

Intrathecal chemotherapy: perceptions and meanings attributed by patients with hematological cancer

Quimioterapia intratecal: percepções e significados atribuídos por pacientes com câncer hematológico

Quimioterapia intratecal: percepciones y significados atribuidos por pacientes con cáncer hematológico

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ABSTRACT

Objective: analyze the meanings and perceptions of patients undergoing intrathecal chemotherapy about this treatment

Method: qualitative and descriptive study carried out with 13 participants attended at a Chemotherapy Center of a University Hospital in the interior of Minas Gerais, from 2015 to 2016, whose data were submitted to the analysis of the collective subject discourse. Approved by the Research Ethics Committee of the study development institution. **Results:** the information obtained through the interviews was coded and five discourses emerged: lack of treatment, pain, anxiety, faith and hope. **Conclusion:** intrathecal chemotherapy is unknown to patients undergoing treatment, causing anxiety, pain and adverse reactions that impair their quality of life. This creates mechanisms for coping with the disease through faith and hope.

Descriptors: Hematologic Neoplasms; Drug Therapy; Injections Spinal; Oncology Nursing.

RESUMO

Objetivo: analisar os significados e as percepções dos pacientes submetidos à quimioterapia intratecal sobre esse tratamento.

Método: estudo descritivo de abordagem quantitativa, desenvolvida com 13 participantes atendidos em uma central de quimioterapia de um hospital universitário do interior de Minas Gerais, entre os anos de 2015 a 2016, cujos dados, obtidos por meio de entrevistas, foram submetidos à análise do discurso do sujeito coletivo. Aprovado pelo Comitê de Ética em Pesquisa da instituição campo do estudo. **Resultados:** dos dados codificados emergiram cinco discursos: desconhecimento do tratamento, dor, ansiedade, fé e esperança. **Conclusão:** a quimioterapia intratecal é desconhecida pelos pacientes em tratamento, causando ansiedade, dor e reações adversas as quais trazem prejuízo para a qualidade de vida desses indivíduos. Com isso criam-se mecanismos de enfrentamento da doença por meio da fé e da esperança.

Descritores: Neoplasias hematológicas; tratamento farmacológico; injeções espinhais; enfermagem oncológica.

RESUMEN

Objetivo: analizar los significados y las percepciones de los pacientes sometidos a quimioterapia intratecal sobre este tratamiento. **Método:** estudio de enfoque cuantitativo y descriptivo desarrollado con 13 participantes atendidos en un Centro de Quimioterapia de un Hospital Universitario en el interior de Minas Gerais, entre 2015 y 2016, cuyos datos fueron sometidos al análisis del discurso del sujeto colectivo. Aprobado por el Comité de Ética en Investigación de la institución de desarrollo del estudio. **Resultados:** la información obtenida a través de las entrevistas fue codificada y surgieron cinco discursos: falta de tratamiento, dolor, ansiedad, fe y Esperanza. **Conclusión:** la quimioterapia intratecal es desconocida para los pacientes sometidos a tratamiento, lo que causa ansiedad, dolor y reacciones adversas que deterioran su calidad de vida. Esto crea mecanismos para hacer frente a la enfermedad a través de la fe y la esperanza.

Descriptores: Neoplasias hematológicas; quimioterapia; Inyecciones en la columna; Enfermería Oncológica.

INTRODUCTION

Oncological diseases evoke images of suffering, impotence, losses and finitude in the social imaginary and still pose challenges for demystifying the disease and its treatment. They are the second largest cause of morbidity and mortality in the world and Brazilian population, being considered a public health problem^{1,2}.

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The World Health Organization (WHO) estimates that in 2030 there will be 27 million new cases of cancer, 17 million deaths and 75 million people living with the disease annually. The estimate for Brazil, between 2016 and 2017, points to about 600 thousand new cases, with the exception of non-melanoma skin cancer. For 2016, 5,540 new cases of leukemia in men and 4,530 in women were estimated. These values correspond to an estimated risk of 5.63 new cases for every 100 thousand men and 4.38 for every 100 thousand women. As for non-Hodgkin lymphomas, the figures are 5,210 new cases of lymphoma in men and 5,030 in women in Brazil. These values correspond to an estimated risk of 5.27 new cases for every 100 thousand men and of 4.88 for every 100 thousand women¹.

Cancer therapy includes surgeries, radiation therapy and chemotherapy³. Chemotherapy is the most frequently used modality for the cure and control of cancer and palliative care for cancer patients. This treatment works in a systemic way, in which the drugs act indiscriminately in the patient's cells, whether they are normal or sick, producing quite unpleasant and compromising adverse effects. The main routes of administration of chemotherapy are the following: intravenous, subcutaneous, intramuscular, oral and intrathecal⁴.

