

Spiritual dimension of pain and suffering control of advanced cancer patient. Case report*

Dimensão espiritual no controle da dor e sofrimento do paciente com câncer avançado. Relato de caso

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ABSTRACT

BACKGROUND AND OBJECTIVES: Spiritual pain and suffering are commonly experienced by advanced cancer patients and their relatives. Spirituality is a natural and individual phenomenon encompassing human needs and a sound belief in its transforming potential. This study aimed at showing the integration of the spiritual dimension to the health-disease binomial.

CASE REPORT: Female patient, 43 years old, evangelical, referred to the Pain Ambulatory of the Service of Pain Therapy and Palliative Care, Foundation Center of Oncology Control, with advanced pancreas cancer, refractory to anti-tumor treatments. Patient had nociceptive visceral pain difficult to control in upper abdomen associated to substantial ascites, upper limbs edema and dyspnea. She was living a spiritual conflict and was discouraged with faith, evolving with severe disabling pain episodes which were related to anguish, sadness and fear of past mistakes linked to occultic practices (Afro religion). With these symptoms, she started to be evaluated at home by the multiprofessional team, including the chaplain. Gradually with spiritual intervention, pharmacological handling of pain, initially difficult to control, was helped and totally controlled at the end of her life.

CONCLUSION: This case shows the importance of recognizing the spiritual dimension during adequate total pain evaluation, in cases refractory to pharmacological treatment. It also stresses the spiritual dimension as a factor intensifying pain and suffering during finitude.

Keywords: Pain, Palliative care, Spirituality.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A dor espiritual e o sofrimento são comumente experimentados por pacientes com câncer avançado e por seus familiares. A espiritualidade é um fenômeno natural e individual que engloba as necessidades humanas e sólida crença no potencial transformador. O objetivo deste estudo foi demonstrar a integração da dimensão espiritual ao binômio saúde-doença.

RELATO DO CASO: Paciente do gênero feminino, 43 anos, evangélica, encaminhada ao Ambulatório da Dor do Serviço de Terapia da Dor e Cuidados Paliativos da Fundação Centro de Controle de Oncologia com diagnóstico de câncer de pâncreas avançado, refratário aos tratamentos antitumorais. Apresentava dor nociceptiva visceral em abdômen superior de difícil controle associada a ascite volumosa, edema em membros inferiores e dispnéia. Vivenciava conflito espiritual e desânimo na fé, evoluindo com episódios de dores intensas incapacitantes que foram relacionadas a angústia, tristeza e medo dos erros do passado ligados a práticas ocultistas (religião afro). Com esse quadro, passou a ser acompanhada no seu domicílio pela equipe multiprofissional que incluía a capelã. Gradativamente com a intervenção espiritual o manejo farmacológico da dor, inicialmente de difícil controle, foi facilitado e totalmente controlado no final da vida.

CONCLUSÃO: O caso retratou a importância do reconhecimento da dimensão espiritual na avaliação adequada da dor total, nos casos refratários ao tratamento farmacológico. Destaca ainda a dimensão espiritual como fator intensificador da dor e do sofrimento na finitude.

Descritores: Cuidados paliativos, Dor, Espiritualidade.

INTRODUCTION

The incidence of pancreatic ductal adenocarcinoma in males is 13.6 for every 100,000 and in females it is 10.7 for every 100,000 in the United States. In Brazil, it is responsible for approximately 2% of all types of diagnosed tumors and for 4% of total deaths due to this disease. Its 5-year survival rate is below 5%. This poor prognosis is primarily due to early invasion and metastasis, leading to diagnosis in an advanced and incurable stage for most patients.

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Currently, the only potentially curative treatment is radical surgical resection, because chemotherapy and radiotherapy have limited effects. When the tumor is advanced, a common warning is pain of increasing intensity in the dorsal region, progressively associated to a painful behavior and severe physical and spiritual suffering^{1,2}. When facing patients experiencing their terminality, professionals value not only changed physical aspects, such as control of pain and other symptoms, but also other dimensions making up the totality of human beings and which emerge intensively in situations of suffering and death, such as psychological, social and spiritual dimensions.

