

# The trajectory of cancer as told by nurses: moments of revelation, adaptation and the healing experience

*A trajetória do câncer contada pela enfermeira: momentos de revelação, adaptação e vivência da cura*

*La trayectoria del cáncer contada por la enfermera: momentos de revelación, adaptación y vivencia de la cura*

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## ABSTRACT

**Objective:** To describe the trajectory from diagnosis to end of chemotherapy for colorectal cancer. **Methods:** Qualitative research developed in an oncology clinic in Curitiba/Paraná. Data collection occurred through narrative interview technique through life stories, from January to May/2011, with ten participants, adults of 35-60 years. **Results:** There were three categories: development, adaptation and experience of healing. In these, there was the abandonment of poor habits and concern for the family before receiving the diagnosis. However, inserting the disease in their daily routine adjustments were necessary to address the problems facing the treatment. At the end, many subjects felt good to return to their professional activities, and this correlated with the sense of autonomy that it was common before the disease. **Conclusion:** It was noted that reports of life possible to know the care, the experience and the feelings of the participants in an attempt to face positively the course of cancer.

**Keywords:** Oncologic nursing; Colorectal neoplasms; Drug therapy; Adult health.

## RESUMO

O objetivo deste estudo foi descrever a trajetória de pessoas com câncer colorretal do diagnóstico ao fim da quimioterapia. **Métodos:** Pesquisa qualitativa desenvolvida em uma clínica de oncologia de Curitiba/Paraná. A coleta dos dados ocorreu mediante entrevista narrativa por meio da técnica relatos de vida, de janeiro a maio/2011, com dez participantes adultos de 35 a 60 anos. **Resultados:** Evidenciaram-se três categorias: revelação, adaptação e vivência da cura. Nestas observou-se o abandono de hábitos inadequados e preocupação com a família diante do diagnóstico recebido. Contudo, ao inserir a doença na sua rotina diária foram necessárias adaptações para enfrentar as dificuldades diante do tratamento, mas, após o término deste, muitos sujeitos sentiram-se bem para retornar a sua função profissional, sendo esta correlacionada à sensação de autonomia que lhes era comum antes da doença. **Conclusão:** Verificou-se que os relatos de vida possibilitaram conhecer os cuidados, a vivência e os sentimentos dos participantes na tentativa de encarar positivamente a trajetória do câncer.

**Palavras-chave:** Enfermagem oncológica; Neoplasias colorretais; Quimioterapia; Saúde do adulto.

## RESUMEN

**Objetivo:** Describir la trayectoria desde el diagnóstico del cáncer colorrectal hasta el final de la quimioterapia. **Métodos:** Estudio cualitativo desarrollado en una clínica oncológica en Curitiba/Paraná. Los datos fueron recolectados a través de la técnica narrativa de entrevista de historias de vida, de enero a mayo/2011, con diez adultos de 35-60 años. **Resultados:** Emergieron tres categorías: la revelación, la adaptación y la experiencia de la curación. Se observó la eliminación de hábitos inadecuados y preocupación con la familia antes del diagnóstico. Sin embargo, al insertar la enfermedad en su rutina diaria, se hicieron necesarias adaptaciones para enfrentar las dificultades al tratamiento, pero después de lo término de este, muchos sujetos se sintieron bien para retornar su función profesional, siendo esta correlacionada a la sensación de autonomía que le era común antes de la enfermedad. **Conclusión:** Se verificó que los relatos de vida permitieron conocer los cuidados, la vivencia y los sentimientos de los participantes en la tentativa de encarar positivamente la trayectoria del cáncer.

**Palabras-clave:** Enfermería oncológica; Neoplasias colorrectales; Quimioterapia; Salud del adulto.

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## INTRODUCTION

Individuals from all over the world in general are affected by chronic disease; they can cause changes in their lives and in their families in various ways, in different times of illness diagnosis to treatment and rehabilitation.

Among the chronic diseases, cancer configures itself as a public health problem. It can be defined as a set of more than 100 diseases, including malignant tumors in different locations. It has been considered, since 2003, an important cause of death in Brazil, the estimate for the year of 2012 also valid for the year 2013, shows the occurrence of approximately 385,000 new cases, excluding the cases of non-melanoma skin, enhancing the magnitude of the problem in the country<sup>1</sup>.

