Revista de Ciencias Médicas de Pinar del Río

ISSN: 1561-3194 **RNPS:** 1877
Rev Ciencias Médicas. 2026; 30(S1): e7211

ORIGINAL ARTICLE

Effectiveness in reducing cancer suffering through the continuos palliative care model

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Citar como: Celada-Cifuentes CM, García-Gutierrez J, Gámez-Pérez A. Efectividad en la reducción del sufrimiento por cáncer con el modelo de cuidados paliativos continuos . Rev Ciencias Médicas [Internet]. 2026 [citado: fecha de acceso]; 30(S1): e7211. Disponible en: http://revcmpinar.sld.cu/index.php/publicaciones/article/view/7211

Received: May 6, 2026
Accepted: May 7, 2026
Published: May 7, 2026

ABSTRACT

Introduction: deducing suffering is the essence of Palliative Medicine. Primary Health Care is the setting for multiple care strategies for people suffering from cancer; the continuous palliative care model allows real-time evaluation of effectiveness and adjustment of intersectoral and interdisciplinary actions.
Objective: to evaluate the effectiveness of the continuous palliative care model in reducing multidimensional suffering caused by cancer.
Methodology: mixed-method technological development research, with a care intervention in which the continuous palliative care model was implemented in a sample of 38 users. The study was conducted with scientific rigor to ensure validity; three instruments and the suffering reduction evaluation index were applied. Ethical requirements were met.
Results: the complexity of cancer-related suffering generated a strategy that grouped identification of suffering, intervention, immediate evaluation, and delayed evaluation. Easy crying was the most frequent sign. Anxiety and depression were constant symptoms across the five care codes. Continuous palliative care focused on three pillars for multidimensional assistance, with the spiritual sphere providing the greatest opportunities for strength development. Overall, it demonstrated high effectiveness in reducing suffering.
Conclusions: continuous palliative care model is effective in assisting cancer patients, from the moment of clinical suspicion until the end of life. Due to its high effectiveness, it is applicable to both rural and urban settings.

Keywords: Bioethics; Continuity of Patient Care; Integrative Palliative Care; Palliative Medicine; Psychological Distress; Medicina Paliativa.

ISSN: 1561-3194 **RNPS:** 1877
Rev Ciencias Médicas. 2026; 30(S1): e7211

INTRODUCTION

Reducing suffering is the center of every care strategy. The approaches of palliative medicine in Oncology vary from one era to another. Cancer is both cause and effect of suffering, which is why actions ranging from community initiatives to national and global care policies are sought. This challenge is addressed with the new continuous palliative care model.

Currently, there is a quest to understand cancer-related suffering to create and improve care methods. Serious health-related suffering (SHS), according to the Lancet Commission definition, is: "pain, suffering, and intense distress associated with conditions that may lead to death or that limit life, which cannot be alleviated without medical intervention and can be alleviated with palliative care intervention."[1]

Benito et al.,[2] define suffering as a specific state that occurs when a person's integrity is threatened or broken. A medical intervention might appear appropriate, but at the same time become a source of suffering itself. It is necessary to differentiate between physical pain and suffering and to evaluate the effectiveness of an intervention that recognizes the fragility and vulnerability of the human being.

There are various organizations, strategies, and definitions of palliative care worldwide that confer great relevance to care. The present research provides the results of implementing the continuous palliative care model in reducing cancer-related suffering, according to the global development indicators of the World Health Organization (WHO). With an integrated health service and a specialized consultation at the primary care level.[3]

Before the main theoretical references, it is recognized that suffering associated with cancer is a multicausal mystery, a complex experience that encompasses different dimensions and affects the sick person, their family, and the community. In this case, suffering must be conceptualized, identified, and treated in clinical practice, within a theoretical-methodological model consistent with the social reality of a community and at a specific time.

This imposes the need to diagnose cancer-related suffering and implement the three pillars of the model: effective communication, symptom control, and strength development. With five care codes that reflect accompaniment from clinical suspicion to the end of life. As a scientific novelty, care during cancer diagnosis or clinical suspicion is addressed in a singular way, and these patients are given visibility through code C-0; furthermore, the effectiveness index in suffering reduction is applied as a numerical indicator.[4] Given this, the present research aimed to evaluate the effectiveness of the continuous palliative care model in reducing multidimensional suffering caused by cancer.

