● **Original article**

MULTIDIMENSIONAL PAIN AND SYMPTOM ASSESSMENT SCALE FOR ELDERLY PEOPLE IN PALLIATIVE CARE

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ABSTRACT: The objective was to assess pain and associated symptoms in elderly cancer patients in home-based palliative care. Quantitative and cross-sectional study involving 33 elderly in Foz do Iguaçu, state of Paraná, Brazil, between January and May 2015, using the Edmonton Symptom Assessment System and analyzed using descriptive statistics. The prevalent age range of the elderly was between 60 and 69 years old, mostly women, married, suffering from breast cancer, low income and low education, with other diseases associated with cancer. It was verified that 90.1% of the patients mention daily and continuous moderate burning pain in the site affected by the tumor. The associated symptoms were anxiety, fatigue, depression and reduced wellbeing. Pain and symptom control measures need to be readjusted and health managers need to invest further in order to permit better palliative care at home.
DESCRIPTORS: Elderly; Palliative care; Pain management; Home nursing; Nursing.

ESCALA MULTIDIMENSIONAL NA AVALIAÇÃO DA DOR E SINTOMAS DE IDOSOS EM CUIDADOS PALIATIVOS

RESUMO: Objetivou-se avaliar a dor e sintomas associados em idosos com câncer em cuidados paliativos em domicílio. Estudo quantitativo de corte transversal, realizado com 33 idosos, no município de Foz do Iguaçu, estado do Paraná, no período de janeiro a maio de 2015, por meio do *Edmonton Symptom Assessment System* e analisados pela estatística descritiva. Os idosos tinham a idade prevalente na sexta década de vida (60 a 69 anos), em sua maioria mulheres, casadas, com câncer de mama, baixa renda e baixa escolaridade, e portadoras de outras doenças associadas ao câncer. Verificou-se que 90,1% dos pacientes referem dor moderada, em queimação, diária e contínua no local acometido pelo tumor. Os sintomas associados à dor foram ansiedade, cansaço, depressão e redução do bem-estar. Conclui-se que é necessária a readequação das medidas para controle da dor e sintomas e maior investimento de gestores em saúde para possibilitar melhor assistência paliativa em domicílio.
DESCRITORES: Idosos; Cuidados paliativos; Manejo da dor; Assistência domiciliar; Enfermagem.

ESCALA MULTIDIMENSIONAL DE EVALUACIÓN DEL DOLOR Y SÍNTOMAS EN ANCIANOS EN CUIDADOS PALIATIVOS

RESUMEN: La finalidad fue evaluar el dolor y síntomas asociados en ancianos con cáncer en cuidados paliativos en domicilio. Estudio cuantitativo de cohorte trasversal, desarrollado con 22 ancianos en la ciudad de Foz do Iguaçu, estado de Paraná, Brasil desde enero hasta mayo del 2015 mediante el *Edmonton Symptom Assessment System* y analizados mediante estadística descriptiva. La edad prevalente de los ancianos era entre 60 y 69 años, la mayoría era mujer, casada, con cáncer de mama, baja renta y baja escolaridad, y portadoras de otras enfermedades asociadas al cáncer. Se verificó que 90.1% de los pacientes indican dolor moderado, en quemazón, diario y continuo en el sitio acometido por el tumor. Los síntomas asociados al dolor fueron ansiedad, cansancio, depresión y reducción del bienestar. Se concluye que es necesaria la readecuación de las medidas para control del dolor y síntomas y mayor inversión de gestores en salud para posibilitar mejor atención paliativa en domicilio.
DESCRIPTORES: Ancianos; Cuidados paliativos; Manejo del dolor; Atención domiciliaria de salud; Enfermería.