In this work, the primary focus will be the colorectal cancer, malignant tumor that affects the colon and the rectum, considered the most frequent of the digestive tube. Epidemiologically, this type of cancer is configured as the third most common throughout the world in both genders. In Brazil, for the year 2012, the number of new cases was estimated at 14,180 cases in men and 15,960 in women. Especially the south and southeast regions that exhibit this type of cancer as the second most common in women and third in men without considering the non-melanoma skin cancer<sup>1</sup>.

In the state of Paraná, in 2012, the coefficient of prevalence of colorectal cancer was estimated at 17.2/100,000 women and 16,37/100,000 for men<sup>1</sup>. In developed countries the average survival rate overall in five years is around 55% and in the developing countries by 40%<sup>2</sup>.

Among the treatments used, the chemotherapeutic drug, due to its complexity and the yearning that causes in patients and their family members is a matter constantly addressed in research. The side effects, the change in the routine of life, self-esteem, self-image, are fears associated with this drug therapy. For these and other reasons, oncologic patients deserve a specialized attention, focused in their biopsychosocial needs, and are therefore a source of information about their perceptions and feelings about the illness and their care.

As well as the stigma of mutilation, the changes perceived in interrupt the life of patients with cancer and each one interprets these changes according to their knowledge and experience of life<sup>3</sup>. The social meaning of the disease usually reflects the association of cancer to a fatal disease, unseemly and commonly regarded as a synonym of death, marginalizing and cultivating negative feelings in relation to the disease<sup>4</sup>. Nevertheless, having cancer brings, beyond certain very stressful, a concrete approach of death<sup>5</sup>.

The patient experiences an avalanche of changes physical, physiological, emotional, social, cultural, psychological, and spiritual, in addition this impact generates feelings such as fear, anxiety, despair, doubt and anger<sup>6</sup>. The experience of a cancer is considered one of the most critical moments in the life of people,

by referring to the analysis and reflection of their own biography, whose meanings were built along their life's experiences<sup>3</sup>. Therefore, the diagnosis of cancer and all its consequences disrupt the balance of the individual and their family.

Such changes are triggered by the disease itself and its treatments, such as surgical incisions, drains, ostomy, and effects of radiotherapy as well as of antineoplastic chemotherapy. Change in body image, the functioning of the human body, the changes in supply and new adaptations required by cancer of large intestine make this population an important source of information about the way they perform their care.

With respect to this, colorectal cancer treatment varies according to the size, location and extent of tumor, and the patient's condition. Being surgical, chemotherapy or radiotherapy, and still, the combination of more than one form of treatment.

Through all the changes that the cancer and the treatment entail in the patient and his family, epidemiological data, and the projections of their behavior in the population, with special emphasis on the colorectal cancer, justifies the continuation of studies with emphasis for listening to the needs and uncertainties experienced by them in search for restoring their health. As well as provides resources for increasing the quality of care, the nurse helps to find better ways to approach this individual interventions that will improve their relationship with themselves, and assists them in reinsertation in society<sup>7</sup>.

Based on these perceives an aspect little contemplated in the process of care for people with colorectal cancer, the nurse needs to go beyond guiding their patients due to the discovery of a disease, should also monitor how individuals are incorporating new information received and adapting them in their life.

Due to the severity of chemotherapy, the subject matter dealt with here with different health professionals, especially the nurse who will monitor and guide throughout the course of treatment and rehabilitation. Thus, it has been established that the following objective: to describe the trajectory of people with colorectal cancer diagnosis at the end of the chemotherapy.

## METHODOLOGY

Research with a qualitative approach that was used as a method of data collection and analysis the report of life, which is the approximate description of history, really lived, both objectively and subjectively<sup>8</sup>. This technique uses narrative interviews as a way of obtaining the reports.

The data were collected in January after the approval of the ethics committee to May/2011 when there was a convergence of speeches, in a private oncology clinic specialized in cancer treatment, located in the city of Curitiba, Paraná. This study included 10 adults of both genders who have applied voluntarily after being informed about the research and conform to the inclusion criteria: diagnosis of colorectal cancer, with localized

disease without dissemination to other regions or anatomical structures have completed treatment with cancer chemotherapy in that institution, in a period exceeding three months, 18 years of age and under 60 years, being able to communicate verbally and feel in good clinical condition

The participants were six men, four women, with ages ranging from 35 to 60 years, seven with complete college, being one of them with post-graduation *stricto sensu* (PhD) and the rest with complete high school. Seven of them were married, two singles and a divorced with an average of two children per participant.

