

ORIGINAL ARTICLE

EVALUATION OF SYMPTOMS IN ONCOLOGICAL PATIENTS ADMITTED TO AN EXCLUSIVE PALLIATIVE CARE UNIT

Karen Evellin Souza Neves¹, Talita Silva Muniz², Karine Marques Costa dos Reis³

ABSTRACT

Objective: to assess symptoms in cancer patients admitted to an exclusive Palliative Care Unit.

Method: Prospective quantitative study of 30 advanced cancer patients admitted to a specialized unit in Distrito Federal, Brazil. Data were collected between November 2018 and May 2019, in two moments: on admission and 72 hours after admission. Two validated scales were used to assess symptoms and functionality, and paired Wilcoxon test was used to assess the score at both moments.


Results: Functionality worsened in thirty (30) individuals, but not significantly ($p = 0.564$). As for the management of symptoms, the median was significantly lower for pain ($p = 0.032$) and higher for tiredness ($p = 0.020$) and drowsiness ($p = 0.012$).


Conclusion: The study suggests that palliative care is crucial in the management of pain in cancer patients, improving quality of life, in addition to enhancing the role played by nurses in the delivery of this care.


DESCRIPTORS: Signs and Symptoms; Palliative care; Oncology; Pain; Nursing.

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¹Nurse. Escola Superior de Ciências da Saúde. Brasília, DF, Brazil. 

²Nurse. Escola Superior de Ciências da Saúde. Brasília, DF, Brazil. 

³Nurse. Master degree in Nursing. Nursing Professor from Escola Superior de Ciências da Saúde. Brasília, DF, Brazil. 

AVALIAÇÃO DE SINTOMAS EM PACIENTES ONCOLÓGICOS INTERNADOS EM UNIDADE DE CUIDADOS PALIATIVOS EXCLUSIVOS

RESUMO

Objetivo: avaliar os sintomas em pacientes oncológicos internados em uma Unidade de Cuidados Paliativos exclusivos.

Método: estudo quantitativo prospectivo de 30 pacientes oncológicos em fim de vida, internados em unidade especializada do Distrito Federal, Brasil. Coletaram-se dados entre novembro de 2018 e maio de 2019, em dois momentos: na internação e após 72 horas. Utilizaram-se duas escalas validadas para avaliação dos sintomas e funcionalidade e o teste de Wilcoxon pareado para avaliação do escore nos dois momentos.

Resultados: em 30 indivíduos, evidenciou-se piora da funcionalidade, porém não significativa ($p=0,564$). Quanto ao manejo dos sintomas, a mediana foi significativamente menor para dor ($p=0,032$) e maior para cansaço ($p=0,020$) e sonolência ($p=0,012$).

Conclusão: o estudo sugere que os cuidados paliativos podem ter papel fundamental no manejo da dor em pacientes oncológicos, colaborando com a melhora da qualidade de vida, além de contribuir para a atuação do enfermeiro.

DESCRITORES: Sinais e Sintomas; Cuidados Paliativos; Oncologia; Dor; Enfermagem.

EVALUACIÓN DE SÍNTOMAS EN PACIENTES ONCOLÓGICOS INTERNADOS EN UNIDAD DE CUIDADOS PALIATIVOS EXCLUSIVOS

RESUMEN:

Objetivo: analizar síntomas en pacientes oncológicos internados en una Unidad de Cuidados Paliativos exclusivos.

Método: estudio cuantitativo prospectivo de 30 pacientes oncológicos en final de su vida, internados en unidad especializada de Distrito Federal, Brasil. Se obtuvieron los datos entre noviembre de 2018 y mayo de 2019, en dos momentos: en la internación y tras 72 horas. Se utilizaron dos escalas validadas para evaluación de los síntomas y funcionalidad, así como test de Wilcoxon pareado para evaluación del score en los dos momentos.

Resultados: en 30 individuos, se evidenció empeoramiento de la funcionalidad, sin embargo no fue significativa ($p=0,564$). Acerca del manejo de los síntomas, el promedio fue significativamente menor para dolor ($p=0,032$) y mayor para hastío ($p=0,020$) y somnolencia ($p=0,012$).

Conclusión: el estudio sugiere que los cuidados paliativos pueden tener papel fundamental en el manejo del dolor en pacientes oncológicos, ayudando con el mejoramiento de la calidad de vida, además de contribuir para la actuación del enfermero.

