communicating with the patient and family about the prognosis; respect for surgical hierarchy when opinions disagree; aspects related to authoritarian training and decisive mentality of a surgeon.	Delay in forwarding to the PC or no forwarding.
Tapera et al. (2020) [21]	Zimbabwe	Patients with cervical cancer (n=134); health professionals (n=78)	Lack of knowledge and little understanding about cancer and PC approaches; diagnosis of cancer and PC associated with death; limited implementation of public policies.	Limited access to PC; obtaining analgesics with own resources.
Harding et al. (2019) [22]	India	Patients with advanced cancer; Family caregivers (n=10); Oncologists (n=10)	Communication of advanced cancer diagnosis and prognosis; discuss death; perception of PC only for pain management and without difference from other services.	The expectation of cure and acceptance of futile care at the end of life; high cost of care; under-use of PC services; psychological and spiritual suffering.
Clercq et al. (2019) [23]	Switzerland	Health professionals in pediatric oncology (n=29)	The negative definition of PC; the concept of pediatric PC associated with the absence of curative therapeutic options; cultural and religious differences; language: the term "palliative care" makes the approach difficult.	Late referral to PC; lack of guidance to implement PC in practice.
Brickey et al. (2022) [24]	USA	Patients with advanced cancer (n=504)	Disease severity; Misunderstanding of the role of the PC; family, caregiver, and physician surveillance; the PC delivery model.	Refusal to participate in surveys that offer access to and receive PC, and to benefit from such care; the burden borne by patients must be recognized; propose alternative care models to increase participation in studies in the area of PC.

Abbreviations: PC, palliative care; USA, United States of America.

Table 3. Study quality assessment (Tool from U.S. Department of Health &amp; Human Services)

Criteria	Uribe et al. (2019)	Pacurari et al. (2021)	Purkey et al. (2019)	Lee et al. (2019)	Tapera et al. (2020)	Harding et al. (2019)	Clercq et al. (2019)	Brickey et al. (2022)
1. Was the research question or objective in this paper clearly stated?	YES	YES	YES	YES	YES	YES	YES	YES
2. Was the study population clearly specified and defined?	YES	YES	YES	YES	YES	YES	YES	YES
3. Was the participation rate of eligible persons at least 50%?	NA	NA	NA	NA	YES	NA	NA	YES
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	NR	NR	YES	NR	YES	YES	NR	YES
5. Was a sample size justification, power description, or variance and effect estimates provided?	NR	YES	NR	YES	YES	NR	NR	YES
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	YES	YES	YES	YES	YES	YES	YES	YES
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	YES	YES	YES	YES	YES	YES	YES	YES
8. For exposures that can vary in amount or level, did the study examine different	NA	NA	NA	NA	NA	NA	YES	NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	NA	NA	NA	NA	NA	NA	NA	YES
10. Was the exposure(s) assessed more than once over time?	NA	NA	NA	NA	NA	NA	YES	NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	NA	NA	NA	NA	NA	NA	NA	YES
12. Were the outcome assessors blinded to the exposure status of participants?	NA	NA	NA	NA	NA	NA	NA	NA
13. Was loss to follow-up after baseline 20% or less?	NA	NA	NA	NA	NA	NA	NA	NA
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	NA	NA	NA	NA	NA	NA	NA	YES
Score	4 poor	5 poor	5 poor	5 poor	7 fair	5 poor	6 poor	10 good

\*Legend: YES = 1; CD, cannot determine = 0; NA, not applicable = 0; NR, not reported = 0.

However, Pacurari *et al.* (2021) found that the emotional overload of the profession and specific area of activity, together with insufficient manpower and the need for a professional qualification, emerged to directly care for the mental health of these professionals (Pacurari, 2021), which, as a consequence, may reflect on the assistance to the patient and family. In particular, the study by Lee *et al.* (Lee, 2019) conducted semi-structured interviews with surgical residents in the state of Michigan (USA) and identified that predicting the patient's prognosis, communicating this prognosis with the patient and their families, an authoritarian and decisive mentality profile of a surgeon, were the barriers associated with the delay in referring the patient to the PC or not being referred (20). To overcome these barriers, the findings reflect the need for qualification and training of all health professionals involved in cancer patient care, not only physicians, reaffirming the principles of PC and the positive impact on the patient's life (Zhi, 2015).

Countries such as the USA and the United Kingdom are the countries with the highest number of articles on barriers to accessing cancer PC (10). Although they are considered the birthplace of PC, they understand that the development of PC services in a country can be closely linked to knowledge of access barriers<sup>10</sup>. In our findings, 2 studies were carried out in the USA, 1 in Canada, and 2 in European countries (Switzerland and Romania). Among these, in the Brickey *et al.* (Brickey, 2022) studies, the researchers, through exploratory descriptive analysis, sought to assess the reasons why 504 patients with advanced disease from 11 emergency departments in the United States refused to participate in a Phase IV randomized controlled trial comparing two modalities of providing PC. 47% refused for reasons related to the severity of the disease, 28% because of the PC delivery model, 24% misunderstanding or stigma related to PC; general research barriers (16.5%), family/caregivers barriers (11.7%), and medical barriers (< 1%). The findings of refusals were considered barriers to accessing the PC and prevented them from receiving this specialized care and benefiting from it (Brickey, 2022). This study had some limitations. For the literature search, the descriptors 'BARRIERS' and 'STIGMAS' were used. Although 'BARRIERS' and 'STIGMAS' is a well-defined terms in PC publications, they are outside the controlled vocabulary, and it was difficult to predict synonyms. The results commonly evaluated on the implications of stigmas and barriers to PC in the care of cancer patients were few, and in general, the studies were heterogeneous concerning the results and study design. More studies are needed to better characterize the impact of stigmas and/or barriers to PC in the care of cancer patients.

## CONCLUSION

The evidence found indicates that the stigmas and barriers concerning palliative care can impact the care of cancer patients since they do not benefit from the care and support offered by palliative care. The implications of barriers and stigmas related to palliative care in the care of cancer patients identified in previous research were systematized in this study to collaborate for future investigations, elaboration of protocols as well as adaptations, and greater referral to palliative care by professionals. In addition, it can serve as a theoretical and scientific basis to assist in future studies. Additional studies are needed to confirm this finding.

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**Informed Consent:** Not applicable.

**Data Sharing Statement:** No additional data are available.

**Conflict of Interest:** The authors declare no conflict of interest.

**Similarity Check:** It was applied by Ithenticate@.

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