The interviews were scheduled according to availability, preferably on the same day that he had a medical consultation or with another professional, favoring the appearance of participant, without interfering in their routines and commitments. The reports were recorded and transcribed, and returned to the participants that they could change, include or restrict the use of any information.

Approved the transcript, the material was organized in narrative form, with the ordering of events according to the temporal sequence of events, and inserted the completion of the information field notebook during the transcriptions in parentheses.

The next step was to perform consecutive readings, in order to identify recurring topics, which were deployed to lead to the creation of core topics of the information<sup>8</sup>. Found on three core topics were, namely: development, adaptation and healing experience.

The project was approved by the ethics Committee under the registration number 1019.144.10.09, and the ethical principles of Resolution 196/96 were respected. For the presentation of data, the participants were not identified, these are coded as a participant (P1), two (P2) and so on.

## RESULTS

The analysis of the interviews revealed that the life stories of participants with cancer of large intestine expose a trajectory of revelation-adaptation-experience of healing.

### Revelation

Life before the cancer for the interviewees was characterized with negligence about their body, physical and mental health. The lack of care or the approximation of factors harmful to the body were aspects addressed by the participants.

*Before I discovered the colon cancer, I led an unregulated life [...]. I drank before discovering the cancer [...]. Before I smoked a pack per day, now I'm smoking on average eight cigarettes per day, sometimes ten [...]. I had no time to eat, it was dawn, it was in the morning [...]. In addition, I ate everything, whatever might come, everything that I liked, what I didn't like I didn't eat (P2).*

On the other hand, there were those who expressed longer adopting care practices for promotion and restoration of health, influenced by previous diseases, as noted in the report below.

*I always had very good health. I do not drink or smoke, I have nightlife habits where I would stay out til late. [...] I had bypass surgery six years ago [...]. Therefore, you already have that habit of taking care, even more than it already did (P3).*

Cancer diagnosis is not always fat and simple, because often, individuals find some justification for postponing the demand from the doctor, hoping that it changes not being perceived as a disease or by believing that one sign or symptom disappears spontaneously without the need for professional evaluation. This behavior was found in the report from participant P7:

*The stronger symptoms and the diagnosis took three to four months. Because I kept postponing going to the doctor, I kept taking analgesics for the cramps, to be able to work. This time lasted about three to four months. I went to the doctor, he requested the colonoscopy on the same day of the colonoscopy I went for emergency surgery. My belly vein was a ball [pointing to their belly, simulating the size and laughs] (P7).*

The stigma that surrounds the cancer and the pre-conceptions created by experiences observed during life result in fear, fear of sickness and death. As evidenced by the following report:

*I thought about what life is worth, and now this disease, how is going to be cancer my God. [...] I had fear, it is fear of death, how is going to be now and pulling me, but why? If I always had a healthy life, and took care of me, such a thing happens. But then it passed, today I am one hundred per cent (P3).*

By involving the family and other people close to them in this new stage of their life, the subject can trigger feelings of concern for their loved ones, as perceived in the words of P6:

*I have a greater concern for having lived this experience, if I had known this before, in my youth, my 30's, someone had been, I would have asked the doctor to do [...]. I already said to my daughter, when you get to 40 you have to do it. Everyone was concerned, even friends. I don't think that it just needs to be with the family [...]. (P6).*

The disease revelation process was associated by participants with the care that they had with them even in the past, with the perception of the disease in their body, with the search

undertaken by diagnosis and with the feelings related to the discovery. Thus, they experienced the challenge of constant adaptation to new existential situation, the treatment and its repercussions.

### **Adaptation**

In most cases, the treatment is time consuming, exhausting and painful, leads to changes in life style. In addition to a first time, trigger feelings of sadness and powerlessness, in relation to the disease and treatment. As noticed in the following reports:

*What happened (during the chemotherapy) was that I was a little depressive, I was pretty depressed, but I went and saw it was getting better, I was improving as well [Emotion! Eyes filled with tears, hoarse voice]. [...] I saw that things were progressing well, I got better, I got well (P3).*

The fear of the unknown is inevitable and the confrontation of the first contact is something that strengthens the being, demonstrating that this obstacle can be overcome in a less torturous way. The initial impact caused by the need to undergo a treatment taken as aggressive will gradually be replaced by the expectation of reaching a cure, as reported by P3.

*Chemotherapy I always saw as a therapy. [...] I thought that it was a benefit and that it was necessary (P1).*

*[...] The person becomes depressed, just knowing the person is already depressed. I have always taken care to not become depressed. Always tried think positive... And sure that I was going to leave cured and that is what happened [...] (P2).*

The participants of this research were to meet means able alleviate their pain and discomfort. There have been reports of the use of tea of soursop, royal jelly and Canova method associated to traditional medical therapy.