DESCRIPTORES: Señales y Síntomas; Cuidados Paliativos; Oncología; Dolor; Enfermería.

INTRODUCTION

Increase in life expectancy of the population reflects the increasing predominance of some types of illnesses. Cancer, a non-communicable disease (NCD), is among the leading causes of death of the world population^(1,2). In Brazil, it is estimated that in the 2020-2022 triennium there will be 625 thousand new cases of cancer⁽³⁾.

Faced with the impact of the disease, scientific advances have been made that led to the emergence of new treatments, which have increased the life expectancy of this population. Thus, there was an increase in patient survival. However, the treatments failed to provide better quality of life and control of the symptoms of these individuals⁽⁴⁾.

Palliative Care (PC) provides the theoretical knowledge necessary to modify this reality and offer greater dignity to the patients⁽⁵⁾. This care is defined as the active holistic care of individuals with serious health-related suffering, especially those at the end of their lives. It is based on symptom control, interdisciplinary work and the recognition of death, assuming the individuals as an integral being and not dissociated from their families⁽⁶⁾.

In this context, PC proposes to modify patient care through some principles, such as promoting pain relief and providing quality of life; and, for that, an efficient evaluation of the symptoms presented by the patient due to the extent and progression of cancer is necessary⁽⁴⁾.

In 2014, the World Health Organization (WHO) published the Global Atlas of Palliative Care, with the results of its survey on the progression of this philosophy of care around the world. Brazil was classified in group 3A, which means that the provision of palliative care is offered in an isolated way, irregularly, with limited availability of medicines such as morphine and the supply of these services is insufficient to meet the needs of the country's population⁽⁷⁾.

In view of the relevance of the service and the divergence of data published in meta-analysis, which does not identify the improvement of symptoms from the service in this care philosophy⁽⁸⁾, the scope of the present study is to collaborate in the identification of clinical effects produced by hospitalization in this type of service. Therefore, the study aimed to evaluate the symptoms of cancer patients admitted to an exclusive palliative care unit, which is justified by the need to extend research on the service in order to improve and consolidate this practice. Based on this, the following guiding question was proposed: which symptoms improve after 72 hours of admission to an exclusive palliative care unit?

METHOD

A prospective quantitative study conducted between November 2018 and May 2019. The sample was initially composed of 30 cancer patients. However, in 14 participants, symptom assessment was discontinued after 72 hours due to worsening in functionality and cognition. All selected patients were hospitalized in an exclusive Palliative Care Unit of Distrito Federal.

This unit has been operating for 25 years and has 19 beds for cancer patients, with an occupancy rate of 70%. There are seven wards, each with three beds. Sample calculation used hospitalizations in the previous year (80), the margin of error was 5% and the confidence level was 90%.

Cancer patients without indication of disease-modifying treatment, over 18 years old, hospitalized and with preserved level of consciousness. Individuals in palliative home care

and using radiotherapy or palliative chemotherapy were excluded, as they might could experience worsening of symptoms.

Interviews were carried out at the bedside, in two moments: on admission and 72 hours after the first assessment. The first analysis would be done up to 24 hours after the patients' hospitalization in the unit. The variables were obtained through interviews with the participants, using a socio-demographic questionnaire prepared by the researchers, as well as two scales validated in Portuguese, to assess functionality and symptoms.

The Palliative Performance Scale (PPS), applied by the researcher, assesses functionality based on the functions of walking, activity and evidence of the disease, self-care, intake and level of awareness. For full performance and autonomy of these functions, a score of 100% is assigned, and this score decreases to 0 as the disease progresses and the patient is in the last 48 hours of life⁽⁹⁾.

As for the Edmonton Symptom Assessment System (ESAS) scale, it is a Likert-type quantitative assessment tool (0 to 10), completed by the participants to avoid measurement bias. This scale consists of the patient's self-report for the intensity of nine physical and psychospiritual symptoms: pain, tiredness, nausea, sadness, anxiety, drowsiness, appetite, well-being and shortness of breath. For each symptom assessed, the patient was asked to assign a score from zero (absence of symptoms) to ten (worst symptom manifestation). The ESAS score has a maximum value of 90 points⁽¹⁰⁾.

