The Zubrod performance status and the Karnofsky index in quality of life evaluation of children with cancer

Performance de Zubrod e Índice de Karnofsky na avaliação da qualidade de vida de crianças oncológicas

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ABSTRACT

Objective: To describe the epidemiologic profile of children undergoing chemotherapy and/or radiotherapy and to assess the quality of life during treatments, by means of the ECOG scale and the Karnofsky index. Methods: A descriptive exploratory study, with quantitative approach. The sample consisted of children with cancer undergoing chemotherapy or radiotherapy. Results: Twenty-four children, most males (67%), were interviewed; chemotherapy was the primary treatment in 56% of them. The most frequent condition was acute lymphoid leukemia in both sexes. Chemotherapy was the treatment modality interfering most with the quality of life, altering aspects such as: socialization, behavior, nutrition, sleep and rest, performance of activities. Regarding the ECOG scale, 75% of the patients who scored 1 were symptomatic, and only 25% of patients scored 0 and were asymptomatic. As to the Karnofsky index, 25% of patients were asymptomatic and performed their daily activities, whereas 71% presented with mild symptoms of the disease, yet performed their daily activities. Conclusion: A chronic disease, like cancer, changes some aspects in the daily routine of the children and their family. However, individual characteristics must be respected aiming at the child’s quality of life.

Keywords: Neoplasms; Child; Oncologic nursing; Oncology; Ambulatory care/utilization; Quality of life; Chemotherapy; Radiotherapy

INTRODUCTION

Malignancies are a group of disorders which have in common the uncontrolled proliferation of abnormal cells and may occur anywhere in the body. The most common malignancies in childhood are leukemias, central nervous system tumors and lymphomas(1). Cancer treatment begins with the correct diagnosis, which requires reliable laboratory and imaging studies. Because of its complexity, treatment must be done in specialized centers, and involves three major modalities, chemotherapy, surgery and radiotherapy, used rationally in an individualized manner for each specific tumor and according to the extension of the disease. Currently,
70% of children with cancer may be cured if diagnosed early and treated in specialized centers(1). Some instruments that measure the quality of life of patients were devised to assess the response to the treatment. Important parameters, such as the degree of physical activity, symptoms of the disease and the amount of help required are assessed(2).

In addition, these evaluations allow the oncology nurse to determine tolerance and response to treatment, and they help defining the duration of the treatment employed. The nurse performs several activities in order to meet the needs of the child and family, establishing contact with the child and the family to explain their doubts about what the nursing team will do. This information is very important when a treatment is planned, reviewing the diagnosis and prognosis of the disease(3).

The instruments or scales most used are the Karnofsky index and the ECOG (Eastern Cooperative Oncology Group) or Zubrod performance status.

The Karnofsky index describes the levels of activity and independence using scores from 0 to 100. Zero indicates death and 100, normal physical performance and attitude to perform normal activities(2). It is the most used instrument for prognosis of cancer therapy because it is a measure of performance for the classification of a person’s skills for an activity, assessing the patient’s prognosis after a certain therapeutic procedure and determining its capacity for the treatment(4).

Another instrument used is the ECOG, which establishes scores from 0 to 5. Zero score indicates that the patient is fully active and able to perform normal activities and score 5 is given to the dead patient. It is also known as the “Zubrod Performance”, a more recent and simplified instrument to measure the quality of life of a cancer patient. It was elaborated by the ECOG of the United States of America and validated by the World Health Organization (WHO)(2). The main function of the ECOG scale is to rate cancer treatments, taking into account the patient’s quality of life. It assesses the outcome of the patient’s capacities in its daily life, keeping its autonomy at its fullest(2).

The patients who are fully active and have mild symptoms respond better to the treatment and survive longer than those who are less active or have severe symptoms. A clear goal of the performance scales could be sorting those patients into clinic-therapeutic study groups, comparing the different protocols of chemotherapy and determining treatment efficacy(5).

As important as cancer treatment itself, is the care delivered to the social aspect of the disease, because the child is in the family context. Nursing care requires skills to assess the child’s condition, based on the knowledge about what childhood cancer is and also on the technological advances of treatment, in addition to the psychosocial and family aspects that involve it(3).

Chronic disease can be a stressor on the patient and the family in different ways, as well as living with the disease and its symptoms. In this case the assessment of quality of life regarding the child’s and adolescent’s health, the treatment of cancer or those who survived this experience is the first step for assessing the potential impact in the general quality of life of the individual(6-7).

The scales help nurses to assist patients, and are extremely important in oncology nursing in evaluating the response to treatment.

**OBJECTIVES**
To describe the epidemiologic profile of children with cancer undergoing chemotherapy and/or radiotherapy, and to assess the quality of life of the child with cancer during treatments of chemotherapy and/or radiotherapy, by applying the ECOG scale and the Karnofsky index.

**METHODS**
**Type of study**
This is a descriptive, exploratory, level I study, with a quantitative approach.

**Setting**
The study was carried out in a private hospital in the city of São Paulo, at the chemotherapy and radiotherapy units.

