

THE QUALITY OF LIFE OF PATIENTS WITH HEMATOLOGICAL NEOPLASIA UNDERGOING CHEMOTHERAPY

QUALIDADE DE VIDA DO PACIENTE COM NEOPLASIA HEMATOLÓGICA SUBMETIDO À QUIMIOTERAPIA

CALIDAD DE VIDA DEL PACIENTE CON NEOPLASIA HEMATOLÓGICA SOMETIDO A QUIMIOTERAPIA

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ABSTRACT

This study aimed to analyze the quality of life of patients with hematological neoplasia undergoing chemotherapy. A quantitative research was carried out based on the application of the WHOQOL-bref generic questionnaire. The sample was composed of 16 patients in the outpatient high risk chemotherapy sector in a teaching hospital in the city of Curitiba-PR between February and April of 2010. The results showed a prevalence of males with ages between 20 and 64 years old. Among the types of hematological neoplasias, 46.7% were acute lymphocytic leukemia, 33.3% were acute myelogenous leukemia, and 20% were divided between non-Hodgkin's lymphoma, multiple myeloma, and hairy cell leukemia. The treatment period varied between 2 weeks and 24 months, and the number of chemotherapy sessions between 1 and 80. The analysis showed that the physical and psychological domains suffered the most changes, however, no statistically significant difference between all domains was observed. Cancer arguably changes every aspect of an individual's life and brings profound changes in their routine and habits of life. Thus, the necessity and importance of nursing care intervention in this process is observed.

Keywords: Nursing; Quality of Life; Chemotherapy.

RESUMO

Este estudo teve por objetivo analisar a qualidade de vida do paciente com neoplasia hematológica submetido à quimioterapia. Realizou-se pesquisa quantitativa a partir da aplicação do questionário genérico WHOQOL-bref. A amostra foi composta de 16 pacientes do setor de ambulatório de quimioterapia de alto risco de um hospital de ensino do município de Curitiba-PR, no período de fevereiro a abril de 2010. Os resultados evidenciaram a prevalência do sexo masculino e a média de idade dos participantes esteve entre 20 e 64 anos. Entre os tipos de neoplasias hematológicas encontraram-se 46,7% de leucemia linfocítica aguda, 33,3% de leucemia mieloide aguda e 20% entre linfoma não hodgkin, mieloma múltiplo e tricoleucemia. O período de tratamento foi de duas semanas a 24 meses e o número de sessões de quimioterapia foi entre uma e 80. Mediante análise, pode-se inferir que os domínios físicos e psicológicos foram os que sofreram mais alteração, porém sem diferença estatisticamente significativa para todos os domínios. Ressalta-se que o câncer altera indiscutivelmente todos os aspectos da vida do indivíduo e acarreta profundas alterações na sua rotina e hábitos de vida. Neste sentido, observam-se a necessidade e a importância do cuidado da enfermagem na intervenção desse processo.

Palavras-chave: Enfermagem; Qualidade de Vida; Quimioterapia.

RESUMEN

Este estudio tuvo como objetivo analizar la calidad de vida del paciente con neoplasia hematológica sometido a quimioterapia. Se realizó una investigación cuantitativa a través de la aplicación del cuestionario genérico WHOQOL - bref. La muestra estuvo compuesta de 16 pacientes del sector ambulatorio de quimioterapia de alto riesgo de un Hospital Universitario del municipio de Curitiba/PR, entre Febrero y Abril de 2010. Los resultados mostraron la prevalencia del sexo masculino, edad de los participantes entre 20 y 64 años. Entre los tipos de neoplasias hematológicas se encontró 46,7% de leucemia linfocítica aguda, 33,3% leucemia mieloide aguda y 20% entre linfoma no-hodgkin, mieloma múltiple y tricoleucemia. El período de tratamiento varió entre dos semanas y 24 meses y el número de sesiones de quimioterapia entre una y 80. Mediante análisis se puede inferir que los dominios físicos y psicológicos fueron los que sufrieron más alteraciones, pero sin diferencia estadísticamente significativa para todos los dominios. Se realza que la presencia del cáncer altera indiscutiblemente todos los aspectos de la vida del individuo y que lleva a profundas alteraciones en su rutina y costumbres de vida. En este sentido, observamos la necesidad y la importancia del cuidado de enfermería en la intervención de este proceso.