Data analyzes were performed using the SPSS (Statistical Package for the Social Sciences) program 23, 2015. The level of significance used throughout the study was 5%. Qualitative variables were presented using frequency (n) and percentage (%). For comparison of ESAS and PPS scales at the two moments of data collection, the distribution of the variables under study was first assessed by the Kolmogorov Smirnov test. For most variables, the null hypothesis of normality of the data was rejected and, therefore, non-parametric tests were used to evaluate the dependent samples. The most suitable test was the paired Wilcoxon test, which evaluates measurements of the position of two related samples.

The study was approved by the Ethics and Research Committee under protocol number 2,889,109.

RESULTS

Thirty (30) individuals, of whom 19 (63.3%) were male and 11 (36.7%) were female were evaluated in the study. The predominant age group was 50-59 years old (30%); of the total number of participants, 14 (46.7%) reported being married, 16 (53.3%) had incomplete primary education and 21 (70%) came from the Emergency Care Unit (UPA), as shown in Table 1.

Table 1 – Socio-demographic characterization of cancer patients admitted to an exclusive palliative care unit (N = 30). Brasilia, DF, Brazil, 2019 (continues)

Variable	N	%
Gender		
Male	19	63.3
Female	11	36.7

Age		
20-29 years	1	3.3
30-39 years	2	6.7
40-49 years	6	20
50-59 years	9	30
60-69 years	7	23.3
70-79 years	2	6.7
80 or over	3	10
Marital status		
Married	14	46.7
Single	9	30
Divorced	4	13.3
Widowed	3	10
Education		
Incomplete primary school	16	53.3
Complete primary school	8	26.7
Complete secondary school	4	13.3
Illiterate	2	6.7
Origin		
UPA	21	70
Hospitals	5	16.7
Home care	4	13.3
Total	30	100

Regarding the clinical characterization (Table 2), there is a higher incidence of cancer of the digestive system, 12 cases (40.0%), of which the most prevalent types are gastric and colorectal cancer, both with four cases (13.3%). Metastasis occurred in 22 (73.3%) of the evaluated participants, with bone metastasis being the most common occurring in six patients (19.9%), followed by pulmonary metastasis, present in four patients (13.3%). The prevalent time elapsed since diagnosis was up to 11.9 months.

Table 2 - Clinical characterization of cancer patients admitted to an exclusive palliative care unit (N = 30). Brasília, DF, Brazil, 2019 (continues)

Variable	n	%
Medical Diagnosis		
Cancer of the Digestive System	12	40
Cancer of the Respiratory System	7	23.3
Cancer of the Reproductive system	5	16.7

Head and neck cancer	3	10
Non-solid tumor	2	6.7
Cancer without specification of site	1	3.3
Metastasis		
Yes	22	73.3
No	8	26.7
Time elapsed since diagnosis		
Up to 11.9 months	12	40
12 to 23.9 months	8	26.7
24 to 35.9 months	3	10
36 to 47.9 months	1	3.3
48 to 59.9 months	1	3.3
Over 60 months	5	16.7
Total	30	100

The main caregiver was also assessed, and the result is shown in Figure 1, where the children (43.3%) represented the largest support network, followed by the spouse (23.3%) and siblings (20%).

