

THE THERAPEUTIC ITINERARY OF PATIENT IN ONCOLOGICAL TREATMENT: IMPLICATIONS FOR NURSING PRACTICE¹

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ABSTRACT:

The course of oncology patients is still crossed by setbacks that interfere with their prognosis and quality of life. This study aims to map the itinerary of cancer patients from diagnosis to treatment and to analyze its implications in nursing healthcare practices for the control of cancer. This is a qualitative study, conducted using oral history technique with ten cancer patients treated in a federal hospital in the city of Rio de Janeiro, Brazil. The data were analyzed according to thematic analysis technique and with the making of representations of the therapeutic itinerary of each interviewee. Three main themes were identified: course before diagnosis, course from diagnosis to the beginning of treatment, and course during treatment. We observed that the access to medical services is presented as a problem that culminates in the worsening of the disease, appearing of metastases and death of the patient, in addition to creating conditions that hinder the adherence to treatment.

Keywords: Nursing. Oncology. Health care service access.

INTRODUCTION

The impact of cancer worldwide makes it a public health problem to be faced mainly by developed countries. Thus, a relevant increase in the estimates for new cancer cases can be observed. In Brazil, 600,000 new cases for the biennium 2016-2017, and, globally, by 2025, an estimated 25 million new cases of cancer are expected⁽¹⁾.

In Brazil, this situation represents a challenge for the health system in what concerns to the ways to ensure full and balanced access of the population to the diagnosis and treatment of cancer, due to the gradual increase in its incidence and mortality rates, in proportion to population growth, aging population and socioeconomic development of the country⁽²⁾.

The use and access to health services has been a problem for Brazilian society, since it is connected to the characteristics of service supply and the behavior of people when facing its

morbidity character. It is known that in this scenario, many factors are involved in the course of oncological care services, from the frequency of demand for public hospitals and the waiting time to be attended in institutions, to the availability of complex procedures with high costs to the population with a chronic disease⁽³⁾.

It is also known that there is a consensus regarding the relevance of an early diagnosis, coupled with appropriate management of cancer treatment for its effective control, since any delay in the commencement of treatment means less chance of cure and higher costs for the patient, family and health system⁽⁴⁾.

However, the poor preparation of health professionals to detect cancer in early stages due to lack of qualification in oncology area, in addition to the barriers in the health system itself, contribute to patients to be referred to an appropriate health facility only after a long period that is not compatible with the development and severity of their disease⁽⁵⁾.

Based on these considerations, this study

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aims to map the itinerary of cancer patients from diagnosis to treatment and to analyze the implications of this course in nursing actions for the control of cancer.

METHODOLOGY

This is a qualitative exploratory study, developed in the city of Rio de Janeiro, Brazil, at a federal hospital chemotherapy department, classified as a Cancer High Complexity Care Center (Centro de Assistência de Alta Complexidade em Oncologia - CACON).

Data was collected through interviews, from November 2014 to February 2015, using the oral history technique, which can be understood as a method of research (historical, anthropological, sociological...) that uses interviews with people who witnessed or participated in events, situations, points of view, as a way to approach the object of study⁽⁶⁾. Thus, the interviews were guided by the theme of the therapeutic itinerary of cancer patients from diagnosis to start of treatment.

The study participants met the following inclusion criteria: patients older than 18 years of age, diagnosed with cancer and aware of this, and hospitalized or undergoing outpatient treatment.

A first contact with participants was necessary to inform them about the study and its goals. At this point, an informal dialogue with the potential participants was established and their conditions to be approached were observed. Should the participant present any discomfort by remembering these moments, the conversation was closed and the interview was not carried out, a fact that occurred with three participants. Once the opportunity to participate in the survey was identified, the Informed Consent Term was signed, and the interview continued.

All interviews were recorded in an MP3 player device, resulting in 10 appearances. It is relevant to note that after four months of data collection, a recurrence of specific situations in patients' courses was detected and thus the researchers decided to interrupt the interviews.

After the transcripts, the return of the material produced to the participant was used as a reliability criterion, in addition to the signing of the letter of transfer of interview content rights to the Federal University of the State of Rio de Janeiro.