Palabras clave: Enfermería; Calidad de Vida; Quimioterapia

INTRODUCTION

Annually, the extent reached by oncological diseases has been gaining more attention with these diseases becoming an evident global public health problem. The World Health Organization (WHO) estimates 27 million new cases and 17 million deaths from cancer in 2030.¹

The term cancer is used generically to represent a set of more than 100 diseases, which have the disordered growth of cells and compression or invasion of tissues and organs in common. Among the types of cancer, hematological neoplasias are expressed by changes in the blood or blood forming tissues. Hematological diseases known as leukemias, lymphomas, and myelodysplastic syndromes showed an estimation of 18,150 new cases in Brazil, in 2013. In 2012, it was expected that among those cases of incident cancers, approximately 3.5% corresponded to non-Hodgkin's lymphomas and leukemias. Despite leukemia being among the types of cancer with low incidence, it is still a hematologic neoplasia of important clinical relevance² because 257 thousand new cases occur worldwide per year.¹

Among the types of treatment, the chemotherapy (QT) is currently the one that shows the best results to cure many types of tumors and increases patient survival. Among the used therapies, it is the most used and the most effective, often curing main hematological neoplasias such as leukemia.³ Chemotherapy consists in the use of drugs, alone or in combination.⁴

Cancer treatments allowed increased survival and cure; however, their conditions carry some of the strongest stigma associated with the disease.⁵

The broad action of anticancer medicines on different stages of cellular metabolism leads them to affect both malignant cells and healthy tissues causing various side effects.⁶ The effects of invasive oncologic therapies leave the body vulnerable and debilitated, negatively impacting the patients' quality of life.⁷

In addition to the deleterious effects of treatment, the impact of a cancer diagnosis may represent an emotional overload for the patient and family leading to several disorders such as depression and anxiety among others. Therefore, assistance must be planned to provide care for the overall health and not only for the disease, aiming at promoting improved quality of life for this individual.⁸

Due to the treatment's complexity and the different physical and mental demands that afflict these patients, more attention to the dimensions related to the quality of life of these individuals is required.

Therefore, a concern for patients affected by different neoplasias in relation to their quality of life is evident. The WHO conceptualizes quality of life as "the individual's perception of his position in life in the context of culture and value system in which he lives, and in relation to his goals, expectations, standards, and concerns".⁹

The definition of quality of life is still not unanimously accepted because it is a controversial and broad concept.¹⁰ It emerged in the scientific world as an important means to investigate and evaluate the health of individuals¹¹ similarly to the term health-related quality of life (HRQL), which came to be used to assess how much the chronicity of a health condition interferes in the everyday life of an individual.^{12,13}

In the context of Oncology, quality of life is accentuated as the individuals' subjective vision in relation to their disability and satisfaction with their present level of functioning. This causes the individual to consider being good or not and at the same time to compare with what he sees as possible or ideal.¹³

In the recent decades, there is a growing concern about the quality of life of cancer patients. The HRQL has been used in clinical studies evaluating chemotherapy drugs to measure the inherent toxicity of this treatment, enabling the investigation to verify positive and negative impacts on the quality of life of patients undergoing chemotherapy treatment.¹⁴

Studies on the quality of life of cancer patients are critical to identify affected domains and plan nursing interventions.¹⁵

Hence, the objective of this study was to analyze the quality of life of patients with hematological neoplasia undergoing chemotherapy.

MATERIAL AND METHOD

This is a quantitative research, with a cross-sectional design, developed in the High-risk Chemotherapy Sector and Chemotherapy Outpatient Clinic from a teaching hospital in the city of Curitiba, State of Paraná, between February and April of 2010.