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● **INTRODUCTION**

The aging process has turned into a public health issue that affects the different spheres of the social, economic, political and cultural structure, with specific demands and needs for changes in the various sectors of public and private care[1]. That is the context for the increased prevalence of Non-Transmissible Chronic Illnesses (NTCI), characteristic of the epidemiological transition in Brazil, which gains intensity as from the age of 60 years, particularly musculoskeletal diseases, Systemic Arterial Hypertension (SAH), cardiovascular diseases, Diabetes Mellitus (DM), chronic respiratory diseases, cerebrovascular disease and cancer. Thus, the demand for health services increases, as the elderly suffer from multiple diseases that continue over a long period, resulting in greater and longer use of these services[2].

Age is an important risk factor for all types of cancer, as both the incidence and mortality increase exponentially after the age of 50 years. This age group demandsattention as, differently from younger patients, radical cancer treatment (surgery, associated or not with adjuvant treatment and radiotherapy/chemotherapy) has been open to discussion, considering that the treatment symptoms interfere significantly in the quality of life[3].

Concerning the treatment, when the patient is beyond therapeutic possibilities, Palliative Care (PC) emerges, an approach that improves the quality of life of patients and their relatives through the prevention and early identification and relief of suffering and the correct assessment and treatment of pain and other physical, psychosocial and spiritual problems[4].

PC can start in the hospital context or in primary care, in this case in stable clinical situations, with progressive chronic illnesses or irreversible conditions, which require less complex care than in the hospital context[5]. Home care contributes to optimize the hospital beds and reintegrates the patient into the family and support group. As for the elderly, home care preserves their autonomy to the most, in the attempt to recover their functional independence[6].

Among the countless symptoms present in individuals with cancer, pain is a cause of intense suffering, disability and losses in quality of life[7]. Being subjective and an individual experience, it is difficult to assess and requires educational support, knowledge and tools from the professionals that contribute to its understanding(8). One of the methods used to assess the pain is the Edmonton Symptom Assessment Scale (ESAS), a tool that uses the combination of physical and psychological symptoms and consists of nine symptoms frequently found in patients with cancer[7].

In view of tools that can survey the pain more precisely, being a very frequent symptom that causes intense suffering to cancer patients, and in view of the importance of PC and control of the symptoms elderly without cure perspectives present, the objective in this study was to assess the pain and associated symptoms in elderly people with cancer in home-based palliative care.

● **METHOD**

A quantitative and cross-sectional study was undertaken, involving elderly people with cancer from a city in the South of Brazil, with an approximate population of 254 thousand inhabitants, of whom 7.2% (18,000) are over 60 years of age, below the national average of 10.8%[9], who are attended by 28 Primary Health Care (PHC) services and four hospitals.

For the sake of this research, the population consisted of elderly people who use the services of the Interdisciplinary Cancer Support Group (GISO), which offers end-of-life care at home to cancer patients without perspectives of cure. To use this service, the patient should be forwarded by the professionals of the Specialized Oncology Center, a referral hospital in cancer care for nine cities in the neighborhood.

The GISO includes health professionals from different areas, who deliver home care through periodical visits, aiming to improve the patient's quality of life and also considering the family as a care object. On the occasion of the research, in January 2015, 717 users were registered.

The sample was initially set at 150 elderly registered in the program. The following criteria were established for inclusion in the study: age 60 years or older, with verbal or written communication skills and updated registration data. Patients who did not comply with these criteria were excluded. To collect the data, which took place between January and May 2015, the elderly's registration form was obtained from the service for the sociodemographic identification and clinical data, such as tumor location, therapeutics and drugs used.

Next, the patient or caregiver/relative were contacted by telephone to invite them to participate in the study, and a questionnaire was applied on the personal, socioeconomic and health monitoringprofile. In this phase, individuals without telephone contact or incorrect data; who had moved; died; and cases in which the patients did not comply with the inclusion criteria or refused to participate were excluded. In case of difficulty to locate the patients at home, the call or visit (in case of a previous appointment) was repeated up to three times, after which the subject was replaced in the order of the list. The final sample consisted of 33 elderly.