The data produced were analyzed according to the thematic analysis technique⁽⁷⁾. At the time, we observed that the statements had a chronological order of events, which resulted in structuring themes for better understanding and presentation of data.

With regard to ethical criteria, the study followed the rules in Resolution 466/2012 of the National Health Council, and was approved by CEP-UNIRIO under Opinion No. 894 108. Participants were identified by the letter E, and numbers in sequence that followed the order of interviews: E1, E2, E3...

RESULTS AND DISCUSSION

Of the total respondents, seven were female, aged between 29-77 years. Regarding patients' income, nine had a monthly income from 1 to 3 minimum wages; and only one, between 3 and 5 wages. In terms of occupation, all were retired due to illness. In what concerns to their level of education, seven had completed high school; two completed higher education; and one completed elementary school.

Of the cancer diagnoses, the following were found: breast, ovarian, colon/rectum cancer and Hodgkin's lymphoma. The predominant diagnosis in female patients was the breast cancer, with four cases.

Thematic analysis of the contexts resulted in the construction of three themes: history before diagnosis, course from diagnosis to start of treatment, and the treatment course; these allowed us to map the itinerary taken by clients in the search for health care (Figure 1).

Course before diagnosis

The path taken by cancer patients seeking treatment is marked by multiple barriers that begin even before establishing the diagnosis and which extend further on after this moment. From this, we highlight the therapeutic itinerary as "a key to coping with the disease and its treatment, since the paths the patients choose influence the health/disease process"⁽⁸⁾.

In this sense, the difficulty in recognizing the signs and symptoms of cancer was one of the initial problems faced by patients and their families, which resulted in establishing wrong diagnoses and treatment, and the use of

medications to circumvent the complaint at the moment instead of treating the cause.

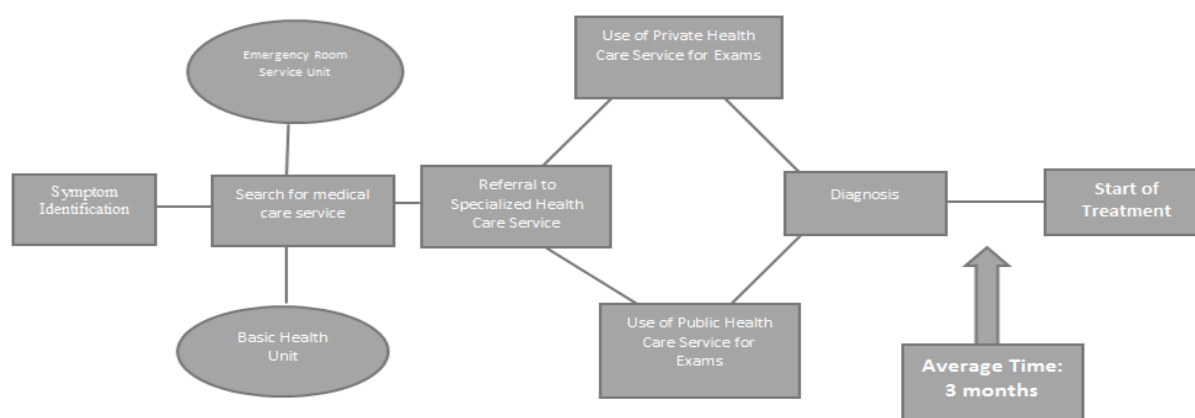


Figure 1 - Schematic representation of the itinerary of cancer patient in the search for health care and early treatment. Rio de Janeiro, 2015. Source: Author's research.

But when the professional identified any abnormalities and no solution after the implemented interventions, the referral to a specialist was required. At this time, the cancer patient was faced with another problem, the time factor.