ISSN: 1561-3194 **RNPS:** 1877
Rev Ciencias Médicas. 2026; 30(S1): e7211

METHODS

Technological development research with a mixed approach was conducted in a Primary Health Care institution. The model was implemented in a specialized consultation in the Mariel municipality, at the Orlando Santana Valdés Teaching Polyclinic. The study allowed identification of cancer-associated suffering, with an intentional stratified sample of 38 users from urban and rural areas.

Effectiveness was estimated as the degree to which the intervention reduces suffering according to the perception of users receiving continuous palliative care. Suffering, as a complex and dependent variable, was evaluated in four analytical categories. Instruments validated by the Delphi method according to expert criteria were applied, with high empirical validity. These were: the Brief Guide to identify and treat cancer-related suffering, the Care Plan, and the Satisfaction Survey to evaluate users' perception of suffering reduction.

Effectiveness is evaluated with the Suffering Reduction Evaluation Index (ERS). ERS = (ESM+ISM) X (B+S) / 1000.

Null effectiveness (0-10); low effectiveness (11-20); intermediate effectiveness (21-30); and high effectiveness (31-40). Where ESM represents the evaluation of multidimensional suffering, ISM corresponds to the intervention of multidimensional suffering, includes the three pillars and if it is continuous, this means it has a chronological sequence in the five care codes. B: Immediate well-being and S: Satisfaction level. All components have a range of 0 to 100.

RESULTS

Identification of cancer-related suffering in the specialized consultation of continuous palliative care and Oncology

Patients were characterized by sex and age in a sample of 38 patients, 18 female and 20 male. Regarding the initial location or primary tumor, a heterogeneous distribution was presented that included 11 anatomical locations, with higher incidence in breast cancer 24 %, lung cancer 18 %, and colon cancer 13 %. In the characterization according to place of origin, patients originated from five localities: Urban Mariel, Quiebra Hacha, Boca-Mojica-Henequén, Nodarse, Cabañas, and Zayas. The highest incidence was among inhabitants of the town of Urban Mariel and Quiebra Hacha, with 53 % and 16 % respectively. According to the characterization of the link with the primary caregiver, it was found that 47 % received care from their spouses and 26 % from their children; the minority received care from siblings and parents. 21 % did not have the accompaniment of a well-defined primary caregiver.

In the distribution of patients according to the care code, the highest frequency was identified in codes C-0, clinical suspicion, and C-4 without specific oncological treatment in progression, as observed in Figure 1.

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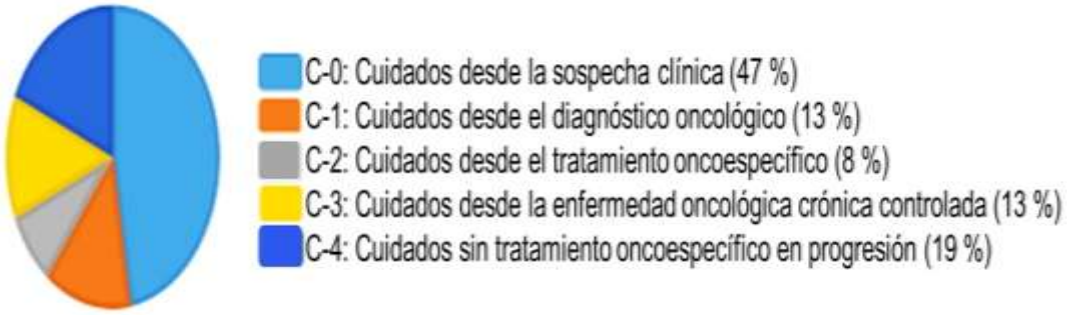

Fig. 1 Incidence of continuous palliative care code in the first specialized consultation.

It was identified that tears are the main language of suffering. Family members tend to limit these expressions, with phrases such as: "don't cry", "but say something", "dry your tears", which prevent the patient from releasing the emotional burden they carry. Easy crying was quantified at 60 %. Figure 2 shows the incidence of signs in each of the codes.