*A time until my sister in law said she takes what is everyone talking about. It was in a capsule and I took it, later I stopped. [...] In addition, I was not taking anything, I think that it is more the psychological part, of the sort "look I'm armed" [...] (P4).*

It is clear, by declaration of P4, that the association of alternative therapies with conventional treatment, influenced by affective bonds, you can even provide an improvement of physical symptoms, mainly, fills a gap caused by emotional instability, because, in the sick, the oncologic emotional variations are more intense, since the set of new factors added to their routine life.

*I felt very angry and impatient, so much so that I ruined friendships from intolerance. I was very intolerant. This I realized after chemotherapy, today I am still a little. I can't stand the people; I can't stand things (P8).*

The treatment has resulted in new directions and behaviors in the lives of patients. Hardly their routine will be as before, then they begin a new stage of care, called follow-up or monitoring that was called to experience of the healing.

### **Experience of the Healing**

During this period, it is clear that one of the concerns of greater impact is the fear of recurrence of the disease, as stated by P9.

*I am truck driver, continuous working, even during the chemotherapy I worked... it is not good to have activity dysfunctional, this influences too, the stress on the nervous system. It is for this reason that I'm afraid, so I'll stop. Not worth staying if stressed, I have to take care of myself more so, now. Because if you go back, many people say that if you go back now it will really kill you (P9).*

It is clear that fear remains constant in their lives, as reported below P8, which each hold examinations accompanying manifest physically and emotionally reactions of anxiety and dread forward to the results and uncertain future, that life holds.

*[...] you become very sensitive after a chemotherapy, it is feeling poorly, is with more panic attacks, you need not necessarily to seek a psychiatrist, but you are like that. [...] every six months I have to do a colonoscopy. [...] Then when it comes close, I look at the calendar, it makes me nervous, I lose my appetite. [...]. It is a thing so complicated, but you have to have structure, breathe deeply and do it (P8).*

Not only will the remembrance marks the cancer experience, but physically, for some time evidence that the turbulence was present one day:

*I still have the catheter; I perform maintenance every 30 days, [...]. It does not bother me at all. I know that I have to take care, not hitting it on anything, I'm even not playing ball, and I am not doing anything, so it doesn't bother me (P1).*

The physical restriction is still evidenced by P1 who admits to not having the same provision of before and assume, with responsibility, the care that they need to have in this phase of living without the disease.

With some exceptions, many subjects if they feel well to return to their professional function after completion of treatment and this may be one of the ways to get back to their routine and feel again the autonomy that was common before the illness. As reported by P3.

*I Stopped running approximately a year ago. I was relieved. I returned to work, I have the time to retire, but would not like to [...] my work it is on the street, I'm here, I'm there. [...] I'm not stuck in four walls there, times, timeclock. That could give me stress at work. That's why I am still holding on (P3).*

It should be noted that the end of treatment is a victory for the subject and for those who have traveled this arduous path beside them. The pleasure to celebrate the end of this phase shows the optimism by have faced and overcome a cancer. Leveraging the current moment, knowing that he will outline our future conditions, such as the statement below:

*The only thing that I did, when I finished the routine, that I finished the chemotherapy was exits take a good dose of wine along with my wife, a dinner, to be able to celebrate that had finished chemotherapy, but life continued the same, life goes on normally. Look, I faced cancer and chemotherapy and all that can come ahead is like a natural situation in life (P1).*

## DISCUSSION

In P2 we perceive little importance attributed to their health, there is the recognition of adverse factors, but the feeling of pleasure and freedom unleashed by these habits are overshadowing the acuteness with life.

It is verified in study<sup>9</sup> a conduct similar, in which the participants showed recognize as well as here, the risk factors for all kinds of health problems, however, not enough for the change of attitude, but it is essential, in addition to being the path to a healthier society.

For anyone who has already undergone a treatment for a serious illness and knows the routines that involve this path, you can probably accept and deal more comfortable and quiet a new treatment<sup>10</sup>. This was observed in the testimonies of P3 previously submitted to bypass surgery, a situation that also has the stigma of death. Despite being two distinct diseases, both are rooted with appeal of suffering, but the prior experience of a serious illness can lead to a modification in the treatment.