The intrathecal route is used as a treatment or prophylaxis route for tumors capable of compromising the central nervous system. This route is chosen due to the inability of most drugs used in chemotherapy regimens to cross the blood-brain barrier to prevent or eradicate cancer-related impairment in the central nervous system. This technique consists of a lumbar puncture done at the level of the L3 and L4 vertebrae to allow the administration and access of chemotherapeutic agents to the neuraxis structures, and it is performed by a health care practitioner. A sample of cerebrospinal fluid is collected for cytological analysis and, shortly thereafter, chemotherapy drugs are administered slowly^{5,6}.

LITERATURE REVIEW

Studies on the administration of intrathecal chemotherapy highlight toxicity factors that can help to maximize safety in different populations^{5,7}. It is also emphasized that this type of chemotherapy administration is particularly effective for the treatment of acute leukemia and non-Hodgkin lymphomas and, therefore, is widely accepted and used. These studies point to variability in the method of preparation and in the administration technique, indicating that the clinical practice can influence the efficacy and toxicity of this therapy⁶. A number of research studies point to the need to establish a care plan and actions aimed at minimizing the effects of stress caused by intrathecal chemotherapy, despite its efficacy and acceptance by international groups of the drugs and doses administered, but also including the method of preparation and the administration technique^{3,4,6-8}.

For the planning and development of quality care, the health team must have technical and scientific knowledge and skills in interpersonal relationships. Cancer patients undergoing chemotherapy need humanized care, based on emotional, spiritual, social and affective needs as a consequence of the impact of the diagnosis and the notable physical changes faced by these patients^{5,8}.

In this sense, hospital care should be directed to the patient, their family and other significant people, through welcoming and trusting actions, between professionals and patient, enabling dialog between the parties involved^{2,5,7}. The nursing staff as a member of the health care team must be prepared to comprehensively perceive and strengthen humanized care. Given the above, this research aimed to analyze the meanings and perceptions of patients undergoing intrathecal chemotherapy about this treatment.

METHODOLOGY

This is a descriptive study using a quantitative and qualitative approach⁹. The study was carried out at the Chemotherapy Center of a university hospital in the inland of Minas Gerais. The inclusion criteria were the following: age over 18 years old, diagnosis of acute leukemia or non-Hodgkin lymphoma with indication for intrathecal chemotherapy, starting treatment in January 2013, with at least one administration of intrathecal chemotherapy. It is worth noting that 13 patients met the inclusion criteria.

Data was collected through semi-structured interviews, carried out in a private office, at outpatient follow-up. At that moment, the patients, who agreed to participate freely in the research, signed the Free and Informed Consent Form (FICF). This moment was chosen because the patient is believed to be less vulnerable to the effects of chemotherapy. Data was collected between October 2015 and May 2016.

The script used was structured in the following manner: sociodemographic data; data from cancer treatment and guiding questions of the interview – What is your perception about intrathecal chemotherapy? What are the meanings attributed to this experience?, Why?, What are the feelings attributed to the treatment with intrathecal chemotherapy? This instrument was previously tested and readjusted according to the patients' needs.

The interviews lasted an average of 40 minutes, were conducted in a private room at agreed times, recorded on electronic media and then transcribed in the *Microsoft Word* text editor. The subjects were identified by the letter E followed by the order of the interview (E1, E2, E3...) to maintain confidentiality.

After transcription, the interviews were analyzed using the Brazilian collective subject discourse (*Discurso do Sujeito Coletivo*, DSC) technique, which is a proposal for organizing qualitative verbal data, seeking to preserve the collective thinking and to extract Key Phrases (KPs) and Central Ideas (CIs) from each of the interviews. The corresponding CI was extracted from each KP identified. The next step was to group similar CIs and, for each group, synthesis speeches were created in the first person singular, in which the group's speech appeared as an individual speech, in this case, the DSC⁹. The analysis of the testimonies resulted in five DSCs. The patients' sociodemographic, clinical and therapeutic data were treated using elements of descriptive statistics, such as absolute frequency and percentage.

The study project met the ethical requirements of Resolution No. 466/2012 of the National Health Council, and was approved in 2015 by the Research Ethics Committee of the Federal University of Triângulo Mineiro, under Certificate of Presentation for Ethical Appreciation No.: 41887915.4.0000.5154, by means of the following opinion number: 1,019,061.

RESULTS AND DISCUSSION

Profile of the clients

Of the 13 (100%) participants, 9 (69.2%) were women and 4 (30.8%) were men. The mean age of the participants was 47.6 years old, aged between 19 and 74 years old. Among the study participants, the following characteristics stood out: 7 (53.8%) were married, 4 (30.8%) did not complete elementary school and 5 (38.5%) were from the city of Uberaba (MG/Brazil). The predominant religion was Catholicism, with 11 (84.6%) Catholics.