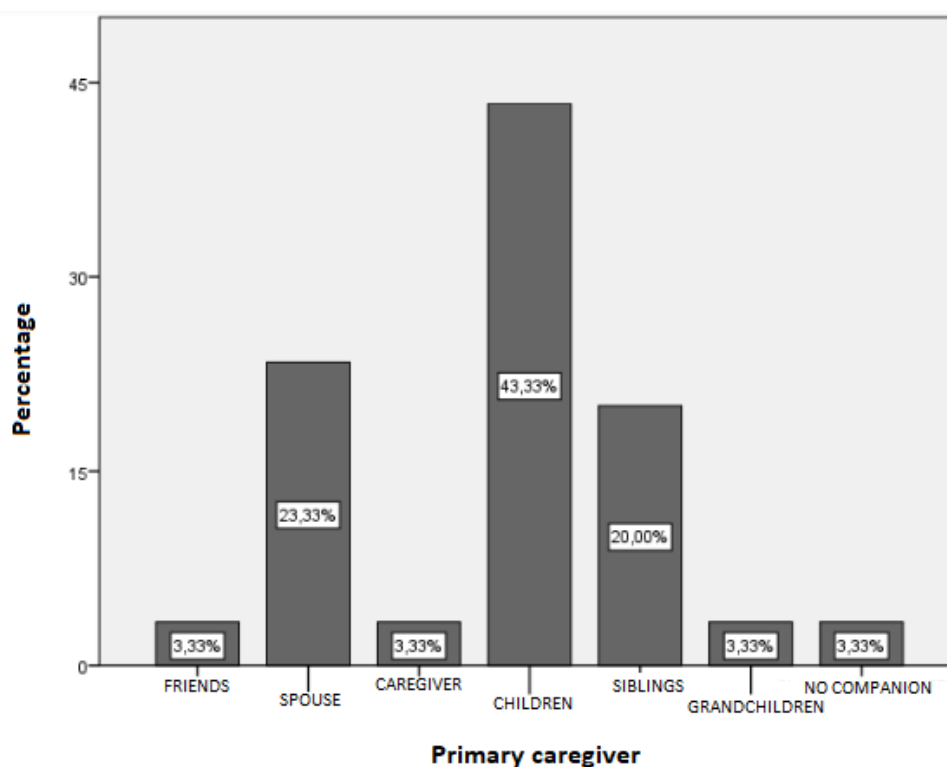


Figure 1 - Primary caregiver, in percentage, of patients with cancer disease hospitalized in an exclusive palliative care unit (N = 30). Brasília, DF, Brazil, 2019

In a prospective and descriptive analysis from the first to the second assessment, the Palliative Performance Scale (PPS) showed stability of functionality in 13 (43.3%) individuals (Table 3). In the first assessment, the PPS presented mean, median and standard deviation of 35.67, 40 and 8.17 respectively. In the second assessment, the values were 33.13, 30 and 7.04 in the same order (Table 4). It is noteworthy that nine (30%) individuals had worsening of their level of consciousness (Table 3).

Table 3 - Analysis of PPS regarding the improvement or worsening of the indicator on admission and 72 hours later (N = 30). Brasília, DF, Brazil, 2019

PPS assessment (comparison)	N	%
Worsening	9	30
Same score	13	43.3
Improvement	2	6.7
Medical discharge	1	3.3
Temporary discharge	3	10
Death	2	6.7
Total	30	100

As for the association between symptom management and hospitalization, as shown in Table 4, there was a statistically significant difference for the variables ESAS - Pain, ESAS - Tiredness and ESAS - Drowsiness, whose median of the values after 72 hours was significantly lower for pain ($P = 0.032$) and higher for tiredness ($P = 0.020$) and drowsiness ($P = 0.012$).

Table 4 - Analysis of association of PPS and ESAS data at admission and after 72 hours (N = 30). Brasília, DF, Brazil, 2019 (continues)

Variable	On admission					72 hours later					P*		
	N	Absent	Mean	Standard Deviation	Median	Interquartile range	N	Absent	Mean	Standard Deviation		Median	Interquartile range
PPS	30	0	35.67	8.17	40	10	16	14	33.13	7.04	30	10	0.564
ESAS	30	0	35.87	15.51	34	24.75	16	14	35.31	16.64	41.50	27	0.755
ESAS – Pain	30	0	3.77	3.47	3.50	7	16	14	1.50	2.16	0	3	0.032
ESAS – Tiredness	30	0	3.53	3.10	3.50	5.25	16	14	4.50	3.25	5	6.25	0.020
ESAS – Nausea	30	0	3.20	3.81	1.00	5.50	16	14	2.19	3.06	0.50	4.50	0.423

ESAS – Sadness	28	2	4.61	4.07	4.50	8	15	15	3.93	3.92	3	8	0.408
ESAS – Anxiety	30	0	3.93	4.03	3	8	16	14	4.25	3.75	4.50	8	0.396
ESAS – Drowsiness	29	1	4.28	3.39	4	7.00	15	15	6.53	3.11	8	3	0.012
ESAS – Appetite	30	0	5.67	3.39	6.50	5.50	16	14	6.63	2.99	7.50	4	0.409
ESAS - Well-being	29	1	4.28	2.90	4	5.50	15	15	3.07	2.66	2	3	0.507
ESAS - Shortness of breath	30	0	3.20	3.52	2.50	6	16	14	3.56	3.83	3	7.50	0.778

* Paired samples Wilcoxon test

DISCUSSION

Most patients in this study were adult married men aged 50-59 years, with low educational level and whose primary cancer site was the GI tract. Such data is consistent with a survey by the National Cancer Institute José Alencar Gomes da Silva (INCA)⁽³⁾.

