Hodgkin’s Lymphoma: Impacts and Changes in Life of Carriers Undergoing Treatment

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Abstract

Diagnosis and treatment of Hodgkin’s lymphoma introduce a new routine, and the habitual life of the young adult is interrupted because the treatment imposes on patients withdrawing from their environment, their productive activities, their relatives and their daily life. The aim of the present study was to understand the experience of the young adult carrier of Hodgkin’s lymphoma in the face of treatment. This is a qualitative study; subjects were patients diagnosed with Hodgkin’s lymphoma at a reference hospital in northeastern Brazil. Inclusion criteria were being undergoing treatment or follow-up of Hodgkin’s lymphoma, and aged 18 to 35 years. The information was collected through an interview at the home of each subject in the period from August and September 2015. The interviews were recorded, transcribed in full and analyzed through thematic analysis. The study was approved by the Research Ethics Committee. The subjects went through a rather individual pathway to discover the disease. After reading the interviews, the following category emerged: Impact and changes in life with cancer. They feel the impact of cancer and of the process of illness and treatment that promote physical and social changes. They reveal the coping of the disease with liveliness, and present strategies for this process, such as the support of family and friends. They recognize the existence of difficult moments and face situations of death, but they show intention to return to their daily activities and have perspectives for cure.

Keywords
Experience; Hodgkin’s Lymphoma.
Introduction

Cancer today is the second cause of death in Brazil due to disease, behind only cardiovascular diseases [1]. Following a clinical reasoning that guides the programs of prevention and control of cancer in Brazil, the Brazilian Cancer Institute (INCA in Portuguese) presents urbanization, industrialization and longer life expectancy as social determinants of cancer.

Among the various types of cancer that afflict the general population, this study addresses the Hodgkin’s Lymphoma (HL), which reaches the lymphatic system. The latest study conducted by the World Health Organization identified and numbered more than 30 different types of lymphomas.

HL comprises a variety of diseases with incidence patterns that vary among populations. The number of new cases grows each year and, according to estimates of incidence carried out by the Brazilian Cancer Institute, 1,300 new cases are expected in men and 800 in women by the year 2015 [1].

According to Coutinho and Trindade [2], taking into account the life moment of the patient who has the diagnosis of cancer is important, since the meaning of this disease is very particular and personal, and depends on a variety of factors, such as past experiences, cultural prejudices and information obtained by the media.

Cicogna, Nascimento and Lima [3] share this view by saying that physical and mental exhaustion, fear and uneasiness caused by the process in patients and their families reinforce the uncertainties of life in the face of cancer, making it more painful.

The patients have their habitual cycle of life interrupted, because the treatment imposes on them withdrawing from their environment, their productive activities, their relatives and their daily life [3]. Currently, the diagnosis and treatment of Hodgkin’s lymphoma introduce a new routine of hospital visits, since some treatments are outpatient and require continuous returns to the hospital [4].

During treatment, patients undergo different stages, adaptations, mechanisms of defense and struggle to face the difficult situations to which they are submitted. They need psychological, emotional, spiritual, physical, and social balance to achieve it, so they must reorganize their way of seeing and living life [5] and they also require a humanized care. Fundamental in this confrontation is the support from the family, whose role is to stay together with the person, trying to alleviate their suffering [4].

In providing care for oncological patients and their families, the nursing care plan should take into account that these users will undergo a long and complex treatment, that they will receive a lot of information about the disease and that they will need to adapt to new people, namely the health team, who will tell them what to do, what to eat and how to act [3].

Therefore, in this fight against cancer, the impact of the unknown affects not only the patient but the whole family, since they become naturally weakened and cannot live normally [6].

Since cancer is a disease perceived as traumatizing, its approach becomes particularly difficult. From the discovery of cancer by the patient, a long and new process full of peculiarities will begin to occur, so it is important to look carefully at this moment to carry out an analysis about this type of experience. However, understanding it from the point of view of the person who experiences it is necessary.

In this sense, this study sought to know the experience of people with Hodgkin’s lymphoma by seeking the patients themselves as source of information, from their testimonies, showing the patient’s point of view is important and should be considered, since they are the main connoisseurs of their own needs. Also, the present study sought to understand the physical and emotional weaknesses experienced by them as well as the stigma of cancer, hope, suffering, hospital routine, coexistence with the team of professionals in order to present a little of the huge group of people fighting cancer by demonstrating the importance of a humanized care based on qualified listening.
The objective of this study was to understand the experience of the young adult carrier of Hodgkin's lymphoma in the face of treatment.

Methods
This is a qualitative descriptive research. The study subjects were patients diagnosed with Hodgkin's lymphoma whose identities were preserved, being denominated by fictitious names.

The selection was carried out in a reference hospital in the northeast of Brazil. The health team was asked to indicate patients that fit the inclusion and exclusion criteria of the study. Five patients were selected, but two did not agree to participate in the study.

Inclusion criteria were being undergoing treatment or follow-up of Hodgkin's lymphoma and aged 18 to 35 years of age, since the HL age range has a bimodal distribution, with its first peak in young adults between 15 and 35 years and the second peak over 60 years [7]. The age group of young adults was selected because the aim was to understand the interference of cancer in a stage of the life of many plans and dreams.