**Population and sample**
The population was composed of children with cancer undergoing treatment with chemotherapy or radiotherapy at the time the data was collected.

The sample comprised the children who met the following inclusion criteria: to be undergoing chemotherapy or radiotherapy; to have a legal guardian who agreed to participate in the study and signed the informed consent form.

**Instrument for data collection**
The authors elaborated a questionnaire for data collection containing the identification and five semi-closed questions dealing with fundamental aspects: sleep and rest quality; nutrition; performance of daily activities; humor and behavioral changes during treatment; interpersonal relationships.
At the end of the interview, ratings according to the ECOG scale and the Karnofsky index were done, to evaluate the quality of life of these patients.

**Data collection**

Data was collected after approval of this project by the Scientific Committee of Faculdade de Enfermagem do Hospital Israelita Albert Einstein (FEHIAE) and by the Research Ethics Committee of the Institution. The authorization of the sector coordinator where the data were gathered was also obtained. Data collection was conducted in 2008, by the first author, who explained the objectives of the study and applied the scales, after the legal guardians had agreed to participate in the study and signed the informed consent form. These instruments were gathered right after they were answered.

The authors committed to use the survey data solely for this study, abiding to the ethical and legal principals involved in research with human beings.

**RESULTS**

**Part 1: identification**

Twenty-four children were interviewed, 16 (67%) were male and 8 (33%) female. Among males, seven children (44%) had radiotherapy as the primary treatment and nine (56%), chemotherapy. Among females, seven children (87%) had chemotherapy as the primary treatment and only one (13%) was submitted to radiotherapy (Figure 1).

As to the type of treatment, the four to six year-old patients underwent the two treatments separately (17 children in total). Among them, 13 were submitted to chemotherapy and four to radiotherapy (Figure 3).

Regarding the types of cancer, there was a difference between the sexes; males have a higher incidence of acute lymphoid leukemia (ALL) with seven patients (44%) affected. ALL occurred in seven female patients (87%). (Figures 4-5)

Analyzing the types of cancer according to age groups, ALL occurred in seven patients aged four to

The predominant age group among males was four to six years, with 11 children in it. Three children were aged from one to three years, one child was in the seven-nine year group, one in the 13 to 15 years and one in the 16 to 18 years. The predominant age group among females was also four to six years, with three children in it (Figure 2).
six years, in four from seven to nine years and in three patients from one to three years (Figure 6).

As to companions, 65% of male patients had the mother with them and 10%, the grandparents; 35% of females had the mother as the companion, 10%, the grandparents and only 5% were fathers and siblings (Figure 7).

Part 2: quality of life assessment

Data regarding quality of life will be presented as topics, according to the pattern suggested by the Zubrod and Karnofsky indexes.

Quality of sleep and rest

Among males, 38% had and excellent quality of sleep, 37%, good and 25%, regular. The distribution of sleep quality among females was similar, excellent and good, 50% each (Figure 8).

As to quality of sleep according to the type of treatment, 62% of patients undergoing radiotherapy referred excellent quality of sleep, and 25%, good, as informed by the companion. Regarding those who underwent chemotherapy, 50% of patients reported regular quality of sleep and 25% each, excellent and good (Figure 9).

Nutrition

As regards having three daily meals, 10% of children undergoing radiation therapy refused to have the meals, according to parents and/or companions, while 100% of those undergoing chemotherapy ate the three daily meals. In relation to nausea and lack of appetite, 62% of patients under radiotherapy and 75% of children under chemotherapy had these symptoms (Figure 10).
Performance of daily activities

Regarding daily activities such as playing with friends and going to school as well as feeling fit for these tasks, only 10% of patients undergoing radiotherapy and 12% of those undergoing chemotherapy did not perform such activities (Figure 10).

School attendance

Ninety percent of children undergoing radiotherapy did not go to school regularly because they were not at school age. Considering children undergoing chemotherapy, 62% had normal school attendance (Figure 10).

Behavioral changes

This item involves some aspects, such as feeling happy/motivated, with no drive, revolted, crying a lot, acting shy and ability to cope with the disease.

The companions reported that 100% of children undergoing chemotherapy had some behavioral change, while 80% of children submitted to radiotherapy reported some change (Figure 10).

Socialization

Socialization was assessed according to some aspects: if the child has a good relationship with the siblings, if it is sociable with other children and in the groups it attends. Eighty percent of children on radiotherapy were sociable, whereas 20% were not. However, 93% of children undergoing chemotherapy were sociable (Figure 10).

Performance and function scales: Zubrod performance or ECOG and Karnofsky index.

Based on the answers to the questionnaires, the development and function scales were obtained to measure the quality of life of these patients during chemotherapeutical and radiation treatments.

According to what was previously described, the Karnofsky index describes levels of activity and independence rated from 0 to 100. Zero indicates death and 100 indicates normal physical performance and fitness to perform normal activities.[2]

Only 25% of patients scored 100 in the scale, that is, they were asymptomatic and performed their activities normally (Figure 11). Most of them, 71%, scored 90, with mild signs and symptoms of the disease and/or side effects of the treatment.