To assess the pain and associated symptoms, the Edmonton Symptom Assessment System(ESAS-r) was used in the revised version[10-11]. Through the combination of physical and psychological symptoms, such as: pain, fatigue (lack of energy), sleepiness, nausea, appetite, lack of air, depression (feeling sad), anxiety (feeling nervous) and feeling of wellbeing, this multidimensional scale guarantees a systematic assessment.

The tool is scored on a scale ranging from 0 to 10, in which zero represents the absence of the symptom and ten represents the strongest form of the symptom. This scale can also be graded as of mild (< 4), moderate (≥ 4 and < 7) andsevere intensity (≥ 7)[12]. The patient should assess each of the symptoms according to what he feels at that exact moment, and daily when hospitalized or institutionalized in a retirement home. For this study, the tool was applied a single time, concerning monitoring instead of homecare. For the analysis, the data were included in worksheets and registered as means, minima and maxima, using descriptive statistics.

The study received approval from the Research Ethics Committee under protocol 861.927/2014.

● **RESULTS**

In the group of 33 individuals studied, the female sex was predominant63.64% (n=21), with the sixth decade of life as the mean age 63.64% (n=21), mostly married 51.52% (n=17), with low education level 66.66% (n=22) and low family income 93.94% (n=31). Although 81.82% (n=27) were retired, 18.18% (n=6) depended financially on the family, 39.39% (n=13) lived with relatives, who served as their main caregivers42.42% (n=14), mostly over 60 years of age45.46% (n=15).

The most frequent tumor in the women was breast cancer 27.27% (nine)and in men base of tongue cancer 09.09%(three). The other tumors found were cervical, non-Hodgkin lymphoma, rectal, esophageal, exocervical, laryngeal, spinal, multiple myeloma, lung, endometrial, vaginal, melanoma, nasopharyngeal, skin, prostate and piriform fossae, mentioned in order of prevalence.

Nine elderly (27.27%) were undergoing antineoplastic treatment and the most prevalent was combination therapy 87.88% (n=29), in which radiotherapy and chemotherapy were used associated with surgery or not. Besides traditional medicine, nine subjects (27.27%) reported the use of medicinal plants to seek cure or symptom relief.

Concerning sleep, 54.55% (n=18) reported less than eight hours/day and interrupted sleep75.76% (n=25). Besides cancer, other associated chronic diseases were identified, such as SAH in nine cases(27.27%). Eight (24.24%) reported that, in the last 12 months, they needed hospitalization for different reasons, including pain. What the perceived quality of life is concerned, 75.76% (n= 25) affirmed it was good (Table 1).

In the assessment of the pain and symptoms through the ESAS, the mean score tended to be of average intensity (4├--7). The most stratified symptoms were anxiety, pain and fatigue, demonstrated in Figure 1. Other referred symptoms not contained in the scale were constipation, diarrhea, urinary incontinence and frequent urination, classified as of average intensity.

As for the type, periodicity and duration of the pain, 48.49% (n=16) of the elderly described the pain as "burning", daily 60.61% (n=20) and continuous 48.49% (n=16) (Table 2).

Concerning the use of drugs for pain and other symptom control, the participants cited non-opioid analgesics 69.70% (n=23), followed by opioids 45.45% (n=15), anti-acid drugs andgastric secretion

Table 1 – Sociodemographic and clinical profile of elderly in home-based palliative care. Foz do Iguaçu, PR, Brazil, 2015

