

QUALITY OF LIFE OF CANCER PATIENTS DURING THE CHEMOTHERAPY PERIOD

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ABSTRACT: The objective of this cross-sectional descriptive study was to evaluate the quality of life in cancer patients undergoing chemotherapy. The participants were eighty patients of both genders, 18 years of age or older, with a confirmed cancer diagnosis, undergoing chemotherapy after the second cycle, who had voluntarily agreed to join the study. We used the WHOQOL-Bref instrument, validated in Brazil, through interview, during the period from April to June of 2008. Comparison between domain scores presented a significant difference due to health self-evaluation. The highest scores were in the group with better assessment of their own health. The Psychological domain reached the highest scores, unlike the others, who evaluated the Environment domain best. The results suggest that health self-assessment can be a reliable predictor of quality of life in these patients, therefore it is important to further studies on this topic.

DESCRIPTORS: Neoplasms. Quality of life. Antineoplastic agents.

QUALIDADE DE VIDA DE PACIENTES COM CÂNCER NO PERÍODO DE QUIMIOTERAPIA

RESUMO: Trata-se de estudo descritivo e transversal com o objetivo de avaliar a qualidade de vida em pacientes com câncer sob quimioterapia. Oitenta pacientes de ambos os sexos, com 18 anos completos ou mais de idade, diagnóstico de câncer confirmado, em tratamento com quimioterapia a partir do segundo ciclo e participação voluntária no estudo foram incluídos. Utilizou-se o instrumento WHOQOL-Bref, validado no Brasil, por meio de entrevista, no período de abril a junho de 2008. A comparação entre os escores dos domínios apresentou diferença significativa em função da autoavaliação de saúde. Os maiores escores foram no grupo com melhor avaliação da própria saúde. O domínio Psicológico atingiu os escores mais elevados, diferente dos outros, que avaliaram melhor o domínio Meio Ambiente. Os resultados sugerem que a autoavaliação de saúde pode ser preditor confiável da qualidade de vida nesses pacientes, sendo relevante a ampliação dos estudos.

DESCRIPTORES: Neoplasias. Qualidade de vida. Agentes antineoplásicos.

CALIDAD DE VIDA DEL PACIENTE CON CANCER EN EL PERIODO DE QUIMIOTERAPIA

RESUMEN: Estudio descriptivo y transversal con el objetivo de evaluar la calidad de la vida en pacientes con cáncer recibiendo quimioterapia. Ochenta pacientes, voluntarios, mayores de 18 años o más, de ambos sexos, con el diagnóstico de cáncer, que reciben quimioterapia después del segundo ciclo. Se utilizó el instrumento WHOQOL-Bref, validado en Brasil, empleando entrevistas de abril a junio de 2008. La comparación entre los *scores* de los dominios presentó diferencia significativa en función de la evaluación subjetiva de la salud. Los *scores* más altos fueron encontrados en el grupo con una evaluación mejor de su propia salud. El dominio Psicológico alcanzó *scores* más elevados, diferente de los otros grupos, que evaluaron mejor el dominio Medio Ambiente. Los resultados sugieren que la auto-evaluación de la salud puede ser un predictor fiable de la calidad de vida en estos pacientes, necesiéndose la expansión de mas estudios al respecto.

DESCRIPTORES: Neoplasias. Calidad de vida. Antineoplásicos.

INTRODUCTION

Cancer is a major public health problem in developed and developing countries, deserving increasingly more research in order to promote better quality and humanization of care to patients with this disease. It is estimated that by 2020, the number of new cases per year will be nearly 15 million, of which about 60% occur in developing countries.¹ Because of the increased life expectancy and the aging population, caused by the change in the mortality profile, and reduced rates of communicable diseases, it has been observed that there has been a global increase in the rates of chronic-degenerative disease, particularly cardiovascular diseases and cancer.²