Study participants were patients with hematological neoplasias undergoing chemotherapy treatment. The population was composed of 16 patients who met the inclusion criteria: being an adult, from both genders, with a diagnosis of hematologic neoplasia, undergoing chemotherapy treatment, being hospitalized in the High-risk Chemotherapy Sector or tended at the Outpatient Chemotherapy clinic, and being able to answer the study questions. After inclusion in the study, all patients were evaluated in the High-risk Chemotherapy Sector and the Outpatient Chemotherapy clinic during hospitalization or consultation during the application of the study protocol.

The data was collected using a form containing two parts: one, aimed at sociodemographic, clinical, and therapeutic data; and one containing the WHOQOL-*bref* questionnaire to evaluate the quality of life.

The WHOQOL-*bref* instrument, validated in Brazil¹⁶, consists of 26 questions: two general and the other representing each one of the 24 facets that make up the original instrument. It consists of four domains: physical, psychological, social, and environmental relations. There are five degrees of intensity for

each question, worth different points, and subjected to the patient's choosing.

To meet the proposed objectives, a descriptive statistical analysis was performed on the data using the statistical program *Statistical Package for Social Sciences* (SPSS) and according to the WHO recommendations¹⁷ for evaluation of answers to the quality of life *WHOQOL-bref* questionnaire, and for statistical analysis.

Non-parametric tests were used to verify the relationship between the *WHOQOL-bref* domains and disease-related measurements. The *Kruskal-Wallis* test was used to verify significant differences between the averages of variables with more than two categories. The *Mann-Whitney* non-parametric test was used for variables with two categories. The tests were conducted at a significance level of 5%.

All ethical procedures required by the Resolution 196/96 from the National Health Council were adopted for the participants' inclusion in this study. The objectives, the voluntary character of the study, guaranteed anonymity, and data confidentiality were explained to participants, who subsequently signed a Volunteer Informed Consent form.

The project was submitted to the Research Ethics Committee from the Curitiba Clinical Hospital and approved on January 27, 2010 under protocol number 2117.012/2010-01.

RESULTS

A total of 16 subjects participated in the study; 11 men and 5 women with ages between 20 and 64 years old. One subject was excluded from the study for not being under chemotherapy treatment. Four patients died in the course of the study.

The epidemiological data highlights that 46.7% (n = 8) were married, 33.3% (n = 5) were single, and 20% (n = 3) divorced. Around 46.7% (n = 8) were employed, 33.3% (n = 5) were retirees, and 20% (n = 3) were students. Around 46.8% (n = 8) had elementary school education, 26.6% (n = 4) high school, and 26.6% (n = 4) college. The sociodemographic profiles showed a predominance of males representing 68.75% (n = 11) of all participants.

A total of 60% (n = 10) of the participants lived in other cities and 40% (n = 6) in Curitiba.

The clinical and therapeutic variables identified different types of hematological neoplasias distributed as: 46.7% (n = 8) acute lymphocytic leukemia (LL), 33.3% (n = 5) acute myelogenous leukemia (AML), and 20% (n = 3) between non-Hodgkin lymphoma (NHL), multiple myeloma (MM), and hairy cell leukemia.

The treatment period ranged between two weeks and 24 months and chemotherapy sessions between one and 80. The data related to hematological diseases and side effects resulted in the following numbers: 22% nausea, 22% alopecia, 13% mucositis, 6% inappetence, 6% vomiting, and 31% others.

The most cited chemotherapy drugs in the study sample included: cytarabine, daunorubicin, and methotrexate. The lack of use of a broader range of drugs was probably because the interviewed patients attended a single institution where the same protocols are applied according to the diagnosis, that is, because most had diagnosis of LLA and LMA, the variability between treatment schemes was reduced.

Tables 1 and 2 show the results from the *WHOQOL-bref* questionnaire for the assessment of quality of life. It is possible to observe that the average standard deviation calculation in Table 1 with the low scores in Table 2 (although not statistically significant $p = 0.17$) is related to the physical and psychological domains, i.e. the most affected domains: domain 1 and domain 2, respectively.