Each individual may present divergent reactions to envisage the antineoplastic treatment. Negativity is a common feeling in this situation and should be resolved for the success of the treatment is achieved with fewer difficulties. On the other hand, when optimism prevails it can be considered a strong ally, mainly of the patient, but also of the healthcare team that accompanies and their family.

It is known that each individual faces the changes caused by the disease and the therapy in a unique way and that each one builds their own strategies to overcome these processes. With the passing of time, it is observed that the feelings are negative for positive change, both with respect to treatment as the disease itself<sup>11</sup>.

Currently the complementary therapies are part of the routine of many individuals, with injuries or not. Perhaps one of the justifications by constant search of these therapies is the limitation that the traditional medicine is to deal with some injuries and/or troubleshoot symptoms arising from them; it is known that the influence of family and friends leads to search for alternative methods.

A similar fact was identified in a research developed in Rio Grande do Sul, which describes this search as "itinerary of care" where the first option of comfort and solution for the pain if the at home with the family coming with the use of teas or homemade remedies. If the pain is not relieved occurs the demand for resources institutionalized health, as an alternative to a doctor<sup>12</sup>.

In relation to social conviviality, which has suffered alteration due to the emotional state of P8, Silva<sup>13</sup> mentions that the circumstance of living with cancer raises revolt against himself, against the other, against the world and envy those who maintain health. In addition, the changes in social life are the result of side effects and of fantasies that the patient has in relation to what the friends and the society may think or say in your respect<sup>11</sup>.

The experience of healing was a moment of reflection about the illness and the cure, thus for P9 stress in addition to contributing to the development of cancer, could also contribute to the recurrence of the tumor. The concept of cancer as ghost is identified by patients and by family members, since any change in the body is associated with cancer and the reason for remembering the experiences<sup>14</sup>. They also emphasize that anxiety is present in the first post-treatment years, and that with the passing of time, this feeling will gradually decreasing, until it becomes a routine submit annually to the exams<sup>14</sup>.

For P9 stress was one of the trigger reasons of cancer. It is perceived that for P9 there is a strong association between work stress and colorectal cancer, and that for this reason there is the intention to stop working. Note that the fear of recurrence is present in his life, reinforced by the thought that a person can never say that is healed. In the same way, was identified in a study<sup>15</sup> that patients seek out information about their disease, regardless of social class, and they know that in the context of oncology the cure of cancer may not be asserted by anyone. Thus, Perpetuating the stigma of fatal disease, upon the possibility of recurrence.

Past the nightmare, the fundamental importance in the life of these subjects is to feel and to live as he lived before. It is clear, a great commitment to maintain and keep your home, your work,

your activities, your routine, as it was before the illness. The meaning of normal life is directly related to make it as similar as possible to the previous<sup>16</sup>. It is clear in the reporting of P1 and P3 the willingness and the yearning for the return to routine, the reintroduction of normal life.

There is a perception of the change in values of the subjects after the completion of chemotherapy, because winning the return to routine activities, feel happy and hopeful, to power balance again his financial life through work and by recovering their role in the family<sup>15</sup>. As reported by P1, to go out and celebrate the end of antineoplastic chemotherapy demonstrated with his wife return to their social life, and reaffirm their family role and their personal relationship.

It is emphasized that the apparent limitation of this research is in differentiated educational condition of the participants, because they have a distinct understanding of the events of their lives. Thus, nursing professionals we need to understand and study other realities, not only the public but also private for us to provide quality care for all within its peculiarities. It adds that a cultural change of perception about cancer will help to reduce the impact on the lives of the individual and their family. Where the cancer will no longer be associated only with the feeling of suffering and death, passing for a disease that can be treated, controlled and cured in many cases<sup>17</sup>.

## FINAL CONSIDERATIONS

The primary focus of this study was to describe the trajectory of the subjects of the diagnosis of colorectal cancer at the end of the chemotherapy, and it was found that since the revelation until the "cure" the course was guided by an attempt to maintain the normality and look positively the effects of treatment.

Although there persists a stigma of death related to cancer in this study this was not the focus of the participants, thus, it can be noted that not only the physical and emotional changes, and the impact caused by antineoplastic chemotherapy were highlights of this study, but also the positive response, such as the well-being. This Fact demonstrates the acceptance by the community of new advances in the treatment of patients with oncological problems.

It is believed that studies concerning the perception of the quality of life of different types of cancer may subsidize the ways of taking care of these patients by enhancing aspects that they consider important in their care forward to technological advance of cancer treatment, and the prospect of increasing survival with quality.

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