The cancer diagnosis brings important changes to the way of living with physical and emotional changes due to discomfort, pain, deformity, dependence and loss of self-esteem. It is common to associate the word "cancer" to a life threatening disease and consider it "morally contagious", even avoiding to pronounce its name.³ In addition, the patient must face the different types of treatment for the disease, such as surgeries and radiotherapy and chemotherapy treatments, frequently associated to adverse side effects.⁴

The adverse effects of chemotherapy may be divided into two groups: acute, beginning minutes after administration of antineoplastic agents and persisting for some days, and late, which appear several weeks or months after the infusion thereof. Most drugs lead to bone marrow depression in varying degrees, depending on the agent and dose used, as well as intrinsic factors. Alopecia and gastrointestinal changes are also frequent.⁴

Even when one reaches the end of a successful treatment, the patient still has to live with the fear of recurrence and the consequences that arise from a cancer treatment. Moreover, this whole routine of chemotherapy and radiotherapy to "take care of cancer" can change dramatically the patients' everyday life, interfering with their quality of life.⁵

There is wide range of concepts and opinions about "quality of life" and, over time, these concepts have been turning to the patient's perception about the disease and treatment and its effects, in an objective and subjective way.⁶ Health and disease represent processes included as a *continuum*, related to economic, socio-cultural, personal ex-

perience and life style aspects. Thus, improving quality of life has become one of the outcomes expected both of care practices and public policies for the sector in the fields of health promotion and disease prevention.⁷

The World Health Organization (WHO) defines quality of life as "the individual's perception of his or her position in life in the context of culture and value systems in which he or she lives, and in relation to personal goals, expectations, standards and concerns."^{8:583} The best understanding of the elements making up this perception can help the health professional to define interventions that envisage patient's integrity, rather than being restricted to addressing the disease and treatment.

Thus, this study sought to evaluate the quality of life of cancer patients during chemotherapy, seeking support for a more comprehensive and human care. This study is relevant given the increased incidence of cancer in Brazil and how this disease affects the daily lives of patients.

OBJECTIVES

To evaluate the quality of life referenced to domains (Physical, Psychological, Social and Environment) in cancer patients, undergoing outpatient chemotherapy, treated at a University Hospital.

To analyze the association between quality of life and variables such as age, gender, education and self-assessment of health in these patients.

PARTICIPANTS AND METHOD

This exploratory and descriptive study was performed, using a quantitative approach, at the Clinical Oncology Service of a university hospital in Campinas (SP), which provides outpatient treatment to cancer patients undergoing chemotherapy and radiotherapy. The HC/Unicamp Hospital is a reference center for the care of cancer patients under the Regional Health Departments of Campinas, Piracicaba and São João da Boa Vista and other States. The service also offers nursing, nutrition, social work, psychology and dentistry appointments. HC is part of the service of the Hospital Information System on Cancer (*Registro Hospitalar do Câncer* - RHC), with compulsory notification of cancer cases treated at hospitals associated with the São Paulo Oncocentro Foundation (FOSP). Currently, the most frequent types of cancer in the

Clinical Oncology Service are colorectal, head and neck, prostate, and stomach.

The participants were 80 patients of both genders, according to the following inclusion criteria: eighteen years of age or older, cancer diagnosis confirmed by biopsy, and undergoing chemotherapy after the second cycle. Exclusion criteria: inadequate clinical conditions to respond to an interview.

After obtaining authorization from the service, patients were approached in the outpatient clinic, when the purpose of the study was explained and they were invited to participate. Patients who agreed to participate were asked to sign an Informed Consent Form (IC) and, next, the instrument was applied in the form of interviews carried out in the room where the patient was undergoing chemotherapy. A total of five to ten interviews were performed per week, in the time and days most suitable for the clinic in the months of April to June of 2008. Each interview lasted approximately half an hour, and all patients were thanked for their participation in the end. It is worth noting that this study did not investigate side effects to chemotherapy and other medications. We investigated the type of cancer and the chemotherapy cycle the patient was undergoing at the time of the interview.