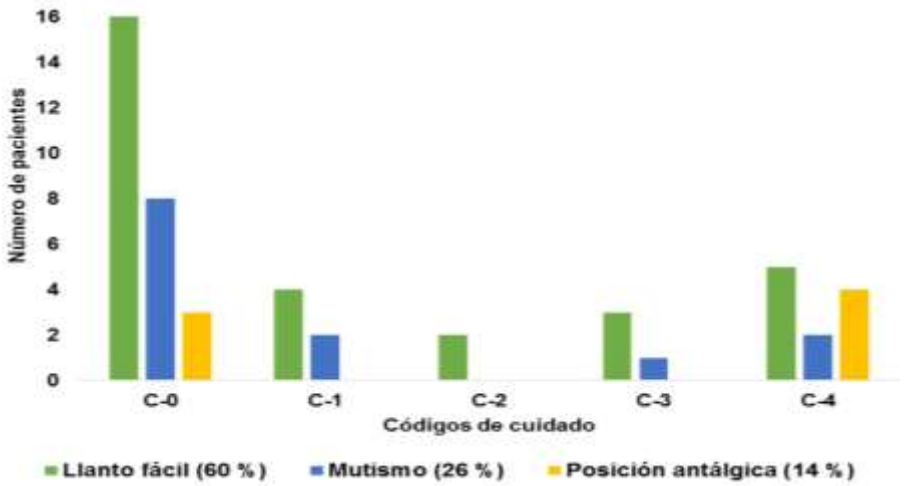

Fig. 2 Signs of suffering in patients assisted in the specialized consultation.

Patients were characterized according to the ESAS Scale and care codes. The ESAS scale was useful and effective from the first contact, which was complemented with expressions such as: "yes, I feel anxious and depressed". Given this, communication had to be more precise and careful so as not to increase suffering. The most relevant symptomatology was in C-0 and in C-4. The three symptoms with the highest incidence were: anxiety (34 %), depression (25 %), and pain (13 %). Figure 3 shows the nine symptoms evaluated.

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Rev Ciencias Médicas. 2026; 30(S1): e7211

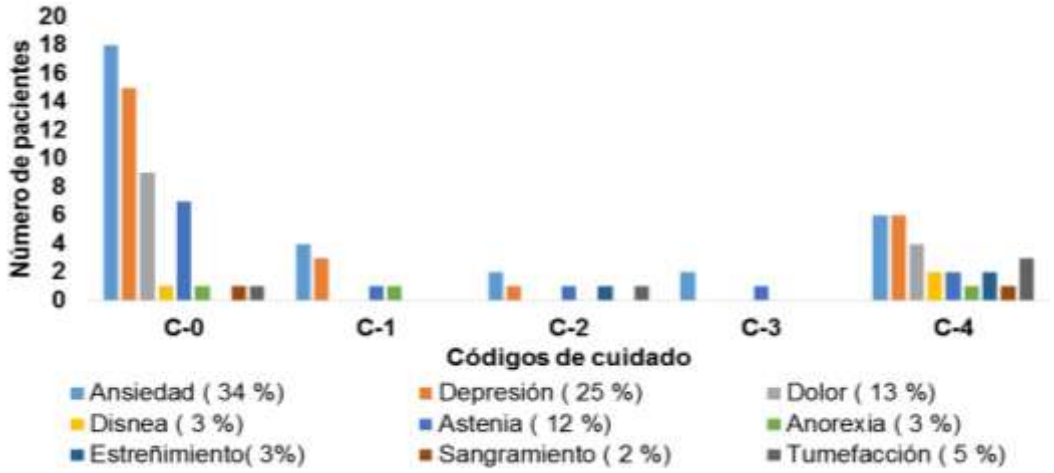

Fig. 3 Incidence of symptoms in patients assisted in the specialized consultation.

Qualitative results allowed characterization of patients by categories: physical, spiritual, emotional, and socioeconomic. More threats than strengths were identified, which points to suffering that may increase and extend over time. The results are evidenced in Figure 4.

Fig. 4 Causes of suffering, threats, and strengths according to the different dimensions of patients assisted in the specialized consultation.