For cultural reasons, men tend to avoid health care environments, either because they believe they are invulnerable, or because they neglect their self-care⁽¹¹⁾. This attitude of delaying the search for health services causes health intervention to occur only in the most advanced stages of the disease, which is related to the insertion of individuals in palliative care only in these phases. The data obtained by this study, where 19 individuals (63.3%), who are men, received a diagnosis less than a year ago and are already receiving exclusive palliative care corroborate this information.

According to an INCA estimate, the prevalent age group for cancer is between 50 and 69 years⁽³⁾. This fact is consistent with the increased exposure to carcinogens due to the change in lifestyle in relation to work, food, and the industrialization process, which can lead to an increase in the number of cancer cases at this age.

Regarding the marital status of the participants, it appears that most of them count on a support network. In fact, human beings need a support network - a set of systems and significant people, with whom they have an affectionate relationship - capable of influencing people's subjective well-being and offering psychological, social and cultural support and emotional in times of crisis or change⁽¹²⁾. The support network, which impacted the present study, may be associated with better controlled symptoms, where the total ESAS at admission and 72 hours after has an average value of 35.83 and 35.31 and standard deviation of 15.71 and 16.64 respectively.

Regarding the educational level, it is known that lack of knowledge contributes to worsening of quality of life, in addition to inadequate self-care and late recognition of signs and symptoms, creating barriers to treatment adherence. Studies suggest that greater knowledge about the disease contributes to greater treatment adherence, as well as to making decisions about it⁽¹³⁾.

As for medical diagnosis and primary tumor site, this study corroborates international data according to which GI tract cancer is more prevalent in transition countries⁽²⁾. These data are consistent with INCA records, which, despite dividing the incidence of cancer by categories, indicate significant numbers of cases of cancer in that site. Bowel cancer (1.4 million cases) ranks third in the list of cancers of highest incidence in the world. In men, bowel cancer (10.0%) also ranks third, and stomach cancer (8.5%) fourth. In women, bowel cancer ranks second (9.2%) and stomach cancer ranks fifth (4.8%)⁽³⁾.

Pain is one of the most prevalent physical symptoms in cancer, and according to the NANDA -1 Taxonomy 2018-2020, it can be characterized by a patient's slower ability to keep performing regular activities, intensity self-report using standardized pain scale and/or facial pain expression, among others⁽¹⁴⁾. This pain can be caused by the treatments administered, clinical condition and cancer site. The incidence of pain in advanced stages of cancer is approximately 70 to 80%⁽¹⁵⁾.

Regarding the provision of care to patients in a PC unit, interdisciplinary and comfort-oriented care showed a significant improvement in pain, whose mean score on admission was 3.77, dropping to 1.5 after 72 hours of hospitalization. Corroborating the present study, pain improvement was observed within 48 hours of admission in a retrospective study that evaluated pain management in cancer patients⁽¹⁶⁾.

According to an integrative review on pain at the end of life, carried out in 2016, the high prevalence of this symptom, as well as its impact on patients' comfort and quality of life were discussed, and palliative care proved to be highly successful in the management of pain⁽¹⁷⁾. Evidence regarding the effectiveness of the PC philosophy in the adequate pain management was also confirmed in a prospective longitudinal study. In the referred study, comfort-based care as well as concrete pharmacological treatment significantly reduced pain⁽¹⁸⁾.

There was a worsening in the score of tiredness, also called fatigue, as this symptom is more difficult to define due to its multi-causal and multidimensional concept⁽¹⁹⁾. It is noteworthy that the concept of cancer-related fatigue most commonly referred to in the literature is an overwhelming and permanent sensation of extreme tiredness, which does not improve with proper rest and is associated with numerous other uncomfortable symptoms that are difficult to manage⁽¹⁹⁾.

The NANDA-1 Taxonomy 2018-2020 presents some defining characteristics for fatigue such as insufficient energy, introspection, among others, and may be related to anxiety, environmental barriers or stressors⁽¹⁴⁾. Thus, despite the high incidence of fatigue in patients with advanced cancer, due to the metabolic demands of the cancerous tumor that cause weakness and fatigue⁽²⁰⁾, there was no improvement after 72 hours of evaluation.