It started with like a boil that appeared in my buttock, here on the right. Then it swelled, really like a boil. And I went to several doctors near to where I live, and they said, you know, 'it is a boil'. Then they prescribed me medication and nothing happened... then I had some benzathine penicillin, and nothing happened. I was in pain, it was no excruciating pain, but it hurt... Then he referred me to Fiocruz. So I went there to Fiocruz. When the nurse passed the eye, she said, 'this here is not a boil, there's some deject coming out of it here'... So they referred me to a doctor... She said, 'I think this is a fistula, I will refer you to a hospital'... then they attended me promptly. Not attended, but marked an appointment with my proctologist. Then after that I did the biopsy, and I was told it was a tumor in the rectum. (E1)

I used to go to the gym, I was doing Muay Thai, and I used to feel pain. Then I went to the orthopedist. He said it was because of the fight, but it (the pain) kept growing. Then he gave me some medicine, anti-inflammatory, ibuprofen, ok. But the effect started to pass, until it had no effect. When I figured it out, it was already there. Our kidneys are small and it was already way too big (the tumor), so I had to do it, they had to remove the kidney. And when they took it out, I found that I had cancer and it had passed to the liver and to my spine... But he did an X-ray and diagnosed a bone spur, then getting the things together, there

was no more tests... any further to know whether it was cancer or not. So it was in 1998, then it took some time, so when I went and saw, it had 5 years already, you know? (E6)

So I had a mammography, you know, then she told me to look for a breast cancer specialist as soon as possible. But in Public Health System this 'as soon as possible' takes time, right? Then I went and scheduled it, I think it took about two months to do it, so I went to, you know, the mastology, handed my mammogram and there was already a suspicion, then when I did the biopsy, then we saw that it was a cancer, you know. (E3)

And since there was a small lump in my neck he referred me to the head and neck specialist here in the Lagoa. Then I came here, they looked, examined me, marked a biopsy. Then I did the biopsy, and they found out it was a lymphoma. (E7)

In general, cancer clinical course is constructed from non-specific signs and symptoms that often are not remarked by patients or health professionals due to socio-cultural and organizational barriers.

The delayed or wrong diagnosis is identified as an existing organizational barrier in cancer discovery period, which is related to the lack of preparation of health professionals to deal with the particularities of oncological health care. Thus, the lack of clarity in the diagnosis coupled with the slow pace of health services contribute to the delay in referral of patients to specialized units. However, it is worthy to emphasize that these factors are crucial to increase survival rates

and improve the prognosis of these patients, especially when the disease burden is at an early stage, since it allows a more accurate diagnosis and appropriate treatment^(9,10).

The delay in carrying out medical exams and visits by Brazilian Public Health System caused patients to seek for private medical service in an attempt to shorten the time taken to get the diagnosis. The long waiting lists for scheduling exams and medical appointments contribute to make patients pay for such procedures by themselves, because the low availability of supply of diagnostic methods is a fact in health care area^(9,10).

[...] yes, in fact that was the first mammography, so to know it faster, I paid a private exam. (E4)

I'd rather have that high resolution mammography and I also came with a paid breast ultrasound exam just to make things easier for the people who would see me, the oncologist and general doctor in this case. (E5)

As local services, basic health units and family health centers were the most sought sites for the interviewed patients when identifying the onset of symptoms. In addition, Emergency Health Service Units (PAM) were mentioned in this, even when patient's clinical status was not acute.

I went to a doctor, a physician, from a Basic Unit. (E7)

It was at, how do we call it? That family unit, a Family Health Center. (E8)

Then I went to a little health unit, to see a gynecologist, she examined me and referred me to elsewhere. (E4)

The public Emergency Service, close to my home, then the doctor referred me to the hospital, up there in São Cristóvão. (E9)

And right after this, I went to look for a doctor. In a hospital, like a public Emergency Unit. So I went there and they diagnosed it. (E2)

It was the Emergency Unit. The one in Duque de Caxias which was at Brigadeiro, and now is into the former Duque de Caxias Hospital. (E5)

The demand for the basic health units is justified because it is the gateway to health services, by its proximity from patients' residence, and their previous bonds with the institutions, as many patients already had

medical follow-ups or used that service at some point. For this reason, the health system needs professionals with a trained eye to detect possible changes that may constitute signs of cancer, in addition to some knowledge of the system network to properly and effectively refer those patients.