Exclusion criteria included patients with persistent distraction, undergoing medical diagnosis investigation or those who were not undergoing treatment or follow-up of Hodgkin’s lymphoma.

Data collection took place in two stages. First, patients selected according to inclusion criteria were approached in the hospital setting before chemotherapy or medical appointment. Second, an interview was performed at each subject’s home, which allowed an individualized, uninterrupted and private interview.

The interviews took place in the period from August to September 2015. They conducted individually, privately, without interruptions and in a predetermined way. A recorder was used in order to capture the subjective aspects of patients’ way of experiencing the current situation.

The questions that guided the research were: how was the discovery of the disease? What were the changes after the diagnosis? How was/has been the treatment? What are your expectations and plans for the future?

Thus, interviewees provided information directly constructed in the dialogue with the interviewer and that deal with their own reflection on the reality they have been experiencing [8].

The interviews were recorded and transcribed in full. The Gomes’s thematic analysis [9] was used for the formulation of the categories.

The present study was submitted to the Research Ethics Committee, with favorable opinion number 216,276. In order to ensure the ethical aspects, this research complied with Resolution No. 466 of 2012 of the National Health Council, which provides for Norms and Regulatory Directions involving human beings. All subjects, after being informed about the objectives, accepted to participate in the study and signed an Informed Consent Form authorizing their inclusion in the study. The subjects were identified by fictitious names so that their names were preserved.

Results
Characterization of the study participants
Study participants went through a very individual pathway to discover cancer. The time of treatment varied according to the stage of the disease and the clinical condition of each. The description of the study participants, denominated by fictitious names, is listed below:

Single, 23, lives in Limoeiro do Norte - CE, business administration student. Before diagnosis, he used to work in a construction company. He was diagnosed with HL 11 months ago and is undergoing chemotherapy.

Fernando.
Single, 19 years old, lives in Limoeiro do Norte - CE, Nursing student. She was diagnosed with HL 1 year and 9 months ago and is now in the stage of maintenance of chemotherapy treatment.

Lia.

25 years old, single, lives in Russas-CE, Human Resources student. He used to work in a motorcycle shop. He was diagnosed with HL 1 year and 10 months ago and is now in the stage of maintenance of the chemotherapy treatment.

Roberto.

After reading the interviews, the following category emerged: Impact and changes in life with cancer.

Impact and changes in life with cancer
The patients expressed their condition of being with cancer and how much this disease had impact in their life. They have undergone treatment, which brings them physical discomforts due to its side effects, such as hair loss, bone marrow suppression and bodily pain.

I was submitted to biopsy and when the result arrived, I was referred to the hospital and then I was sure it was cancer. I was very sad, it was the worst news I received in my life.

Fernando.

My oncologist explained everything, especially how the treatment would be. I was lucky, because my doctors, the nurses, the physiotherapist, they all helped me a lot. They were true angels used for my healing!

Lia.

In addition to the empathic involvement, the patients' speeches shows there is compassion by those who care in relation to the person being cared for and, in this context, the professional can ease the discomfort felt by the patient.

When I heard it, I asked to my doctor, “Is there a cure?” And he said yes, so I said: I’m in!

Roberto.

Cure was mentioned as an expectation on the part of the interviewees, including to return to the interrupted activities and to execute what they had planned for their lives. As observed, being in treatment produced a rupture in the subjects' daily life, and they reported the occurrence of changes in their lives during this period. For the patient, the treatment is shown as a landmark that separates events before and after the illness.

I did six cycles of chemotherapy; I went to Fortaleza and did there. It took almost four hours to finish. I only felt some nausea. I used to go a day before; I used to do a blood test and the next day, if there was nothing wrong with the test, like the immunity, I would take the chemotherapy!

Fernando.

According to the interviewees' reports, the family is perceived as the fundamental support to go through a debilitating illness, which places family members as a source of support and encouragement for the sick person. Also, friends show support by treating the cancer patient in the same way as before and, in addition, give support in this walk.

I did not feel sad. Sometimes I weakened, but my family gave me support and I got better!

Fernando.
Under the patient’s point of view, the hospital has a dual characteristic. At the same time it brings suffering, it also represents a space for healing. In addition, it can become a place to share experiences with other people who are going through the same situation, often creating a bond of friendship. Personal growth happens to be unique in this phase, since the young adult starts to value more their life, giving importance to the small things.

*I did not see chemotherapy as something bad; in there, I would see my friends that I met because of lymphoma and that I will take for the rest of my life!*

*I have many plans for the future, especially now that I have learned to value my life even more!*  
**Roberto.**

*Today I feel like I am different; lymphoma has changed almost everything in my life. I am managing to bounce back. After that, I know I can beat anything!*  
**Fernando.**

Among patients who were in post-treatment stage, as the treatment reached its final stage, especially after the end of chemotherapy, they reported that this was the happiest day of their lives, especially after receiving the result of total healing.