The data collection instrument used was: WHOQOL-Bref, a generic instrument to assess quality of life. This is the abbreviated version of the instrument used by WHO, the WHOQOL-100, already validated in Portuguese.⁶ It consists of two parts: one aimed at the sociodemographic and health aspects and the other at quality of life. The latter consists of 26 questions, being two about quality of life in general and the other 24 representing each of the facets that make up the original instrument. The questions are organized in four domains that make up the short version: Physical (pain and discomfort, energy and fatigue, sleep and rest); Psychological (positive feelings; thinking, learning, memory and concentration; self-esteem, body image and appearance; negative feelings); Social (personal relationships; support/social support; sexual activity); Environment (physical safety and protection; home environment; financial resources; health and social care: availability and quality; opportunities to acquire new information and skills; participation in, and opportunities for recreation/leisure, physical environment, pollution, noise, traffic/weather, transportation). The score of each ques-

tion ranges from one to five and higher scores indicate a better evaluation.⁶

Data analysis was performed using descriptive statistics (frequency, proportion, position measurements and dispersion); statistical tests to compare numerical variables between two groups (Mann-Whitney test) and more than two groups (Kruskal-Wallis test), and evaluate correlation between assignable numerical variables (Spearman rank correlation test). Pearson coefficient was used to evaluate the correlation between domains and between these and the Overall Quality of Life, as well as between the facets forming each domain and its domain score. The value of $p < 0.05$ ($\alpha = 5.0\%$) was adopted as critical level. The raw scores relative to each domain were converted according to the Syntax developed by the group responsible for the WHOQOL using Windows SPSS (Statistical Package for Social Sciences), version 10.0.1 (SPSS Inc., 1989-1999) was used.

Ethical procedures were respected and this research was approved by the Research Ethics Committee of the institution on 03/25/2008 (n. 103/2008), being in agreement with Resolution 196/96 of the CNS that regulates human research in Brazil.

RESULTS

Interviews were performed with 80 patients, 48 of whom were men (60%) and 32 were women (40%). As to the age group, 10 patients (13%) were between 22 and 30 years; 18 patients (22%), between 31 and 50 years; 41 patients (51%) between 51 and 70 years; and 11 patients (14%) between 71 and 90 years. The mean age was 54 (± 16) years, with a median of 56 years. Fifty-two patients (65%) were married and 28 (35%) were separated, single or widowed. Regarding education, 12 (15%) were illiterate, 43 (54%) had complete or incomplete primary education, 14 (18%) reported having complete or incomplete secondary education and 11 (13%) had complete or incomplete higher education.

When asked about self-rated health, 27 (34%) patients rated it as "very good" or "good", 35 (44%) indicated that it was "neither good nor bad" and 18 (22%) said that it was "very bad" or "poor".

The most common location of tumor was the colon (35 patients or 44%), followed by head and neck (14 patients or 18%), higher organs of

the digestive system (14 patients or 18%), lung (eight patients or 10%), male genital system (7 patients or 9%) and other locations (2 patients or 3%). Most patients had undergone two cycles of chemotherapy (39 patients or 49%) while 36 patients (45%) had undergone between three to four cycles, and five patients (6%) had undergone more than four cycles (average of 2.8 ± 1 cycle, mean 3). The time for diagnosis was from 3 to 6 months for 28 patients (35%), from 7 to 12 months

for 36 patients (45%), from 13 to 18 months for 3 patients (4%), from 19 to 24 months for 10 patients (12), and more than 24 months for 3 patients (4%). The average was $11.4 (\pm 8.4)$ months with a median of 9.5 months.

The results obtained with WHOQOL-Bref are shown in Table 1. It was found that the most compromised domains were the Social and Physical and the most preserved was the Environment.

Table 1 - Scores obtained in the WHOQOL-Bref from patients undergoing outpatient chemotherapy (n=80). Campinas-SP, 2008

| Domains | Mean | Standard deviation | Median | Minimum | Maximum |
|-------------------------|------|--------------------|--------|---------|---------|
| Physical | 55.4 | 18.1 | 57.1 | 10.7 | 85.7 |
| Psychological | 64.4 | 14.7 | 64.6 | 12.5 | 91.7 |
| Social | 55.1 | 24.4 | 66.7 | 0.0 | 91.7 |
| Environment | 70.7 | 8.4 | 71.9 | 8.4 | 90.6 |
| Overall quality of life | 12.7 | 3.4 | 12.0 | 4.0 | 18.0 |

All the presented domains correlated with each other and with the evaluation of Overall

Quality of Life, as shown in Table 2.