The emergency units are designed to treat the acute demands in a faster and more concentrated way, since the patient's complaint can pose a health risk. However, much of the demand for such services becomes incompatible with the complexity of the assistance that is offered. This is due to the greater availability of resources in emergency units in relation to the basic health units, in addition to the difficulties in access to primary healthcare services⁽¹¹⁾.

Course from diagnosis to start of treatment

The use of private services was sought in order to minimize the waiting time to get the exams required for the diagnosis. However, due to the cost of treatment, patients returned to the public health system so that the treatment was carried out by the public Unified Health System (SUS).

I had to do private exams in order to be faster. With the exams at hand I would soon begin the chemotherapy. (E2)

Everything was done through public system, but since it takes too long to get blood tests and these things, so I use my pocket and I pay for these. Because I need the blood test to receive medication, without it they can't give me the medication, so to avoid any delay to receive it I do the particular exam. (E6)

This public-private mix is a response to the search for solutions to face health problems, and is part of the therapeutic itinerary of people and families who seek for medical care in a health system that is composed by informal, popular and professional subsystems. Through the resources of these subsystems, several arrangements are made in order to fill the gaps in the access to health services⁽¹²⁾. For the patients in this study, the private service was used as a complementary resource for the public supply in order to carry out necessary procedures which were not as expensive as the costs of hospitalization and effective treatment.

Regarding the time to get their diagnosis, the average period for these patients was three years, and two were unable to inform the time taken for theirs. As for the interval between the diagnosis and start of treatment, there was an average of three months, with periods ranging from 2 months to 1 year, with a pattern that varied according to patients' location.

After the diagnosis, the time factor remained present in the course of these patients, who had to wait for new tests and, finally, the start of treatment.

So it was in level 4 already, but until I could come here and do all the tests, it took six months. Then it got worse. I arrived here, when I did the exams here, I did another breast exam, it was already... it got from 4 to 6. It evolved. (E3)

It took a lot of time, because it had the size of a rice, you know, just the size of a little rice grain, then after one year with treatment, it grew to the size of an orange. From a rice to an orange. So I had to, you know, undergo surgery, quick, to prevent it from affecting other organs... it took one year, more or less. (E9)

Faced with this, we observe that the delay in starting treatment, as well as being a crucial factor that aggravates the disease and mortality rates, can point to a weakness in the service network. To minimize such situations, Law No. 12732/2012 provides that the initiation of cancer treatment must occur within 60 days after diagnosis by public Unified Health System, through surgery, radiotherapy, chemotherapy or bone marrow transplant. However, studies show that the full implementation of this law is not complete and delay situations remain a problem⁽¹³⁾.

Given this delay, patients use other ways of access to services, as informal ways. In other words, they rely on mediators that facilitate the referral to other units. Such mediations are present in health care networks, and are established by the patients and their families in disease situations, providing connections between the existing and new networks, and mobilizing other people and resources that were not considered in the search for health care⁽¹⁴⁾.

In São Cristóvão I met another doctor that knew someone from here, who put me here. And, well, I thank him for this. (E9)

[...] thank God no, because I have a brother who works in Health Ministry, so it makes it easier since he knows some doctors and all. (E8)

In doctor/patient communication, lack of preparation of professionals and non-compliance with confidentiality regarding patient's personal information was highlighted by one of the interviewees.

I went to the gynecologist, and when I opened my shirt, she took a look and almost ran away from the room. And she kept talking, 'you've got a metastasis, you have this and you have that'... I said, 'I know, doctor, yes I know', I was talking lower and lower and she kept speaking louder. I think my situation caused her a great discomfort. (E5)

The moment of diagnosis communication is a delicate time for the patients and their families because of the severe psychological, physical and interpersonal implications that such information may cause in their homes. In order to minimize the problems of the communication of a diagnosis that remains linked to the social stigma of death, there is an urgent need for investment in the preparation of health professionals, whether in undergraduate courses or through courses offered by continuing education, with regard to communication and interpersonal skills⁽¹⁵⁾.

Treatment course

During cancer treatment, patients also faced difficulties as the distance between the residence and the place of treatment, and the resulting costs dispensed with this situation.