*The best day was on the last day of chemotherapy. It was the only day I went there in a happy mood!*  
**Fernando.**

*The best news I ever received in my life was when I knew it was all over; I did not even want to believe it! It was the happiest day of my life!*  
**Lia.**

**Discussions**

The diagnosis of cancer is generally received by the patient as bad news, as it is still regarded as an incurable disease. The term cancer is associated with death, and when mentioned, triggers anxiety, given the imminence of aggressive treatments that bring intense pain, as well as a variety of disorders, including physical, emotional and drastic changes in lifestyle, habits, work and family life [10].

In reflecting on the significance of the discovery of the disease, the patient also thinks about the impact of the disease on their life and how much it causes changes in their way of being. Now they fear for their lives, restricting their daily lives, no longer practicing routine activities [11].

Chronic diseases lead to learning to live with the disease, even those that do not threaten life, but impose patients to learn and live with them. López and Trad [12] perceived, through the reports of patients with hematologic cancer, that the former existence is characterized by active lives in the areas of work, study, more or less complex family and social relations, as well as certain modes of “being”, “acting” or “living” that were somehow reassessed and changed. The “after” is reported by the perception of being somehow different people when compared with the others, with routines, abilities, strengths, uncertainties and limitations.

Salci and Marcon [13] reported that patients and their families, when faced with the diagnosis of cancer, go through experiences that have never been experienced, in which changes in various aspects of life occur, including those related to care.

During this process, patients face the desire to confront the disease and the whole treatment with its consequences, even if unknown, for the purpose of healing. Kleinman [14] reports that patients endure and have to endure pain, loss, the human experience in order to continue to live. The treatment imposes on the patients the withdrawal of their environment, their productive activities,
their relatives and their daily lives. Hospitalization places patients in direct contact with the role of being sick, and they are forced to give up their various other roles and start to live for and according to the disease [4].

Lombardo, Popim and Suman [11] state that, in the course of the treatment, the patient forms a bond with the professionals and this process favors trust and credibility in the team and, in addition, an affective relationship is created.

All health professionals must adapt their clinical intervention, considering the patient as a subject, taking into account the experience of the disease, the patient’s perceptions, thus acquiring a sensitivity and a listening capacity that go beyond the biological dimension [15].

For Gadamer [16], the doctor-patient relationship goes beyond treatment with modern techniques only, and requires sensitive ears and an observant and careful look. Measures employed in the health areas, in which the disease is not seen with the eyes, nor is it heard through the voice, but rather, it is read with standard values and support, are crucial.

Mol [17] stimulates to allow room for sadness, but not much. A physician should offer comfort, but also encouragement. While suffering must be recognized as bad, the disease must simultaneously be accepted as something that needs to be treated in one way or another because life goes on. The logic of care wants professionals not to treat the facts as neutral information, but to meet patients’ values.

In order to take care of young people who are ill, practitioners must build a bond, use empathy, and also put themselves in the patients’ shoes. Merquior [18] affirms that, in the oncology area, professionals must have this conception because emergency situations in high level of stress, anguish and conflicts evidence the necessity of a real intervention with patients, since the explosion of the outgoing emotions must find a welcoming attitude.

In view of the new situations, the young adult will interpret the world, sediment knowledge, motivate themselves, direct their actions and project themselves into the future [19]. Thus, they become hurried as if they do not want to waste more time in their lives. Their reinsertion into their activities becomes fundamental for the continuation of their cognitive development, of their human relations. They start to talk enthusiastically about activities that have returned to developing with others and look for what they left behind in view of the treatment.

The interviewees’ reports showed post-treatment is marked by the hope of a “return to normality”, which guarantees the realization of what has been postponed and allows the creation of new plans. It seems that it is the moment when the interviewees allow themselves to think about the future because they have presented a positive response to treatment until then. Throughout the treatment journey, patients undergo several situations that lead them to mature and overcome the adverse situation.

The reports of patients who were in post-treatment stage showed, as the treatment reached its final stage, especially after the end of chemotherapy, they reported that this was the happiest day of their lives, especially after receiving the result of total healing.

Thus, time leads the patient to absorb the difficult situation through which they are going through and to demystify it according to the journey. They look to the future with optimism, believe the disease has been overcome and that they will be able to resume their daily life as it was before.

Conclusions
Study subjects diagnosed with Hodgkin’s lymphoma experienced the impact of cancer and the process of illness and treatment that promote physical and social changes.
They revealed the coping of the disease with liveliness, and presented strategies for this process, such as the support of family and friends. They recognized the existence of difficult moments and faced situations of death, but they demonstrated intention in returning the daily activities and had perspectives for cure.

Also, the relationship developed between the patient and the team goes beyond the scientific purpose. The patients mentioned the name of the professional who takes care of them and, in this interpersonal relationship that is installed during the care process, the practitioner must identify patients’ feelings about the treatment and know the reality of these individuals. Thus, when the team knows this demand, the patient’s needs, and that the disease is finally seen as something to be overcome, professionals can certainly provide more qualified and targeted care.

The limitation of the present study was the difficulty in finding more patients who met the study criteria and who accepted to participate in it to talk about this disease and to remember what they have been going through.

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