ISSN: 1561-3194 **RNPS:** 1877
Rev Ciencias Médicas. 2026; 30(S1): e7211

When evaluating the physical sphere, a high perception of suffering and threats was identified, as well as in the emotional sphere where a high incidence of causes of suffering was found. The strengths identified in these two spheres do not equate all threats. The spiritual dimension constitutes the greatest strength and with minimal threats; as a crucial fact, it is the only sphere where strengths exceed threats. The socioeconomic dimension indicates high incidence in causes of suffering and threats.

Specialized intervention for reducing cancer-related suffering according to the continuous palliative care model

In the analysis of the suffering hierarchy, it was identified that cancer has a systemic relationship with multiple causes. A paradox was visualized in the development of strengths in all dimensions; however, the spiritual dimension allowed a healing intervention of greater impact.

The immediate intervention was based on specialized assistance, after identifying suffering, with the urgency of not delaying competent care; the continuous palliative care model applied three pillars:

1. Effective communication: explain aspects about the disease and treatment possibilities; explain about the accompaniment that will be received throughout the process.
2. Symptom control: control of symptoms that can be modified with treatments according to evidence-based medicine, with the use of the ESAS scale; guide for obtaining necessary medications; coordinate with the family doctor the use of opioids and provide necessary follow-up for control of refractory symptoms and high-complexity situations.
3. Strength development: coordinate good family dynamics and support structure, manage consultations for hospitals according to regionalization; link care in a transdisciplinary way and maintain follow-up according to needs according to the care code.

The intervention began with communication with the patient and caregiver, value was given to their emotions from a holistic approach, this allowed symptom control with strategies standardized in national and international protocols.

Qualitative and quantitative evaluation of suffering reduction from the users' perspective

User well-being and satisfaction confirms the effectiveness of the intervention immediately and later. 95 % report feeling well and 5 % regular, with the following responses: "well, because I am calmer", "because I understand my illness more", "because I know how the procedure will be", and "because I have people who will support me"; immediate well-being is quantified at 95 %.

Suffering in the physical dimension is related to the high level of satisfaction in symptom control, after the intervention. Satisfaction greater than 91 % was verified in all survey items. In the socioeconomic dimension, 15,8 % dissatisfaction was found. As a disruptive finding, respect for emotions was identified, with greater satisfaction according to users' perception compared to symptom control. The model proved to be a reference in integral and humanized care, suitable for assisting cancer patients from the first encounter; these results are presented in Figure 5.

ISSN: 1561-3194 **RNPS:** 1877
Rev Ciencias Médicas. 2026; 30(S1): e7211

Fig. 5 Degree of user satisfaction with the specialized consultation of the Mariel municipality.

Effectiveness was evaluated with the index ERS= 37,2. In the analysis of this result, it corresponds to high effectiveness as it is in the determined ranges of 31 to 40. A social value is added by considering that the research promotes local strategies centered on social justice and universal coverage, in contexts of marked vulnerability.

DISCUSSION

In recent decades, a marked increase in cancer incidence and mortality is similarly identified; figures rise in low-income countries that do not have technology for timely diagnosis and treatment.[5]

In Cuba, the current cancer control program has algorithms for breast, lung, and colon cancer as they coincide with high incidence at the national level; however, the proposed codes do not allow comparison with previous research in Primary Health Care because none includes code C-0.[6]

Domínguez Cruz,[7] considers that patients in urban populations have greater possibilities than those living in rural areas. However, having a palliative care program integrated into the health system guarantees safer patient care, without discrimination or exclusion. Other authors such as Ismael et al.,[8] reflect aspects similar to those addressed by Cuba for cancer control; furthermore, reference is made to the legislative order. This coincides with the recent Health Law that gives rise to important changes.

The Pan American Health Organization considers that inequity in access to care in PHC are barriers that must be addressed.[9] According to Abreu et al.,[6] there are some threats and weaknesses that make cancer control difficult; however, there are opportunities such as the presence of a unique and free National Health System, with political commitment, which allows advancing with local strategies.

ISSN: 1561-3194 **RNPS:** 1877
Rev Ciencias Médicas. 2026; 30(S1): e7211

Alterations in family dynamics and the lack of a competent caregiver for the task increase the need to incorporate the participation of other community actors for accompaniment. Agreement is found with Alonzo et al.,[10] that oncological pain is a cause of suffering; this can annul and incapacitate the patient. In the model, the development of strengths such as the family, social, and spiritual support network is proposed, which transcend in the reduction of symptoms such as pain, anxiety, and depression.