Variables	N	%	Variables	N	%
Sex			Retired		
F	21	63.64	Yes	27	81.82
M	12	36.36	No	6	18.18
Age range			Whom the elderly lives with		
60 ⊢--- 70	21	63.64	Relatives	13	39.39
70 ⊢--- 80	9	27.27	Partner	11	33.33
80 and older	3	9.09	Alone	9	27.27
Marital Status			Parenthood of caregiver		
Married	17	51.52	Without caregiver	6	18.18
Divorced	7	21.21	Partner	12	36.36
Widowed	6	18.18	Relatives	14	42.42
Single	3	9.09	Friend	1	3.03
Education			Age of caregiver		
Illiterate	6	18.18	No caregiver	6	18.18
≤ 8 years	22	66.66	< 60 years	12	36,36
> 8 years	5	15.15	≥ 60 years	15	45.46
Income (MW)			Antineoplastic treatment		
< 2	31	93.94	Yes	9	27.27
≥ 2	2	6.06	No	24	72.73
Tumor Location			Therapeutics		
Female			Combination	29	87,88
Breast	9	27.27	Radiotherapy/Chemotherapy	3	9.09
Cervix	2	6.06	Surgery	1	3.03
Other	10	30.30	Other treatment methods		
Male			Medicinal plants	9	27.27
Base of tongue	3	9.09	Prayer	7	21,22
Amygdala	1	3.03	Traditional medicine	17	51.52
Others	8	24.24	Hours of sleep		
Other diseases*			< 8 hours	18	54,55
No	16	48.49	≥ 8 hours	15	45,46
SAH	9	27.27	Typeof sleep		
Diabetes Mellitus	5	15.15	Interrupted	25	75,76
Others	9	27.27	Continuous	8	24,24
Hospitalized past 12 months			Quality of life		
Yes	8	24,24	Very good / Excellent	2	6,06
No	25	75,76	Good	25	75.76
			Bad	6	18.18
Total	**33**	**100**	**Total**	**33**	**100**

*The percentage in this category is not equivalent to 100%, as the same individual can present two or more diseases.
Legend: MW: Minimum Wage (equivalentto R$ 788.00, valid at the time of the data collection); SAH: Systemic Arterial Hypertension.

inhibitors (GSI) 60.61% (n=20), besides drugs for other diseases like anti-hypertensive drugs 45.5% (n=15) (Table 3).

The other drugs, in decreasing order of frequency, were: diuretics, thyroidal hormones, anti-angina and vasodilators, antispasmodic, anxiolytics and hypnotics, antineoplastic, antibiotics, anticonvulsants, antihyperlipidemic, antianemic, anticoagulants, antiemetic and prokinetic agents, antihistamines, anti osteoarthritis drugs, expectorants, laxatives, multivitamins and muscle relaxants.
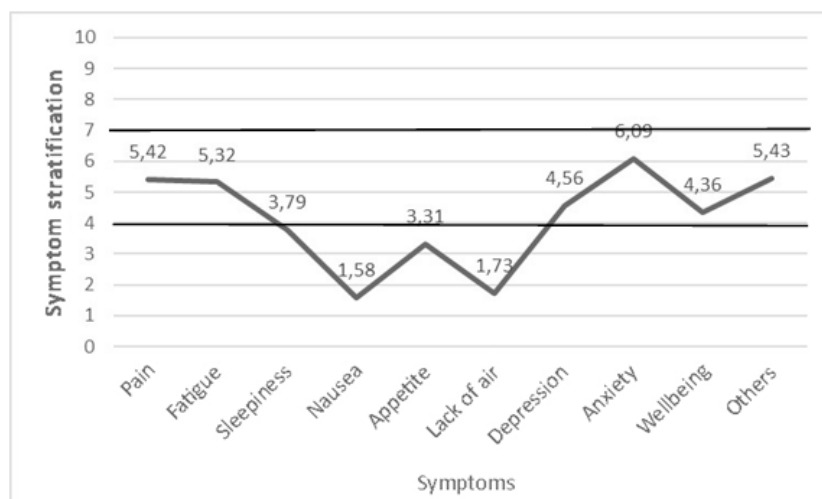

Figure 1 – Self-assessed symptom scores of elderly in Palliative Care based on Edmonton Symptom Assessment System(ESAS-r). Foz do Iguaçu, PR, 2015

Table 2 – Pain characteristics of elderly in home-based palliative care. Foz do Iguaçu, PR, Brazil, 2015

