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HUMANISTIC REFLECTIONS ON THE CARE OF PATIENTS WITH MULTIPLE MYELOMA

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ABSTRACT

Multiple myeloma (MM) is an incurable neoplasm, being the second most common hematological cancer. It mainly affects the elderly and has a course of remissions and disease progression, leading the patient to numerous lines of treatment with chemotherapy and radiotherapy. This evolution leads to several adverse effects with a consequent decrease in the quality of life of these patients. The care of patients with MM must take into account symptom relief, multiprofessional care, preventing uncertainties, through sharing decisions, meeting their needs. There are currently few studies demonstrating this information and this article aims to reflect on the best ways to treat cancer with ethics and empathy.

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INTRODUCTION

Multiple myeloma (MM) is a malignant hematologic disease in which plasma cells, plasma cells that produce antibodies, proliferate abnormally. It is the second most common hematologic cancer, after non-Hodgkin's lymphoma (SIVARAJ, et al., 2017; KANG, et al., 2019; BALDERAS-PENA, et al., 2020; COLUZZI, et al., 2019). The incidence rate of MM is three times higher in more developed countries than in less developed countries5, being typically diagnosed at the median age of 69 years (JEEVANTHAM, et al., 2018; NEJATI, et al., 2019). In general, MM is not considered a genetic disease, however familial cases, although rare, exist (KAZANDJIAN, et al., 2016; RAMSENTHALER, et al., 2016). In MM, the uncontrolled growth of plasma cells leads to increased osteoclastic activity with bone destruction and consequent hypercalcemia and increased risk of fracture 5. In the context of MM, patients can also present with renal failure and anemia (JEEVANTHAM, et al., 2018). The destruction of bone tissue results in bone pain, pathological fractures, in addition to spinal cord compression, compromising the health and quality of life of these individuals (NEJATI, et al., 2019; SAMAL, et al., 2019). Chemotherapy is the first line of treatment, usually followed by more aggressive and invasive treatments such as autologous hematopoietic stem cell transplantation and radiation therapy. Complete remission of

MM is rare, becoming a chronic disease, progressing slowly, requiring long-term treatment (KANG, et al., 2019; KIM, et al., 2015). In addition to destroying neoplastic cells, the cytotoxic drugs used in chemotherapy to control MM also destroy hematopoietic stem cells, leading to neutropenia, with risks of infection, symptomatic anemia, and thrombocytopenia, with risks of bleeding. These patients may also have other possible side effects such as nausea, vomiting, diarrhea, mucositis and hair loss (JEEVANTHAM, et al., 2018). Radiation therapy can be prescribed to treat bone pain and osteolytic lesions and to reduce the size of the tumor, having an analgesic and paralysispreventive effect by decompressing the nerves. In addition, it also induces recalcification and reduces the risk of fractures (JEEVANTHAM, et al., 2018). The last years have seen a lot of growth in the treatment of MM, with the emergence of new therapeutic agents, which have significantly improved the survival of patients with this type of cancer (NEJATI, et al., 2019). However, MM is still considered incurable and the treatment goals are to reduce the tumor burden and prolong the patient's survival with maximum quality of life, minimizing complications caused by the disease or treatment. Significant advances in the understanding of Myeloma include the gain of knowledge in the pathology and new therapies with effectiveness, with the introduction of more selective drugs that lead to a lower percentage of adverse effects, which are often disabling (KAZANDJIAN, et al., 2016; GENADIEVA, et al., 2017. The survival of patients with Multiple Myeloma has been increasing with each new step and with each new chemotherapy drug developed 8. Despite all this, a good portion of patients face a progressive disease, interspersed with intervals of stable disease with minimal treatment, with symptoms which may persist at intervals without treatment, in addition to treatment-related toxicity and sequelae of bone and/or nervous manifestations. All this impacts even more on the quality of life of these individuals (RAMSENTHALER, *et al.*, 2016; GENADIEVA, *et al.*, 2017).

MATERIALS AND METHODS

A documentary research with a qualitative approach was carried out, as it understands the wealth of information that can be extracted and retrieved from documents, enabling the understanding of objects, it also favors the observation of the process of knowledge maturation (CELLARD, 2008). In this sense, a search was made in databases, analyzing five dimensions: (1) context, (2) author, (3) authenticity and reliability, (4) nature of the text, (5) key concepts and internal logic. text. The descriptors used in this search were: multiple myeloma, quality of life, needs and demands and comprehensive health care.