According to Saporetti³, spirituality is a quality of individuals whose interior life is oriented toward God, mysticism or what is sacred, which goes beyond science and instituted religion. So, spirituality is important because it is what strengthens and comforts individuals and may become an even greater concern than the oncoming death^{4,5}. Patients with advanced cancer in general face physical and social suffering and depressive manifestations, in addition to spiritual pain in the context of palliative care. Understanding patients and their families' spiritual structure may help assuring that pain and suffering, experienced by both, may be controlled, reassuring life and considering death as a natural process without accelerating or delaying it^{6,7}.

So, this study aimed at showing the integration of spiritual aspects in pain manifestation and, consequently, its influence on pain and suffering control of a female patient with advanced cancer, by means of the assistance of the multiprofessional team of the Service of Pain and Palliative Care, CECON Foundation – reference center for cancer treatment of Western Amazon, emphasizing the actions of the chaplain.

CASE REPORT

Female patient, 43 years old, from the state of Amazonas, single, cook, evangelist, with background of several visits to Manaus urgency services, was referred in October 2012 for specialized evaluation by the service of abdominal surgery, FCECON. At initial evaluation she presented enlarged abdomen, flaccid, painful at palpation on right mesogastrium and hypochondrium, without palpable mass, but with imaging exams suggestive of tumor lesion in pancreatic topography. Patient was submitted to exploratory laparotomy in December 2012 with histopathological diagnosis of pancreatic duct adenocarcinoma. In spite of chemotherapy and radiotherapy sessions in the first semester of 2013, the disease has rapidly evolved and in October 26 of this same year patient was referred to the Service of Pain Therapy and Palliative Care (STDCP).

Patient was initially evaluated by the Pain Ambulatory presenting visceral nociceptive pain with intensity 10 by the visual analog scale (VAS)⁸. Pain was continuous, heavy in upper abdomen, which irradiated to the dorsal region, associated to bulky ascites and lower limbs edema. Patient had an important family history because her father, with bone cancer, was being treated in the same hospital. After initial analgesic approach and maintenance of initially fortnightly returns, we have identified a difficulty to adhere to multimodal analgesic therapy,

maintaining severe pain with VAS varying between 7 and 9. Opioid analgesics were taken on demand and irregularly, in spite of orientations, which contributed to the difficulty to control pain. Additionally, associated reactive depression and spiritual brittleness contributed to worsen pain.

Due to disease evolution and aiming at patient's needs, she started to be assisted also at home by the multiprofessional team (physician, nurse, psychologist, social worker, physiotherapist and trainees). Visits were fortnightly and lasted in average 40 minutes, aiming at evaluating and controlling uncomfortable symptoms and following functional performance by means of the Palliative Performance Scale (PPS). In addition, she was weekly visited by the chaplain who would stay with her for approximately 60 minutes. All chaplain approaches were in the presence of her son, however without his participation, at request of patient herself.

In the first individual visit of the chaplain, pain remained in spite of regular use of analgesics. It was identified that the patient was living a spiritual conflict because she was still entrenched to occultist practices of her past, when she has been *umbanda* and *candomblé* "mother-of-saint" for 27 years, condition which supported her financially and made her popular in the city. After listening, the initial approach accepted by the patient was the shared reading of God's words (bible), being oriented to dedicate daily moments for meditation and prayer. In the next visit, patient had no pain (VAS = 0) and after the approach she asked for religious worship and hymns of praise. In the third visit, patient reported the return of pain that would not be relieved even with the prescribed rescue analgesic dose. This was related to the loss of her father by bone cancer in this period. During the visit, the patient opened her heart because she believed that her father's death had been revenge due to her past religious option. During next visits she was under regular use of analgesics which would control pain, however patient reported hopelessness since she had surrendered her life to God; today evangelist, she was waiting for her healing that would never come. After identifying the bargain stage experienced by the patient, the chaplain, by oriented and shared listening, has shown the difference between this defense mechanism and the true objective of spirituality, explaining that when you surrender your life to God and trust His plans and objectives you do not fear the future, although it might come without this so expected physical healing.

In the sequence of visits, as a function of accumulated losses, now the abandonment of her companion and her son, there has been pain intensification and loss of sleep quality. At this moment, the chaplain asked for the intervention of the psychologist to approach family members. After this intervention, it was observed that the patient had developed anger as a defense mechanism, starting to reject spiritual assistance, being only visited by the multidisciplinary team. Without the resolution of family conflicts, pain remained refractory which would make her distressed and scared.