Oh, I think it's too far. Too far away. From here to where I live it's some distance. It was a little hard, you know. Even now I still think it takes a little too long to get here, you know. (E1)

I spend too much in taxis, you know, and I couldn't. Because I don't get paid enough for this, neither does my husband, but the treatment here is worth of it. (E10)

The distance covered by the patient must be considered in treatment, since it requires repeated visits to health services for outpatient care and hospitalization. In this sense, the location of the service and its users, the available means of transport, distance, time and costs involved in this should be considered for assessing the accessibility⁽²⁾.

The lack of information and explanations about the disease and treatment is also a difficulty pointed out by patients. The lack of information is not related to the disease in general, but to its treatment and prognosis. The interviewees also indicate the missing of their participation in treatment decisions by professional staff.

Then I looked here, you know, it was really big, the tumor in my right breast, so I had some chemotherapy and it shrunk, but not that much, you know. It got smaller, so how can I say, it didn't really work, you know, but the doctor didn't tell anything about it, you know. (E3)

[...] In the meantime the tumor became too big, I almost could not go to surgery. Then the doctor called me, you know. Because we stay at home, we finish chemotherapy and we go home to wait for the surgery, you know, but I felt it was bigger. Then the doctor called, started it and prepared everything until the anesthesia. But then he stopped everything. Because he looked and saw everything turning red in my chest, thank God I was calm. And he said 'oh, we can't do the surgery with it like this.' Then I asked him: 'So will I be like this?', and then he said: 'oh no, but I won't go into this alone.' Then he called other 2 or 3 doctors, they looked, and he said: 'Hang on, it will hurt.' Because if it was bigger, there wasn't much free space left, you know. Then he pulled my breast to check for some space, to see if there was some skin left. Then he said: 'Ok, let's do it.' Then they did the surgery. (E3)

There was another doctor there, I didn't like that one, because he was, like, that kind of non-accessible person to the patients. (E5)

The biomedical care model emphasizes technical and scientific knowledge about the disease, over the subjectivity and intersubjectivity of the interpretations about the process of getting sick. It values only objective reports of the disease and what is provided by the doctor to the patient, establishing and reproducing systematically asymmetrical relationships⁽¹⁶⁾.

Nurse practice implications

Nursing is a profession provided by a technical and scientific knowledge that is embedded in all health care levels and scenarios, and which carries the duty of providing care for the people and family in the different stages of

life, including the disease. Thus, the measures for control and prevention of cancer are present in the area of action of nurses, since their practice aims to identify and target the risk factors of this disease, and also actively participate in its tracking and detection from primary to tertiary health care.

In this sense, family history of cancer (60% of participants) was a relevant aspect identified in this study, which reveals the need for attention to this factor, in addition to strengthening the integration of genetics counseling in health professionals' area of action, especially nurses.

We discovered my grandmother had a tumor, by the time she was already passing away. (E7)

My mother. She has already passed away. (E2)

I've had a daughter who was called by our God, I also had a son that was called by Him. This son of mine passed away in 2012, he was a lieutenant in Navy, he had pancreatic cancer. (E10)

My Family has it. Sometimes I say all my family is going to die of this disease, God forgive me. (E1)

fortunately, I have it. My aunt died of brain cancer and my grandfather had prostate cancer, but it's common since he was old. (E5)

Genetics counseling is defined as a process of communication or education through which the patient and the family members receive information about the nature, benefits, risks and the meaning of the results of genetic testing, providing support so that they can handle the implications referring to the possible outcomes of cancer predisposition testing⁽¹⁷⁾.

Although cancer prevention and detection are seen as crucial point in public health policies, gaps still persist in this scenario. The medical consultation on the Basic Health Unit in routine appointments or even in an acute case can be an opportune moment for approaching this subject and the beginning of a monitoring.

This way, when doing the routine checks and collecting patient information, the nurses can then refer patients for detection and advise them about risk factors, since their participation is included in the risk assessment and cancer genetic counseling, which comprises clinical (assistance), educational, organizational (as a consultant, coordinator and administrator), and research activities⁽¹⁷⁾.