The tiredness of the individuals assessed in this study increased from a mean score of 3.53 on admission to 4.50 after 72 hours of hospitalization. This data is consistent with a descriptive cross-sectional study carried out in 2017⁽²¹⁾, which emphasized the importance of assessing tiredness in cancer patients in palliative care, since these individuals have a greater tendency to experience this symptom⁽²¹⁾.

The symptom of drowsiness, as well as that of fatigue, increased, from a mean score of 4.28 in the first assessment to 6.53 in the second assessment. The data obtained by this research is based on the fact that drowsiness is a common symptom during the pathophysiological process of death, which is considered an indicator of disease severity on various prognostic scales⁽²²⁾.

Corroborating the fact that drowsiness is directly related to the progression of the disease, a study with 472 cancer patients demonstrated worsening of the level of consciousness, as well as functionality and difficulty in managing end-of-life symptoms⁽²³⁾. Thus, this symptom is directly related to the greater progression of the disease, represented by the PPS with a mean score of less than 50% at the time of admission (35.67) and worsening after 72 hours (33.13).

On the other hand, some symptoms showed no significant improvement or worsening. Among them are sadness, anxiety and well-being. It should be noted, however, that the complexity of the disease, associated with terminality, makes the management of symptoms complex, especially the psychospiritual ones. A study on the experiences of cancer patients in the last year of life proved this hypothesis: there was a higher prevalence of depression or anxiety, as well as loss of quality of life at the end of life, which are difficult to manage⁽²⁴⁾.

Regarding functionality, the patients assessed in this study have been admitted with significant functional limitations, considerable disease progression and came from emergency services. Twenty-one (21) hospitalized patients came from Emergency Care Units (UPA), corroborating a study whose prospective assessment showed that the sample consisted predominantly of impaired individuals admitted to palliative care⁽²⁵⁾. The referred study showed that, even under these conditions, when patients were assisted by the interdisciplinary PC team, there was a non-significant reduction in the PPS scale with practically the same functionality score.

A survey carried out in the city of São Luiz, Maranhão, in 2018, whose sample consisted both of hospitalized patients and individuals in an outpatient pain management clinic, obtained a predominant PPS score between 80% and 90%⁽²⁶⁾. The method of evaluation of these individuals in outpatient Palliative Care draws attention to the importance of early PC.

Despite the late administration of palliative care to the individuals, a randomized evaluation showed evidence of a longer survival and improvement of symptoms in these individuals, although the latter was not significant⁽²⁷⁾. Some studies also demonstrate a lower cost effectiveness of PC based on less invasive management and without therapeutic obstinacy^(28,29).

When patients receive multidimensional care they feel welcomed and consequently their symptoms are more controlled, which is associated with longer survival. Timely care, therefore, establishes self-determination, and thus, instead of emergency hospitalization, the individuals enjoy outpatient care with likely more effective results⁽³⁰⁾. However, more comprehensive studies with a greater degree of evidence are needed to assess the beneficial effect of PC-based intervention, as demonstrated in a meta-analysis⁽⁸⁾. Therefore, it is necessary to discuss the need to start PC at the time of diagnosis of a serious and life-threatening disease.

In view of the results presented, the limitations of this study are related to the observational methodology, as well as to the small sample size, and the fact that the study was conducted in a single reference center. In addition, the worsening of the level of consciousness (almost 50% of the sample was not assessed for symptoms after 72 hours of hospitalization) may have led to less expressive and significant results in other symptoms. Also, the non-characterization of the participants who died during the follow-up recommends greater caution in the analysis of data regarding the effectiveness of this care model in the management of symptoms.

CONCLUSION

Pain management improved in the patients who started receiving palliative care, contributing to the improvement of the quality of life of these individuals. However, there was an increase in tiredness and drowsiness. Thus, the contribution of this study is to allow reflection on the symptoms that most impact the end of life of these patients, empowering nurses in their joint work with the interdisciplinary health team, in addition to ratifying the importance of palliative care.

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Corresponding author:

Talita Silva Muniz

Escola Superior de Ciências da Saúde

Quadra 301 Conj. 4 Lote 1 – 72300537– Brasília, DF, Brasil

E-mail: talitinha.muniz@gmail.com

Role of Authors:

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - KESN, TSM, KMCR

Drafting the work or revising it critically for important intellectual content - KESN, TSM, KMCR

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