With impaired general status, she would remain in bed most of the time, however conscious, she was unable to perform most

activities, dependent for self-care and with reduced intake, which corresponded to a PPS score of 40%⁹. At spiritual assistance return, by patient's request, she reported being living due to faith and that she saw God supplying all her needs, including economic needs. After three months of home follow-up, already with low functional performance (PPS of 20%) and respiratory complications, the chaplain has encouraged patient to talk about her feelings about death and by listening she was able to strengthen links and to address the spirituality issue. Now, patient was feeling that she would not live much longer and, in spite of still being physically and emotionally weak, her pain was controlled (VAS=2). During the last visits, the shared reading of the bible was maintained, which has brought comfort to patient. In the last 48h, patient was relaxed, with her physical and spiritual pain relieved, dying in the presence of her relatives after five months of home assistance by the multiprofessional team, emphasizing the actions of the chaplain in the 12 visits she made.

DISCUSSION

Spirituality started to receive attention in the last decade. There is no doubt about the importance of religious and spiritual aspects in the care of patients, although there are many questions about how to access human beings spiritual dimension and what is a good spiritual care. Published data indicate that 95% of Americans believe in some superior force and that 93% of them would like their physicians to address these issues if they became severely ill^{10,11}. In Brazil, most people have religious-spiritual beliefs and consider this very important. Studies with hospitalized patients have shown that 77% would like their spiritual values to be taken into account by physicians and 48% would even like their physicians to pray with them⁴. This case portrays the influence of spiritual conflicts on pain manifestation and the importance of spiritual assistance for its control, since all spiritual states may directly influence the perception of pain as suffering. In recognizing the conflicts between past and current beliefs, the chaplain was able to understand patient's guilt feelings for having caused damage to third parties, which were manifested through threatening thoughts and the fixed idea of punishment, which would intensify pain, as observed by high VAS pain intensity scores. This scenario confirms the assumption that pain felt by the patient was significantly worsened by non-physical issues, configuring spiritual pain which cannot be medicated. Hence the importance of considering two basic principles when evaluating cancer pain: total pain involving physical, environmental, emotional, social and spiritual factors, and the identification of mechanisms determining and intensifying such pain^{9,13,14}. This is in line with Campbell¹⁴ who has shown that spiritual suffering may express or increase physical symptoms intensity. This is true when individuals are faced with challenges threatening their faith, their meanings or objectives¹⁵. Death is the evidence of the limit, of mortality, of human condition. The diversity of attitudes regarding death in modern society is translated into changes and resistance, symbolism and new practices, such

as palliative care^{4,9}. The interdisciplinary approach in palliative care allows patients' individuality and multidimensionality to be preserved, because different professionals with specific competences aim, together, at healing or relieving. That is the reason why the patient was early assisted by the multiprofessional team at home, as from the moment where difficulties to pharmacologically control pain were identified. In palliative care, the basis for decision-making is the evaluation of functional performance via PPS. Studies have shown that 10% of patients with PPS equal to 50% have more than 6 months survival and their final stage coincides with PPS around 20%. In cancer patients, intensity, complexity, changeability of symptoms and individual and family impacts are difficult to solve without an early and specialized intervention⁹. With PPS of 20%, the chaplain, by helping her dealing with her losses and spiritual suffering, has indirectly allowed patient to live her physical pain in a milder way (VAS=2), thus obtaining a significant pain and suffering control until her death. The better quality of remaining life and death of this patient was reached after 8 visits to the Pain Ambulatory, 6 visits of the clinician, 6 of the nursing team, 7 of the psychologist, 1 of the social worker, 1 of the physiotherapist and 12 of the chaplain. The management of this case is in line with Arrieira et al.¹³ with regard to the competence of the assistance team to promote actions where more personalized, humanized and spiritualized links and relationships are established with patients, aiming at giving more integral care as from the speech which considers individuals in their totality.

CONCLUSION

End of life issues approach, in a coherent way, with patient's cultural, religious and spiritual values, by means of the intervention of the chaplain, was critical for pain control outcome and suffering relief. Recently, there have been evidences that it is common the search for spiritual treatment when concrete answers are not given by medicine, thus justifying the importance of spirituality to cope with chronic conditions¹⁵.

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