RESULTS AND DISCUSSION

Quality of life in Multiple Myeloma: Chemotherapy in the treatment of myeloma is long-term and repetitive and, during this period, patients experience physical and psychological problems, such as pain, fatigue, anorexia, anxiety, depression (BAEK, et al., 2015), leading to a lower quality of life (QoL) (KANG, et al., 2019; BAZ, et al., 2015), which is lower when compared to the general population and other cancer patients (KANG, et al., 2019; KIM, et al., 2015; VAN DER POEL, et al., 2015; SVERLANA, et al., 2020). Several factors can influence the quality of life in patients with MM, the main one being bone pain, the most reported symptom in approximately 75 - 80% of patients. As pain increases, patients' daily activities are affected, thus reducing QOL. Other factors can also influence QOL, such as occupation, economic status, disease duration, activity level and comorbidities, in addition to uncertainty, anxiety, depression 13, 16 and social support (KANG, et al., 2019). Cancer patients, including MM, often experience fatigue due to cancer and related treatments, defined as a distressing, persistent and subjective feeling of tiredness that is not proportional to recent activity and interferes with normal functioning. It is estimated that 30 91% of patients receiving chemotherapy and 25 to 83% of patients receiving radiotherapy experience cancer-related fatigue that is not relieved by rest or sleep. (JEEVANTHAM, et al., 2018; OH, et al., 2016). The clinical course of MM has been related to chronic pain, pathological fractures, renal failure and the treatment itself presents uncomfortable procedures such as the need to use intravenous medications, repeated bone marrow biopsy and various treatment effects, such as myelosuppression, mucositis, thrombosis, neuropathy, prolonged hospital stay and repeated transfusions that potentially impact QoL (BALDERAS-PENS, et al., 2020; SAMALA, et al., 2019).

Renal failure is also related to a decrease in QoL as it is associated with fatigue, pain, insomnia, especially when patients must undergo dialysis. Hypercalcemia, which is part of the diagnostic criteria for MM, has been related to fatigue, nausea and vomiting, in addition to affecting cognitive functioning. Another common complication during the treatment of MM is the presence of chemotherapy-induced peripheral neuropathy, which significantly affects the quality of life. Bone and nervous manifestations can lead to loss of mobility and social role, and a significant decrease in QOL 4,17-19 (COLUZZI, et al., 2019; SADOSKY, et al., 2016; CLEELAND, et al., 2016; MENDOZA et al., 2018). One of the major concerns of patients with myeloma is not being able to carry out their normal activities and the anguish that at any moment the disease can get worse, and they have no control over their future. Patients are concerned about living with an incurable disease and the inevitability of relapse (SAMALA, et al., 2019). There is much evidence that myeloma patients suffer from more symptoms and problems than patients with other types of hematologic malignancies. A study from Denmark reported a higher level of pain, fatigue and constipation, in addition to physical problems 8. Complete recovery at treatment intervals is often not possible for patients with myeloma, with consequent impairment of QoL, thus confirming the results of the study. Nordic Myeloma Study group and the Eindhoven Profiles registry (RAMSENTHALER, *et al.*, 2016).

Myeloma patient care: Research shows that myeloma patients have many unmet needs and poor quality of life 8. There is a rich literature on cancer-related uncertainty, and studies suggest that this uncertainty can diminish fighting spirit and hope, which can cause a decrease in mood, negatively affecting QOL. Myeloma patients face an uncertain future and often live with a sense of fear of not knowing when they will get sick again (KANG, et al., 2019; CORMICAN, et al., 2016). Social support is reported as essential for cancer patients. Support from family and healthcare providers is significant in recovering from challenges and helps to reduce stress and anxiety. Patients undergoing chemotherapy generally experience greater anxiety, with approximately 20% to 63% of patients reporting psychological distress, anxiety, and depression during chemotherapy. Cancer-related anxiety also increases the sensation of pain and negatively influences QOL (OH, et al., 2016). Care of patients receiving chemotherapy should include interventions to alleviate physical symptoms. Uncertainty can change as patients continue treatment and can be reduced with the implementation of interventions by the multidisciplinary team to improve the QoL of these patients. Considering that anxiety and depression are the main factors that influence QoL in patients with MM, several approaches must be taken, including good communication between patients and the health professional (SVETLANA, et al., 2020; MAHER, et al., 2011).