As for the type of cancer, 9 (69.2%) participants had non-Hodgkin lymphoma and 4 (30.8%) had acute lymphoblastic leukemia. In addition to intrathecal chemotherapy, they were all (100%) treated with intravenous chemotherapy, 9 (69.2%) with oral chemotherapy, 3 (23.1%) with subcutaneous chemotherapy and 4 (30.8%) with intramuscular chemotherapy.

According to the pre-established protocol for administering intrathecal chemotherapy, 7 (53.8%) had an indication for 18 administrations and 5 (38.5%) had an indication for eight; 5 (38.5%) received only one administration and 3 (23.1%) received three administrations. All of them (100%) said they did not know which drugs were used and 7 (53.8%) reported feeling pain during administration. Furthermore, 11 (84.6%) said they had not performed any activity before the procedure and 12 (92.3%) had accompanying persons during chemotherapy sessions. All patients report remaining at rest after the procedure for 40 or 60 minutes; 8 (61.5%) patients reported the need for regular trips to return home after the procedure; 8 (61.5%) reported experiencing sleep and rest deprivation the night before the procedure, showing anxiety, concern and the need to travel during the night to undergo treatment. Uberaba is one of the biggest cities of the Southern Triangle, being a reference for the treatment in 26 cities in that region.

The adverse reactions to intrathecal chemotherapy reported were the following: local pain – 2 (15.4%), lower limb pain – 2 (15.4%), headache – 4 (30.8%), diarrhea – 1 (7.7%), constipation – 6 (46.2%), nausea – 4 (30.8%), vomiting – 4 (30.8%) and weakness in the upper or lower limbs – 4 (30.8%). Tremors, sweating and chills were reported by 2 (15.4%) patients. There were no reports of paresthesias or seizures. Only 3 (3.1%) did not report any adverse reaction.

The population participating in this research is similar to the one studied by other authors and is consistent with the Brazilian population. There was a predominance of females, with a mean age between 40 and 50 years old, married or in a stable relationship, Catholic and with low schooling^{10,11}. The predominance of women may be related to the fact that, regardless of their level of education, women seek the health services more often than men. Thus, they can be diagnosed in the early stages of different types of diseases, especially cancer^{10,12-15}.

Advances in chemotherapy have emerged with regard to the management of the adverse effects. Regardless of the route of administration, patients undergoing anticancer treatment are expected to experience physical and mental changes, ranging from mild to severe. To combat these effects, medications that aim to reduce the adverse effects and to improve the quality of life of these subjects during treatment have been extensively studied and developed^{2,11-16}.

From the speeches, it was possible to put together the first CI – strategies that hinder the understanding about the treatment – by elaborating DSC1, identified as lack of knowledge about the treatment. This discourse was constructed using three testimonies.

DSC1 – Lack of knowledge about the treatment

I didn't know I was undergoing chemotherapy, I thought it was just a painful examination [...]. I don't know about intrathecal chemotherapy, I do the treatment, but I don't know anything, they never told me how it works [...]. I know the treatment is in the spinal cord, it removes the liquid part of the spine and injects with the syringe another liquid, which is the medicine [...]. (E1, E7, E9)

The scientific terminology included in these treatments is complex and, many times, incomprehensible to patients. Therefore, the health professionals must seek simpler words to facilitate the understanding of the patients, as in the initial phase they are faced with a new treatment, and the recent discovery of a cancer causes them to be in denial about the disease; thus any new information about their treatment will hardly be understood¹⁷. Cancer patients undergoing chemotherapy need humanized care that considers their individuality, the truth and solidarity, that is, a complex system of values, which respects the autonomy of the individuals and the diversity of ideas, rescuing the subjective expression of care^{2,4,8,10,15}.

The second CI – the pain felt during the procedure – provided the elaboration of the DSC2 and was composed by three testimonies.

DSC2 – Pain

I feel pain during the procedure [...]. This treatment is very hard, I don't know how to define it, but it is painful [...]. I have headaches and I've suffered a lot here in this hospital [...]. This experience with intrathecal chemotherapy is very painful, very painful; I feel my body falling apart [...]. (E3, E8, E11).

Pain is identified as the most frequent sign in cancer patients and it directly affects the quality of life of these people. Studies report that painful sensations have an effect on the psycho-emotional state and on daily activities¹⁸. Additive behaviors related to previous or current cancer treatments related to the etiology of pain are aspects considered essential in the comprehensive analysis of the individual with cancer pain¹⁷⁻¹⁹.

The third CI – the anxiety experienced in the face of cancer treatment – DSC3, consisted of three testimonies.