Seventy-five percent of patients scored 1 in the ECOG scale, meaning that they were symptomatic, while only 25% of patients were asymptomatic, scoring 0. Likewise the other scale, the side effects of treatments, which somehow interfere in their quality of life but not fully prevented them to perform the activities, were included in this assessment (Figure 12).
Quality of life in children with cancer

Figure 10. Quality of life of children with cancer as to nutrition, daily activities, school attendance, behavioral changes and socialization

Figure 11. Karnofsky index score

Figure 12. Classification in ECOG scale

DISCUSSION

According to Instituto Nacional de Cáncer (INCA), pediatric cancer represents between 0.5 and 3% of all malignancies in most populations. By and large, the incidence of malignant tumors in childhood is higher in males(8).

Of childhood cancers, leukemia is the most frequent, and ALL prevails in children in most populations. The central nervous system tumors, which predominate in males, occur mainly in children younger than 15 years peaking at the age of ten years old, accounting for 20% of pediatric neoplasms. Bone tumors are more common in adolescents(8-11). These findings are similar to what was found in this study.

As for companions, the literature shows how important the participation of parents or relatives in caring for the child is, because when hospital care is based on the needs of the child and not only on the disease, allowing parents and other family members to participate in care, thus making patients feel more at ease and confident(12).

Regarding the quality of life of children with cancer, in the item quality of sleep and rest, it is common to find sleep disorders in oncological patients because of sleep cycle inversion and also because of different causes, such as depression, metabolic changes or use of some drugs. Insomnia may cause anxiety and irritability in children, and often it may destabilize the person caring for the child because its sleep is also disturbed(13).
Regarding sleep according to treatment, one of the side effects of radiotherapy is tiredness and fatigue, which added to the stress of the disease, the daily visits for treatment and the effect of radiation contribute for tiredness. However, this disappears with time and may vary from patient to patient\(^{(5,12-14)}\).

Nausea and vomiting are the side effects with greater impact in the quality of life of pediatric patients with cancer and may have severe consequences to their health. These effects may cause refusal of feedings, which may cause metabolic disorders and have negative social and psychological effects\(^{(9)}\). Children learn how to associate food taste stimulation to the physiologic consequences of digestion. A typical example of this type of learning is the aversion conditioned by the results of eating a certain kind of food, which provokes negative consequences like nausea and vomiting. This fact associated with antineoplastic treatments may explain the diminished food acceptance by patients\(^{(15)}\).

On the other side, a sudden increase in appetite may be related to the use of glucocorticoids, which stimulate appetite, associated with parental incentive for the child to eat properly, ensuring a successful treatment\(^{(8)}\).

As to the performance of daily activities, literature points to the concerns with physical issues and hospitalizations, which are so important that parents often find no options to avoid that the child/adolescent misses school, causing school abandonment. It is fundamental for parents to understand the importance of schooling to their children and that the hospital is a partner with specialized professionals in order to promote schooling continuity\(^{(16)}\).

Frequent school absenteeism reduces the child/adolescent motivation, creating a barrier in the relationship between them, the teachers and other children, hindering thus school adjustment.

However, it is possible to identify facilitating situations for adjustment and learning, by understanding of teachers, remedial classes, trying to alleviate the difficulties of these children to go back to school\(^{(17)}\).

Concerning behavioral changes and socialization, some studies report that when the chronic disease starts in certain specific periods of development, such as when learning to walk, this may hinder it and it may restrict, for example, the autonomy. The several aspects involved with drugs, food and schedules may interfere in the child desire to control, generating apathy and passivity. In addition, mothers and fathers often have difficulties in imposing limits needed for behaviors\(^{(18)}\).

The impact of treatment must be observed for the initial and complementary orientation of therapy, avoiding treatments which greatly reduce the quality of life. The Karnofsky index is a physical performance scale developed at first to assess the physical capacity in cancer patients, but its use was broadened to assess it in other disabling chronic diseases. The ECOG is a more recent and simplified instrument to measure a cancer patient’s quality of life of and is very important in studies because the level of activity of patients may be identified by these variables, as well as the degree of medical and nursing assistance needed. It is also an objective way to assess tolerance and response to treatment, which facilitates the choice of treatment to be employed\(^{(19-20)}\).

According to the ECOG evaluation, the majority of patients was asymptomatic, was in ambulatory treatment and performed their daily activities, while the minority was asymptomatic, performing their daily activities regularly. As for the Karnofsky index, the minority of patients was asymptomatic and performed regularly their activities, in spite of the fact that the majority of these patients had light signs and symptoms of disease they were able to perform their daily activities.

**CONCLUSION**

The present study identified the epidemiologic profile of these oncologic patients and evaluated their life quality during treatments, by means of the ECOG scale and Karnofsky index and it was possible to conclude that the child and family daily routines are modified in some aspects by the appearance of chronic diseases, such as cancer, coinciding with childhood development stages. However, despite these conditions, the individual specificities must be respected aiming at the child’s quality of life.

**REFERENCES**