Table 1 - Mean values and standard deviation of domains, Curitiba, 2010

| Number of Subjects | Domain 1 Physical | Domain 2 Psychological | Domain 3 Social Relations | Domain 4 Environment |
|--------------------|-------------------|------------------------|---------------------------|----------------------|
| | Mean (sd) | Mean (sd) | Mean (sd) | Mean (sd) |
| 15 | 56,67 (23,45) | 73,89 (12,94) | 76,67 (11,87) | 70 (12,87) |

Source: data from the study.

Table 3 demonstrates how the participants assessed quality of life. The options of answers were: "very bad", "bad", "not bad or good", "good", and "very good". None of the participants answered having a "very bad" QV. The option that obtained the highest percentage was "good" QV, with 53.4% of the responses.

Table 4 presents the subject's level of satisfaction in relation to health. The response options were: "very dissatisfied", "dissatisfied", "neither satisfied nor dissatisfied", "satisfied", and "very satisfied". The option "dissatisfied" was not answered by any of the participants and was excluded from the table. The answer with the highest percentage was "satisfied" with their health, in 46.7% of all responses.

DISCUSSION

The sociodemographic analysis shows a predominance of males with ages between 20 and 64 years old. These data are characteristic of this type of neoplasia, both for gender and age.¹⁰ The data also corroborated data from the INCA¹ that reports incidence of cancer predominantly in the population with low level of education and age above 40 years. This age group is compatible with workers and retirees represented in this research.

The fact that 60% of the participants did not live in the region of Curitiba is noteworthy among the most significant notes about quality of life; this circumstance influences the QV of these patients, directly or indirectly, because it is harder for them to routinely receive visitation from friends and acquaintances.

Table 2 - Description of the maximum scores by WOOQOL-bref domains, Curitiba, 2010

| Subject | WOOQOL-bref Domains | | | | | | | | Total score (120/100%) | |
|---------|---------------------|-------|-------------------------|-------|----------------------------|-------|-----------------------|-------|------------------------|-------|
| | Physical (35/100%) | | Psychological (30/100%) | | Social Relations (15/100%) | | Environment (40/100%) | | | |
| | n | % | n | % | n | % | n | % | n | % |
| 1 | 24 | 68,57 | 26 | 86,67 | 14 | 93,33 | 38 | 95 | 102 | 85 |
| 2 | 25 | 71,43 | 15 | 50 | 11 | 73,33 | 29 | 72,50 | 80 | 66,67 |
| 3 | 25 | 71,43 | 24 | 80 | 12 | 80 | 33 | 82,50 | 94 | 78,33 |
| 4 | 18 | 51,43 | 21 | 70 | 11 | 73,33 | 22 | 55 | 72 | 60 |
| 5 | 24 | 68,57 | 26 | 86,67 | 12 | 80 | 28 | 70 | 90 | 75 |
| 6 | 26 | 74,29 | 22 | 73,33 | 13 | 86,67 | 33 | 82,50 | 94 | 78,33 |
| 7 | 28 | 80 | 23 | 76,67 | 15 | 100 | 37 | 92,50 | 103 | 85,83 |
| 8 | 17 | 48,57 | 18 | 60 | 11 | 73,33 | 26 | 65 | 72 | 60 |
| 9 | 20 | 57,14 | 18 | 60 | 11 | 73,33 | 27 | 67,50 | 76 | 63,33 |
| 10 | 22 | 62,86 | 23 | 76,67 | 13 | 86,67 | 33 | 82,50 | 91 | 75,83 |
| 11 | 25 | 71,43 | 21 | 70 | 10 | 66,67 | 31 | 77,50 | 87 | 72,50 |
| 12 | 22 | 62,86 | 26 | 86,67 | 11 | 73,33 | 28 | 70 | 87 | 72,50 |
| 13 | 28 | 80 | 23 | 76,67 | 12 | 80 | 27 | 67,50 | 90 | 75 |
| 14 | 27 | 77,14 | 26 | 86,67 | 14 | 93,33 | 34 | 85 | 101 | 84,17 |
| 15 | 17 | 48,57 | 23 | 76,67 | 13 | 86,67 | 36 | 90 | 89 | 74,17 |

Source: data from the study.