Table 2 - Correlation between the domains of WHOQOL-Bref, and these with the Overall Quality of Life of patients undergoing outpatient chemotherapy (n=80). Campinas-SP, 2008

| Domains and overall quality of life | Domains | | | |
|-------------------------------------|-------------------|-------------------|-------------------|-------------------|
| | Physical | Psychological | Social | Environment |
| Physical | ---- | ---- | ---- | ---- |
| Psychological | 0.72* | ---- | ---- | ---- |
| Social | 0.45 [†] | 0.42 [‡] | ---- | ---- |
| Environment | 0.49* | 0.52* | 0.56* | ---- |
| Overall quality of life | 0.73* | 0.68* | 0.40 [‡] | 0.38 [‡] |

* $P < 0.000005$, [†] $p < 0.00005$, [‡] $p < 0.0005$.

There were no significant differences in the scores of the domains and Overall Quality of Life according to the following variables: gender, marital status, tumor type (considering patients with colorectal tumors and other locations), and chemotherapy cycles (comparing patients who had undergone two cycles and those who had undergone three or more cycles). The scores obtained in the domains of WHOQOL-Bref and the score of Overall Quality of Life showed no significant correlation with age and time since

diagnosis. The physical domain scores showed a trend to the difference between the diverse educational levels, being lower for the illiterate ($p = 0.06$).

The comparison between the domain scores and those of Overall Quality of Life in terms of self-rated health showed a statistically significant difference between groups. The highest scores come from the group with better assessment of their own health, as illustrated in Table 3.

Table 3 - Comparison between the domains and the Overall Quality of Life (OverallQL) in terms of self-rated health of patients undergoing outpatient chemotherapy (n=80), according to the Kruskal-Wallis test. Campinas-SP, 2008

| Domains | Self-rated health | | | | | | | | |
|---------------|-------------------|------|--------|----------------------|------|--------|---------------|------|--------|
| | very good/good | | | neither good nor bad | | | very bad/poor | | |
| | mean | dp | median | mean | dp | median | mean | dp | median |
| Physical* | 69.8 | 12.5 | 71.4 | 52.8 | 13.5 | 53.6 | 38.7 | 16.8 | 42.9 |
| Psychological | 77.3 | 8.4 | 75.0 | 62.7 | 11.0 | 62.5 | 48.4 | 10.8 | 50.0 |
| Social† | 67.3 | 17.9 | 75.0 | 51.9 | 24.7 | 58.3 | 43.1 | 25.3 | 50.0 |
| Environment‡ | 76.2 | 8.0 | 75.0 | 68.8 | 7.1 | 68.8 | 66.5 | 7.4 | 65.6 |
| OverallQL‡ | 16.1 | 0.9 | 16.0 | 12.3 | 1.2 | 12.0 | 8.2 | 3.1 | 8.0 |

*p< 0.00005, †p<0.001, ‡p<0.0005

The facets of greater influence on quality of life in each domain of WHOQOL-Bref, were identified through analysis of correlation between each question that makes up the domain and its average score. These results are shown in Table 4.