DSC3 – Anxiety

The first time I underwent intrathecal chemotherapy I was very nervous, feeling a lot of anxiety [...]. I get tense and worried before the treatment, I feel very sad [...]. I'm very afraid of not being able to hold on and having to start all over again [...]. (E5, E6, E13).

As for anxiety, the interviewees showed feelings that encompass fear and anxiety. This last term means to oppress and to suffocate, and is a biological characteristic of the human being that precedes moments of real or imaginary danger, marked by unpleasant bodily sensations, such as increased heart and respiratory rate, intense fear, sweating, among other sensations associated with dysfunction of the autonomic nervous system^{14,17,20,21}.

In the discourse presented here, anxiety may be related to the lack of knowledge about the treatment and to the ritual of administering intrathecal chemotherapy. The presence of anxiety among cancer patients, as well as its negative implications for this experience, confirms that the chemotherapy treatment results in medium to high levels of anxiety. A study carried out with African American women with breast cancer showed that the greater the coping ability, the less psychological suffering and negative religious coping will be²⁰. Another study conducted in Brazil highlighted that anxiety and depression are prevalent disorders in cancer patients²².

Faced with this experience, patients find themselves in an uncomfortable position, which causes fear and anxiety. In this sense, the practice of therapeutic communication can offer patients guidance on the correct way to face chemotherapy, on the sequential stages of the procedure and on the impossibility of viewing procedures, in addition to offering the necessary support and comforting and to meeting their basic needs^{14,17,18,20-24}.

The fourth CI – faith and belief in God as support and help to overcome treatment – helped to compose DSC4, consisting of three testimonies.

DSC4 – Faith

Intrathecal chemotherapy means that my body has nothing else to do, so I leave it up to God [...]. Because first of all it is in the hands of God, then in the hands of everyone here [...]. I have a lot of faith in God that He will solve my problem [...]. (E2, E8, E12)

The faith manifested by these patients carries the hope of curing the disease. The treatment of cancer is a prolonged, arduous process that is difficult for patients to accept, often leading them to exhaustion. Faith tends to be

cultivated as an instrument for strengthening and coping with the disease. In this perspective, how each patient copes with their diagnosis may assign a meaning to their healing-disease process, in search of quality of life and survival. Attachment to faith helps to alleviate suffering and to obtain greater hope and better expectation of healing during treatment^{2,10,14,17,20,21}.

With regard to intrathecal chemotherapy, patients realize it is their last chance of treatment and that, from that moment on, only God can bring the cure. In the literature, studies on this topic are still scarce. The training of professionals with a holistic view of the treatment values the use of spiritual anamnesis as a way of knowing the patient's spiritual needs, and it is extremely important as it intervenes in a balanced way, resulting in strengthening, hope and well-being for the patient^{17,19-24}.

The fifth CI – the hope that treatment will improve their health conditions – contributed to the organization of DSC5, consisting of three testimonies.

DSC5 – Hope

It doesn't get out of my mind that one day I will get better [...]. But I'm glad that I'm doing this, this means that I have resources to deal with the disease [...]. But I feel that I want to get better, I still have a lot to do [...]. I want to be cured, to get better soon, to finish it and stop coming here [...] because for me this is a penance [...]. (E7, E10, E13)

In the DSC in which the participants show a feeling of hope, there is an internal conflict between the desire to be cured and the fear of this desire not being satisfied. Hope is an important feeling in coping with the disease; it allows the patient to be able to dream about their future and set goals for their treatment. Thus, it is important that the nurse is present in this coping^{21,22}.

Regardless of the route of administration, the chemotherapy treatment has a physical and psychological impact on the patient. In this study, it was possible to identify the perceptions and meanings that the patients attributed to chemotherapy administered by the intrathecal route^{19,23,24}.

CONCLUSION

Intrathecal chemotherapy is unknown to patients undergoing treatment, which is a factor that generates anxiety, pain and adverse reactions that affect the quality of life of these individuals. The treatment of cancer patients must be comprehensive; thus, not only physical needs, but also psychological, social and spiritual ones deserve attention, including individualized care, promotion of non-traumatic care and the right to receive information. Consequently, it is necessary to provide these patients with information about the disease and the treatment; to prepare them for the procedures; to adopt measures to relieve their pain and reduce their discomfort; to include the family in the care process, as well as safeguarding personal decision-making and promoting the self-esteem of everyone who experiences this process.

Mechanisms for coping with the disease, through faith and hope, are important for personal empowerment. It is necessary to value the spiritual needs of the patient with cancer, considering their individual perception, religious option and world view.

Among the limitations of the study, attention is drawn to the small sample and to a single research field institution, which prevents the generalization of the findings. Another factor concerns the scarcity of studies on intrathecal chemotherapy, which encourages further research studies on the subject. The results obtained from this research may help health professionals to establish priorities for these patients and support the provision of humanized care based on scientific evidence.

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