Table 3 - Assessment of quality of life by the study participants, Curitiba, 2010

| Category of Responses | n | % |
|-----------------------|---|------|
| Very bad | 0 | 0 |
| Bad | 1 | 6,6 |
| Neither good or bad | 3 | 20 |
| Good | 8 | 53,4 |
| Very Good | 3 | 20 |

Source: data from the study.

Table 4 - Satisfaction of the study participants regarding their health, Curitiba, 2010

| Category of Responses | n | % |
|------------------------------------|---|------|
| Very Dissatisfied | 1 | 6,67 |
| Dissatisfied | 0 | 0 |
| Neither satisfied nor Dissatisfied | 4 | 26,6 |
| Satisfied | 7 | 46,7 |
| Very Satisfied | 3 | 20 |

Source: data from the study.

The cancer diagnosis itself promotes the social isolation of patients. Another factor that is also preponderant in this situation is the long periods of treatment, which in the case of the studied population it becomes an important item to be highlighted because more than half of the participants do not live in the city

where the treatment is performed. Thus, the distance from home and family becomes a negative aspect that may interfere directly in worsening their quality of life. Therefore, the conviviality with family and friends who encourage their experience of everyday activities is crucial to influence the improvement of QV.

Conversely, the interference of daily activities in life such as work and leisure, can contribute, in addition to social isolation, for feelings of uselessness and as being a "load" for the family, given that many of these patients are providers for their families and their isolation bring concerns related to home maintenance and financial resources. This financial difficulty is reported by other authors¹⁸ as the result of most patients becoming unable to continue working in remunerated activities during the course of their oncological treatment, thus, predisposing to poor QV, and often limiting the basic sustenance of the individual and his family.

Adversities as these could invariably be harmful to the therapeutic path. The therapeutic process refers to a variety of side effects that are undesirable and cause discomfort as reported in an analysis conducted with cancer patients undergoing chemotherapy treatment. Nausea and pain are among the most frequent adverse effects from chemotherapy.¹⁹ The impact of nausea on QV also features statistical relevance, especially at the beginning of the treatment.¹⁰

The results presented in the application of the Quality of Life Assessment Questionnaire, the WHOQOL-bref, according

to the data shown in Tables 1 and 2, highlight the physical and psychological domains as the most affected. The physical domain, in accordance with the instrument, is related to questions about pain and discomfort, energy and fatigue, sleep and rest, mobility, everyday life activity, dependence on medications and treatment, and capacity for work.

The physical domain analyzed during the study can be affected by limitations within the diagnosis, chemotherapy side effects, and some presented comorbidities such as febrile neutropenia, diabetes, hypertension, and acquired immunodeficiency syndrome. These factors lead to tiredness and fatigue throughout long periods of treatment and use of medications that are toxic to the body, in addition to invasive and painful procedures such as catheter implantation and bone marrow biopsy and aspiration causing physical limitations and generating restrictions and/or removal from work during the treatment period.

In the physical domain, also relevant to this study, the results show that fatigue is the symptom that most alters the patient's QV.¹⁰

In another study on evaluation of quality of life in cancer patients undergoing adjuvant chemotherapy, the chemotherapy side effects category, after three months, showed that some symptoms such as nausea and vomiting, fatigue, insomnia, and pain increased during the course of treatment when compared with the beginning of the treatment, reflecting a decline in the physical function.⁸

In another research on chronic diseases, the importance of three major dimensions was investigated: mental health, physical functioning, and social functioning on the perception of quality of life and health. The physical functioning dimension was smaller than the others including variables such as energy, fatigue, and pain.²⁰

Another area affected in this study was the psychological area, which is composed by the following issues: positive and negative feelings, memory and concentration, body image and appearance, and beliefs. This domain may be affected by the diagnosis and use of chemotherapy by being related to the concept of death, and strengthened by the presence of death in other patients with similar disease in addition to the lack of information about the disease and treatment protocols.¹⁰