FINAL CONSIDERATIONS

With the increase in the number of cases of cancer and the aging population, the development of specialized cancer treatments is needed. Besides the need to develop treatments, it is necessary to ensure adequate access to these services. To this, knowing the itinerary of cancer patients in details and trying to recognize the difficulties encountered in the provision and planning of services, contributes to the apprehension of knowledge about the network of cancer treatment healthcare services and provides resources for possible interventions and changes for an efficient coordination of the health network.

With the mapping of patients' courses, it becomes clear that cancer patients deal with numerous difficulties that begin before the diagnosis establishment and remain throughout its history of treatment, such as poor access to services, the waiting time for diagnostic tests, and the waiting time for the start of treatment.

Thus, access to services is presented as a problem whose consequences are reflected in the worsening of the disease, the appearance of metastases and ultimately, the death of the patient, in addition to creating conditions for the lack of adherence to treatment. As a strategy to ensure timely treatment, cancer patients associate the private medical services in a complementary way to the public supply. Lack of preparation and knowledge from professionals is also presented as a problem, which also causes a delay in detection of cancer.

We observed the need for adjustments in the therapeutic itinerary of cancer patients as recommended in the National Policy for Cancer Prevention and Control of the Health Care Network of People with Chronic Diseases in Brazilian Public Unified Health System, since in this study, the cancer patients' healthcare network was built with weaknesses in treatment supply, maintenance and/or support to these individuals and their families.

O ITINERÁRIO TERAPÊUTICO DO PACIENTE EM TRATAMENTO ONCOLÓGICO: IMPLICAÇÕES PARA A PRÁTICA DE ENFERMAGEM

RESUMO

A trajetória do cliente oncológico ainda é permeada por percalços que interferem em seu prognóstico e qualidade de vida. Assim, este estudo visa a mapear o itinerário do paciente oncológico desde o diagnóstico até o tratamento e analisar suas implicações nas ações de enfermagem para o controle do câncer. Estudo qualitativo, realizado através da técnica de história oral de dez clientes oncológicos atendidos em um hospital federal no município do Rio de Janeiro, Brasil. Os dados foram tratados de acordo com a técnica de análise temática, além da confecção de representações do itinerário terapêutico de cada entrevistado. Foram identificados três eixos temáticos: trajetória antes do diagnóstico, trajetória do diagnóstico ao início do tratamento, e trajetória no tratamento. Percebe-se que o acesso aos serviços apresenta-se como um problema que culmina no agravamento da doença, no aparecimento de metástases e a morte do paciente, além de criar condições para a falta de adesão ao tratamento.

Palavras-chave: Enfermagem. Oncologia. Acesso aos serviços de saúde.

EL ITINERARIO TERAPÉUTICO DEL PACIENTE EN TRATAMIENTO ONCOLÓGICO: IMPLICACIONES PARA LA PRÁCTICA DE ENFERMERÍA

RESUMEN

La trayectoria del cliente oncológico todavía es permeada por inconvenientes que interfieren en su pronóstico y calidad de vida. Así, este estudio pretende identificar el itinerario del paciente oncológico desde el diagnóstico hasta el tratamiento y analizar sus implicaciones en las acciones de enfermería para el control del cáncer. Estudio cualitativo, realizado a través de la técnica de historia oral de diez clientes oncológicos atendidos en un hospital federal en el municipio de Rio de Janeiro, Brasil. Los datos fueron tratados de acuerdo con la técnica de análisis temático, además de la confección de representaciones del itinerario terapéutico de cada entrevistado. Fueron identificados tres ejes temáticos: trayectoria antes del diagnóstico; trayectoria del diagnóstico al inicio del tratamiento; y trayectoria en el tratamiento. Se nota que el acceso a los servicios se presenta como un problema que culmina en el agravamiento de la enfermedad, el surgimiento de metástasis y la muerte del paciente, además de crear condiciones para la falta de adhesión al tratamiento.

Palabras clave: Enfermería. Oncología. Acceso a los servicios de salud.

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