Follow-up with care codes allows verifiable continuity in each of the periods. Code C-0 symbolizes the greatest challenges before inequities in access to molecular diagnosis of personalized oncology. Walter et al.,[11] agree in verifying that the shortest time for diagnosis occurs in breast cancer detected by screening, followed by lung cancer and symptomatic breast cancer. Pancreatic cancer is diagnosed by its symptomatology in late stages, which causes a transition from C-0 to C-4, without treatment possibilities.

Other authors such as Coletti,[12] agree that crying alleviates pain through hormone release and improves perspective on problems. Crying reduces stress by decreasing cortisol, releasing oxytocin, and promoting calm. These elements manifest from the quality of the relationship in the doctor-patient-caregiver triad.

Donohue et al.,[13] consider that anxiety and depression should be evaluated; they suggest deeper studies, mentioning the Patient-Reported Outcome Measurement Information System (PROMIS) and other instruments such as the Mood and Anxiety Questionnaire (MASQ) and the Positive and Negative Affect Schedule (PANAS). However, evaluation of distressing symptoms with the ESAS scale is feasible for clinical oncology in routine practice with a high care burden.

Findings coincide with national authors such as Reyes et al.,[14] when presenting other tools to recognize suffering. Bátiz et al.,[15] provide an approach to a palliative culture that visualizes the human being integrally with needs and strengths in all dimensions, with marked emphasis on the spiritual sphere. Tegene et al.,[16] perform a deep analysis and report that 56.1% of cancer patients experience a financial crisis considered a catastrophe. Cancer diagnosis and treatment constitute one of the greatest health inequities.

Morales et al.,[17] present end-of-life care from the experience of Cuban oncologists in hospital care. Care actions are aimed at different situations that can be identified, according to the degree of complexity in refractory symptoms. Each care code in the model demands empathy to generate security, tranquility, and peace in patients and their families. The high level of immediate well-being is an important component in effectiveness.

User satisfaction adds to the degree of well-being; to evaluate greater impact, inquiry is made later, which allows fewer biases in opinion. Results are compared with what Bermejo et al.,[18] propose, who study the level of satisfaction and dissatisfaction; they consider that this allows raising service quality. Satisfaction studies allow recognizing how users experience care; they coincide with a high level of satisfaction with symptom control; however, reference is made only to end-of-life care, which corresponds to C-4.

Upon completion, it was not feasible to compare the effectiveness index results, as researchers did not find other similar studies in the systematization performed. This offers readers a new tool to fulfill the promise of improving access to care, according to the slogan of the celebration of World Palliative Care Day 2025.

ISSN: 1561-3194 **RNPS:** 1877
Rev Ciencias Médicas. 2026; 30(S1): e7211

Other researchers agree on the importance of setting goals and working with interventions.[19] These strategies should establish guidelines within Primary Health Care.(20) Agreement is found in presenting suffering as a catalyst for organized care actions in communities of greater vulnerability. The continuous palliative care model is sustainable from the principle of professional responsibility. High effectiveness is proposed as something achievable and measurable, with potential continuous evaluation that allows maintaining care quality and a sustainable compassionate service.

CONCLUSIONS

Cancer-related suffering, due to its high complexity, constitutes the main dilemma of contemporary Palliative Medicine. The continuous palliative care model allows effective reduction of cancer-related suffering. It is the service user who can quantify suffering reduction and intervention effectiveness. Actions can be replicated in urban and rural contexts of other regions of the country with regulatory frameworks within Primary Health Care.

RECOMMENDATIONS

Implement the proposed instruments within clinical trials that allow quantifying suffering with cortisol levels according to evidence-based medicine. Conduct research in larger samples that allow identifying other advantages of the continuous palliative care model in other non-oncological diseases.

Funding
The research did not receive funding.

Conflict of Interest
No conflict of interest is recognized.

Authorship Contribution
CMCC: Conceptualization: Clinical research, Draft writing, Critical review and supervision.
JGG: Critical review and supervision.
AGP: Critical review and supervision.

All authors approved the final version.

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