The diagnosis of cancer interferes significantly in QV, mainly in the physical and emotional aspects. Cancer, despite the scientific and technological advances in medicine, is still regarded as a synonym of death.¹¹

Another relevant point in this domain that deserves attention is the body image. The study that evidenced nausea and pain as prevalent during oncological treatment also referenced some self-image problems that may be related to the event of alopecia, which reached the same percentage of the event of nausea.¹⁹ The self-image related factors are important in assess-

ing quality of life and are also mentioned in another research.²¹ The patient begins to feel excluded from the social surroundings when his image is changed, creating negative feelings about appearance and isolating the individual from the conviviality with people, which resumes the discussion already held previously.

It is important to note that cancer arguably changes every aspect of an individual's life and brings profound changes into his routine and habits. This impairment of ability to perform everyday activities is derived directly from decreased self-esteem, anxiety, and impairment of body image, which are perceived and reported by patients.²²

Hematological diseases and their treatments can cause many changes in the functioning of the body and on the patient's appearance, leading to the feeling of inability and discomfort for everyone. These factors can generate stress followed by depression in more vulnerable patients.²³

Concerns regarding body image come at a time when the patient begins to perceive his body with feelings of self-loathing, of low status before others, and inability to keep their interpersonal relationships.²² The change in appearance is linked to the fact that society identifies them as cancer carriers, which may involve a process of stress and negative feelings.

Anxiety and stress are highly affected items in individuals with diagnoses of malignant diseases and such symptoms are incorporated into their lifestyle and are related to: insecurity, uncertainty about the future, and loss of self-control, physical ability, beauty, freedom, and commitment to friendships, and social entanglements.²²

The predominance of the answer "good" was observed in the analysis of results when participants rated their quality of life. These data support other findings in the literature in which the concept of quality of life is based on the perception of the meanings that people attach to their life experiences considering satisfaction with life in the core of this concept.²⁴

In other studies, quality of life is observed as the subjective understanding of different aspects of life in relation to the state of health. In the case of cancer patients, it is an adaptation process directly influenced by sociodemographic and medical characteristics that may facilitate or hinder the adaptation to illness.²⁵

The factors that contributed to this response may be related to reports of being unconditionally supported by family, friends, and health professionals, and the easy access to health services, good service, and free access to the medicines they need. Thus, they consider having a good QV at the time of the chemotherapy treatment.

When the participants were asked to talk about their satisfaction with regards to health, it was observed that the highest percentage of responses was "satisfied".

Despite all the difficulties presented in the treatment of neoplastic disease, the analysis of the responses from partici-

patient 14, a 22 years old patient, who underwent chemotherapy treatment for over a year after being diagnosed again with recurrent leukemia and being under an intensified treatment protocol, showed that he is very satisfied with his health and plans to get married soon. Even after his evaluation of quality of life as neither good nor bad, he says that he began to give more value to life and tries to enjoy it to the extreme after the illness.

The analyses of answers from participants with severe disease show that despite all their difficulties, they feel well and maintain a good level of autonomy.

CONCLUSION

The presented data leads to the conclusion that there were no statistically significant differences between the physical and psychological, and social and environmental relations domains. The sample size could possibly justify this result. On the other hand, because of the low scores in the physical domain, some changes might occur in the quality of life of patients with hematological neoplasia as the result of the disease's limitations itself and treatment effects.

The assessment of QV demonstrated that 73.4% assessed it as good and very good, and 66.7% were satisfied or very satisfied with their health condition. These data corroborate the literature data that indicates that the concept of quality of life is centered in the perception of the meaning that people ascribe to their life experiences, to the unconditional support of family, friends, and health professionals, a good service received, and free access to the medicines they need. Based on these indicators they consider having a good QV during the time of chemotherapy treatment.

Future studies on quality of life of patients with hematological neoplasia could address larger samples, which could highlight differences in quality of life according to treatment time, differently than what was found in this study.

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