Type of pain	n	%	Periodicity of pain	n	%
Burning	16	48.49	Daily	20	60.61
Throbbing	5	15.15	Two days or more	10	30.30
Absent	3	09.09	Absent	3	09.09
Colic	3	09.09	**Total**	**33**	**100**
Stabbing	3	09.09	**Duration of pain**		
Tensile	2	06.06	Continuous	16	48.49
Stinging	1	03.03	Intermittent	14	42.42
			Absent	3	09.09
Total	**33**	**100**	**Total**	**33**	**100**

Table 3 – Drugs used by elderly in home-based Palliative Care. Foz do Iguaçu, PR, Brazil, 2015

Therapeutic class	No. of drugs used in this class	Main drug used in the class	No. of users	%*
Non-Op analgesics	4	Paracetamol	23	69.70
Analgesics Op	2	Codeine	15	45.46
Anti-acid and GSI	3	Omeprazole	20	60.61
Anti-hypertensive	7	Enalapril	15	45.46
Anti-inflammatory NS	3	ASA	9	27.27
Insulin and OAA	5	Metformin	9	27.27
Antidepressants	4	Amitriptyline	8	24.24

*The percentage of the drugs is related to the number of users, who use one or more drugs, and therefore does not result in 100%.
Legend: Op.: Opioids; NS.: NonSteroids; OAA: Other Anti-diabetic Agents. ASA: Acetylsalicylic Acid.

● DISCUSSION

The ageing rhythm of the population is observed through the Ageing Index (AI), comparing geographical areas and social group. The South ranked first in proportional number of elderly (13.6%) and second in life expectancy (75.5 years)[1]. Together with this population aging process, the number of chronic illnesses rises, such as cancer, being the second cause of death, ranking after cardiovascular diseases only. What the gender is concerned, the "feminization" of population ageing in Brazil is known, explained by the differences in mortality between men and women, which tend to increase in the more advanced age groups[9].

In line with these data, this study appointed the predominance of the female sex, with a low income and low education population, and breast cancer as the most incident type. According to research, the ageing of the female population will provoke a rise in the incidence rates of breast cancer in low and middle-income countries[13], justified by the reduced search for prevention and early detection services[14]. In the male sex, base of tongue and mouth floor cancer showed the highest incidence rates, predominant in the male sex, generally between the fifth and sixth decade of life[15].

About 20% of the elderly remain financially dependent on relatives, who serve as their main caregivers. Taking care of elderly cancer patients in life-threatening situations is a complex event in the course of family life as, besides coping with the care burden, they cope with the process of accepting and preparing the patient and other relatives for the final outcome of the disease[16].

Thus, they seek other treatment methods, such as the use of medicinal plants, in the form of teas, deriving from popular knowledge, and the approach with spirituality, which facilitates the coping with the disease and reduces the suffering. The health professionals could discuss the patients' spiritual needs and use them as a strategy to plan care for cancer patients[17].

These resources were used together with medical therapy, most of which were combination therapies, that is, radiotherapy, chemotherapy and/or surgery. According to the National Cancer Institute (INCA), the therapeutic protocol will depend on the tumor location and staging, as well as on age, tumor size and degree of cell differentiation, besides the diagnostic phase[18]. About the continuity of the antineoplastic treatment in patients with PCs, which was predominant in the study (30%), that is a significant proposal that interferes directly in the length of survival and quality of life of these people[19].

The effects of the disease and the treatmentinclude sleep alteration, described in the literature as frequent in cancer patients. A significant number of elderly in PC manifested interrupted sleep and less than eight hours per day. Sleep disorders, particularly insomnia, are frequent in women with breast cancer, with a higher prevalence than in the general population and more related to the diagnosis of the disease, an aversive condition that, together with the pain, makes the individual identify negative factors of his/her condition in the night period[20]. In cancer patients, the interruption of sleep not only compromises daytime functioning, but also entails fatigue and depression[21].

Fatigue, also presented in the study with a moderate average, is common in elderly under cancer treatment. In another study involving elderly cancer patients identified fatigue in 60 elderly (42%) in chemotherapy. This symptom develops over time and entails cognitive, physical and emotional implications, including the increased need for rest, reduced mental concentration and disinterest in accomplishing daily activities[22], negatively affecting individual wellbeing.