Table 4 - Facets with greater influence in each domain of WHOQOL-Bref of patients undergoing outpatient chemotherapy (Spearman Rank Correlation Test). Campinas-SP, 2008

| Question No. | Facet evaluated | R | P |
|-----------------------------|----------------------|-------|---------|
| Physical domain | | | |
| 10 | Energy and fatigue | 0.84 | 0.00000 |
| 17 | Daily Activities | 0.82 | 0.00000 |
| 3 | Pain and discomfort | -0.80 | 0.00000 |
| 15 | Mobility | 0.78 | 0.00000 |
| Psychological domain | | | |
| 26 | Negative feelings | -0.77 | 0.00000 |
| 19 | Self-esteem | 0.76 | 0.00000 |
| 5 | Positive feelings | 0.70 | 0.00000 |
| Social domain | | | |
| 20 | Personal relations | 0.91 | 0.00000 |
| 22 | Social support | 0.91 | 0.00000 |
| Environment domain | | | |
| 9 | Physical environment | 0.68 | 0.00000 |
| 24 | Health care/social | 0.59 | 0.00000 |

DISCUSSION

The characteristics of the studied patients reflect the national portray of the disease and also the type of care delivered in the outpatient clinic chosen as research field. In Brazil, neoplasias in general are more prevalent in men; the most com-

mon types in 2006 were prostate, lung (including trachea and bronchi) and stomach, the latter two with values well above those observed in women. In females, breast and cervical cancers are more predominant.⁹ Therefore, in our study, the numerical predominance of men over women is due to the type of tumor found and also to the fact that female genital system cancers are not treated at this outpatient clinic because these cases are cared for at a specific center dealing exclusively with women's health.

The most common tumors were those of colorectal, head and neck, high digestive organs, lung and male genital system. In Brazil, colorectal cancer is the fourth most common type of cancer among men and third among women, being in fifth place as a cause of mortality in both genders.¹⁰

Regarding quality of life, it was found that the Social and Physical domains were the most affected and the best preserved was the Environment domain. In a similar study with patients affected by colorectal cancer, the most affected domain was the Environment, and the least affected was the Psychological, in patients without stomas. In ostomy, the most affected was the Physical domain, and the least affected, the Social.³ As to General Quality of Life, the values obtained (12.7 points) in this study were lower than those of the authors mentioned above (15.4 for the patients without stoma and 15.7 for those with stoma), even considering only the patients with colorectal cancer of our case study (13.0 points). These differences cannot be explained with the data collected.

It was observed that the Physical and Psychological domains showed the highest correlation with each other and with other domains, suggesting the inter-relationship between them,

as well as those that had the greatest influence in the General Quality of Life in this population. The Social and Environmental domains showed lower correlation with other areas, although significant, and were the ones with the least effect on Overall Quality of Life. These findings contribute in part to understand the low values found for Overall Quality of Life in the present study participants, since the Environment domain reached the highest average scores, and the Physical domain, the second lowest score.

The Overall Quality of Life scores did not differ according to socio-demographic characteristics and even the history of the disease and tumor location. In literature, some authors point out that factors such as age, female gender, low education level and not having a partner may be related to low quality of life.⁷ In other studies – international¹¹ and national¹²⁻¹³ –, performed with subjects with cancer, just like in the present study, no association was found between quality of life and gender, age, education, being employed, type of surgery, time since surgery, duration of the disease, staging, and chemotherapy.¹¹⁻¹³ It is important to highlight that each individual has a particular way of operationalizing his or her evaluation on quality of life, and the evaluation of one same subject can vary with time, with the variation of priorities along life and with the circumstances through which life can change.

The comparison between the domain scores and Overall Quality of Life as a result of self-rated health showed a statistically significant difference between groups. The highest scores were in the group with better assessment of their own health. A study of 197 patients from eight cancer treatment centers in Japan, with the WHOQOL-100, showed similar results, and the authors emphasize that self-rated health did not always corresponded to the severity of the clinical phase or staging of the tumor. These findings suggest that self-rated health can be a reliable predictor of quality of life in these patients.¹⁴ Another study performed in Norway with women who survived ovarian cancer, suggests that self-rated health was strongly associated to physical symptoms, such as fatigue, but not with variables such as tumor staging, diagnosis time and undergoing chemotherapy. The authors suggest that a single question about self-rated health can constitute a quick method to assess the relevance of symptoms for the patient and, consequently, direct interventions of the health team, highlighting the importance in the

use of this knowledge by nurses and other professionals in the area.¹⁵

It is observed that the perception of quality of life in different domains is affected most by some of the facets that make up the instrument WHOQOL-bref, over others. This suggests that some aspects that comprise quality of life are more relevant than others, for these subjects.