If patients' knowledge level and educational needs regarding the disease are investigated, they can be given adequate explanations in lay terms to understand its trajectory, including symptoms and treatment process to make clear decisions. Thus, your understanding can be enhanced to help reduce uncertainty. Their pain scores are higher than those of other types of cancer patients, so accurate pain assessment and timely interventions are necessary when caring for MM patients (KANG, et al., 2019; KIM, et al., 2015). The goals of cancer treatment go beyond survival and must include quality of life. It is important that health professionals assess the needs of their patients to ensure the ideal quality of treatment. Therefore, decisionmaking has come to play an important role. increasingly important role in the care of patients undergoing cancer treatment and shared decision-making encourages clinicians to clearly describe different treatments with potential risks and benefits and patients to explicitly express their preferences in the treatment process (NEJATI, et al., 2019). Shared decision-making has a number of benefits, including better knowledge, reduced anxiety, reduced decision conflict, and better treatment outcomes, associated with patient improvement, including satisfaction and knowledge (NEJATI, et al., 2019; KAZANDJIAN, et al., 2016). Patients with poor ability to communication, may not be able to articulate their concerns and priorities, but it is up to the multidisciplinary team to take the lead in these cases so that the patient's preferences can stand out in this process, thus improving the doctor-patient relationship. Shared decision-making recognizes a patient's right to fully participate in this process (VAN DER POEL, et al., 2015; LEBLANC, et al., 2019).

Many satisfaction scales have higher scores when information is provided and this moment cannot be different in public environments, where the number of patients seen by the doctor is usually higher, with consultations with less time available. The information provided by the physician is an important factor in conjunction with multidisciplinary support. Supportive treatments can help maximize treatment benefits and enhance the well-being of patients at all stages of the disease (BALDERAS-PENA, *et al.*, 2020). The Code of Medical Ethics even provides among its articles that the physician is prohibited from disrespecting the patient's right to decide on diagnostic and therapeutic practices, always informing risks, benefits and prognosis, which confirms the need to inform correctly and allow the patient and his family are part of the decisions, because the cultivation of a good doctor-patient relationship has always been and will always be the basis of good medical practice (ONCOGUIA, 2020; CFM, 2018; BRENNY, et al., 2022). The identification of markers that are related to quality of life in patients with MM, such as pain, fatigue, anemia and renal failure, are fundamental, as they indicate what needs to be persistent in the relevant therapeutic intervention aimed at modifying these markers to improve quality of life. A good quality of life is related to an improvement in overall survival and in the perception of care in health services (BALDERAS-PENA, e al, 2020). The European Society for Medical Oncology (ESMO) Clinical Practice Guidelines suggest a multidisciplinary approach, including all healthcare professionals (HCPs) involved in the management of cancer patients. In general, all treatments aim to reduce pain and improve functionality. Physical training is recommended in cancer patients, while inactivity should be avoided. Exercise is a potent stimulus for endorphin production; therefore, it could improve not only mobility, but also analgesia and probably mood (COLUZZI, et al., 2019; DIMOPOULOS, et al., 2021). Significant advances in the treatment of (MM) in the last two decades have increased the number of patients living with the disease for longer periods. Although MM remains incurable, the five-year relative overall survival has increased by nearly 30% at the start of 1990 to 40% in the early 2000's because of new treatment modalities 9. As patients live longer, there is a push to put quality of life at the center of their management (KAZANDJIAN, et al, 2016; SAMALA, et al., 2019). Since many new effective therapies are available today, a personalized approach is becoming essential for the treatment of MM, a disease that predominantly affects elderly patients. Frailty assessment is useful in choosing the most appropriate therapeutic approach and defining the treatment goal for each subgroup of patients. The goal of therapy for healthy patients is to achieve complete remission and improve survival, while in frail patients it is more important to improve and preserve quality of life as much as possible, that is, it will allow patients to receive personalized treatments, with greater effectiveness and less toxicity (GENADIEVA, et al., 2017). The importance of regular assessment of symptoms and quality of life, current practice and not a single assessment, assessing not only physical but also mental problems throughout treatment and early integration of support services can help maintain or optimize the patient's quality of life. Focusing on traditional parameters to monitor disease progression may not help to identify those myeloma patients who experience a poor quality of life (RAMSENTHALER, et al., 2016). The cancer patient deals with terminality and goes through many questions, sometimes not expressed. It is important to include the patient in reflections and discussions about therapeutic options, in a collaborative construction. The treatment must pay special attention to the human being and not just the disease, seeking empathy and respecting the patient's wishes, creating a relationship of trust with the entire team, with a positive environment at a time of high fragility (LEBLANC, et al., 2019; SANTA LUCIA, 2017).

FINAL CONSIDERATIONS

Multiple myeloma is an incurable disease and does not follow a linear and predictable trajectory, where we do not know exactly how to define the end of life. As it is a progression interspersed with periods of remission and stable disease, with relapses and various lines of treatment, with progressive sudden deterioration and death due to complications related to the disease or treatment. There is a wide variety of symptoms and psychological factors that impact the quality of life of patients with multiple myeloma, but this very important aspect is still underrepresented in myeloma research, especially in relation to treatment and supportive care. Therefore, we still know very little about quality of life in the context of a chronic and incurable disease, which would be of paramount importance to understand the benefit of additional support from the health team involving all professionals. This would help target services to individuals at greatest risk who could benefit from early and preventive supportive care interventions.

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