Anxiety and depression, of medium intensity, can be related with low education, low socioeconomic level, chronic and disabling diseases, abandonment and social isolation, besides the lack of physical activity[23]. In addition, it is common in the aging process for concomitant chronic illnesses to manifest, aggravating the symptom and demanding greater care with the management of the disease. The need for hospitalization the elderly in the study mentioned should include a detailed assessment of the cause, as it involved factors like drug interaction, infection and metabolic alteration[24].

Pain is the most frequent symptom, manifested in 90.1% (n=30) of the elderly in the research. The pain symptoms add up to the disabilities related to the cancer and its treatment, which can cause insomnia, anorexia, confinement to the bed, loss of social contact, reduction of professional and leisure

activities[25]. The pain entails stress and suffering not only for the patients, but also for the relatives/ caregivers, and can result in negative emotional, social and economic changes for all stakeholders.

As regards the drugs used, the Ministry of Health indicates opioid analgesics like morphine and codeine, and non-opioid analgesics likeacetaminophen and dipyrone and the antidepressant amitriptylinefor pain control[26]. It should be highlighted that pain treatment can take place through pharmacological (non opioid analgesics, opioid analgesics and adjuvants), non-pharmacological (psychological, physical intervention or radiotherapy) and invasive measures (intrathecal analgesia, nervous block, palliative surgery, neurosurgery). Pain events are observed in patients around the world, affecting up to 80% of patients during the cancer stages. Half of the cases describe it as moderate and 30% as unbearable[27].

When observing the main drugs present in the control of these elderly people's symptoms, the need for reassessment is clear with a view to readjusting the drug therapy, as the presence of pain and its intensity in these individuals are representative, associating the nutritional, psychological and physiotherapeutic interventions with a view to improvements in the quality of life of this population.

It should be highlighted that complementary therapeutic modalities are available, such as music therapy, massage and acupuncture to control the pain and other symptoms, which benefit the quality of life, promote relaxation and pleasure, and also strengthen the patient/family/professional bond[28].

● **CONCLUSION**

The objective in this study was to assess the pain and other symptoms in elderly cancer patients in palliative cancer. The profile of the participating elderly was mainly female, in the sixth decade of life and with low education. The most frequent tumors in women were breast cancer and, in men, base of tongue cancer, with combination therapy. The symptom assessment appointed that 90.1% of the individuals refer "burning" pain in the tumor site, which is continuous and daily.

Anxiety, fatigue, depression and feeling of wellbeing/malaise are moderate to severe, besides constipation, diarrhea, urinary incontinence and frequent urination. When associated, these symptoms cause discomfort in the elderly, reducing their quality of life and motivation for physical exercise, social activities and leisure.

In view of the data, readjustments are needed in the measures to control the patients' pain and symptoms, as they affect the individuals' quality of life. In Brazil, PC is not appropriately structured yet, despite presenting significant growth as from the year 2000, including the consolidation of some services and the creation of others. New initiatives are emerging, but the work remains challenging.

Collecting the data at home permitted observing the reality the elderly and their family experienced at home, such as the physical and emotional conditions. The lack of basic orientations regarding the disease, symptom control and comfort measures was perceived, revealing the important role of the health team, knowing that most of the anxiety is due to fear or insecurity in view of the unknown.

The low human, financial and technological resources the city offers make the palliative professionals' wok solitary and exhausting. The investment in professional training in primary care is another consistent medium to respond to these patients' needs, as they are at home, close to the family health teams or primary health care services.

The low investment in continuing education for the professionals and the non-hiring of human resources for PC contribute to the non-hiring of policies and programs for elderly health care, in view of the complexity and chronicity of elderly care in PC.

For future studies, the scale could be applied at more than one time to the same patient, as the study limitations include the lack of time and resources, limiting the research for comparative analyses of the pain and its associations.

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