Regarding the facets that influenced the Physical domain the most, the following was found in order of higher to lower: energy and fatigue, daily activities, pain and discomfort and mobility. It is proposed that these four facets are very well related between them. It is highlighted that fatigue is a prevalent symptom in advanced cancer disease, occurring in 75% to 95% of patients,¹⁶ though not everyone is capable of expressing, spontaneously, what they truly feel about the damage that fatigue caused in their lives.¹⁷ This has to do with a complex and debilitating symptom because it compromises the activities of daily life and causes damages to life quality.¹⁶

The Psychological domain had influence predominantly of the facets: negative thoughts (inverse correlation), self-esteem and positive thoughts, whereas in literature the spirituality/personal beliefs facet was the most influente.³ Other authors point out that the suffering coming from the tumor, other symptoms related to the disease, waste caused by the treatment and the emotional charge involving the diagnosis.¹⁴

Regarding the facets that affected the Social domain the most, we found personal relationships and social support. Cancer and its treatment can cause significant changes in vital functions related to communication and social interaction of patients and may result in a significant negative impact on their quality of life and that of their family members.¹⁴

In the Environment domain, which received the highest scores, the physical environment and health and social care were the facets with the strongest effect. One possible explanation is the fact that these patients were undergoing treatment at a reference state hospital and in Brazil, in addition to the welcoming they received at the outpatient clinic, which may contribute to their safety and well-being.

It is asserted that it is critical that nurses and other health team members adopt, in the care of cancer patients, a broader view on the feelings emerged towards the disease, their consequences and the results achieved in the rehabilitation pro-

cess. In one study, nurses verbalized fears and insecurities in care often due to misinformation about the disease itself and forms of treatment, as well as the fantasies that are formed around the patient diagnosed with cancer.¹⁸ This research, by identifying that fatigue, pain, social relations and social support influence in negative evaluation of life quality, can contribute to subsidies so that the nurse and the health team can focus on more adequate interventions, aiming at minimizing their impact. Thus, one can also reduce misinformation and, consequently, the feelings of fear and insecurity of the team, as material aspects are presented specific to be addressed in the interventions.

A study for knowledge production in oncology nursing in the period 1994 to 2004 reports the specificity of the knowledge produced in the dimensions and formalities of the nurses' performance in the area of oncology nursing. This indicates that such knowledge is consistent with the complexity and attempts to explain the art of caring for clients with cancer and with efforts to establish/expand criteria and assistance standards.¹⁹

Thus, nursing research must be evidence-based on clinical practice and planning of health care to these patients should be individualized and based on respect for their values and beliefs. Hence, one seeks to meet, more broadly, expectations and needs of people with cancer, contributing to the necessary decision-making toward improving the quality of life, not just the extension of survival.²⁰

Another study conducted in southern Brazil at chemotherapy units with 48 patients with colorectal cancer showed that WHOQOL-Bref domain most affected was the Psychological domain. This fact is similar to the present study, which calls for further attention to aspects that may affect clinical practice.²¹

Furthermore, there is a need for more research in the area, aimed at investigating whether nursing education encompasses the areas identified above, thus contributing to their performance at the level of excellence that cancer patients require.

CONCLUSIONS

Regarding the quality of life of the 80 patients in outpatient clinic chemotherapy, it was found that the Social and Physical domains were the most compromised, while Environment was the most preserved. The comparison between scores showed significant difference only in terms of

self-rated health. The highest scores were found in the group with better assessment of their own health. For these patients, the Psychological domain reached the highest scores, unlike the other groups, who evaluated the Environment domain better. The results suggest that health self-assessment can be a reliable predictor of quality of life in these patients, being relevant to further studies on this topic. Furthermore, this study demonstrates the need for health professionals to be aware of the aspects that may affect the Physical and Psychological domains, since these were the most compromised aspects in this study.

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