

“The back and forth of consultations”: therapeutic itinerary of people bearing head and neck cancer

“Entre uma consulta e outra”: itinerário terapêutico de pessoas com câncer de cabeça e pescoço

“Entre una consulta y otros”: personas terapéuticas itinerario con cabeza y cuello

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ABSTRACT

Objective: The study’s purpose has been to gain further understanding about the therapeutic itinerary of people bearing head and neck cancer that are undergoing radiotherapy treatment. **Methods:** It is a descriptive research with a qualitative approach, which was carried out in a school hospital from the *Rio Grande do Sul* State. The study counted with 18 participants and was performed through open interviews. Data analysis used the thematic content analysis. **Results:** It was found that the patients followed a therapeutic itinerary in both the public and the private health services system, which showed delay in getting the diagnosis and the treatment. The search for alternatives aiming to solve the health problem occurred also in the sociocultural environment. **Conclusion:** Regarding the nursing profession, it is essential to understand the context in which the experience of illness was experienced, and also the timing in which the steps of the diagnostic process and the treatment have been developed aiming to provide a better health care service.

Descriptors: Therapeutic itinerary, neoplasms, radiotherapy, nursing.

RESUMO

Objetivo: Conhecer o itinerário terapêutico de pessoas com câncer de cabeça e pescoço em tratamento radioterápico. **Metodologia:** Estudo descritivo de caráter qualitativo, realizado em um hospital-escola do Rio Grande do Sul, com 18 pessoas, por meio de entrevista aberta. Para tratamento dos dados utilizou-se a análise de conteúdo temática. **Resultados:** O itinerário percorrido pelos pacientes deu-se nos serviços de saúde do sistema público e privado, sendo marcado pela demora para o diagnóstico e o tratamento. A busca por alternativas

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para resolver o problema de saúde ocorreu também no meio sociocultural. **Conclusão:** Para a Enfermagem torna-se relevante compreender o contexto em que a experiência de adoecimento é vivenciada e o tempo em que as etapas do processo de diagnóstico e tratamento foram desenvolvidas, a fim de oferecer uma melhor assistência.

Descritores: Itinerário terapêutico, Neoplasias, Radioterapia, Enfermagem.

RESUMEN

Objetivo: Conocer el itinerario terapéutico de personas con cáncer de cabeza y cuello que se someten a tratamiento de radioterapia. **Metodología:** Investigación descriptiva y cualitativa, realizada en un hospital universitario de Rio Grande do Sul, con 18 personas, a través de entrevistas abiertas. Análisis de datos utilizó el análisis de contenido temático. **Resultados:** Se encontró que la ruta fue recorrida por los pacientes, tanto en el sistema público y privado en los servicios de salud. El retraso en el diagnóstico y tratamiento marcó el camino de los encuestados así, también, buscó alternativas en el entorno socio-cultural a través de relaciones con amigos, familiares y vecinos con el fin de resolver sus problemas de salud. **Conclusión:** En la enfermería, es importante entender el contexto en el que se vivió la experiencia de la enfermedad y el paso de tiempo del tratamiento e diagnóstico se han desarrollado y proporcionar una mejor atención.

Descriptores: El itinerario terapéutico, Neoplasias, La radioterapia, Enfermería.

INTRODUCTION

Known for many centuries, cancer was considered a disease of developed countries and with great financial resources. Nonetheless, this scenario has undergone changes and, currently, cancer can also be observed in developing countries, especially those with few and medium resources. Estimates suggest that the impact of cancer on the population for the coming decades account for 80% of the more than 20 million new cases of the disease predicted for 2025.¹

In the face of epidemiological evidence, in the last decades, cancer has become an important global public health problem. In Brazil, the estimates for the biennium 2016-2017 indicate the incidence of 600 thousand new cases of cancer. The magnitude of this disease reveals the need to monitor its morbidity and mortality in order to develop actions to prevent and control its risk factors, and such actions are associated with health management.¹

Head and neck cancer pathologies include cancer of the mouth, larynx, and other sites in this region, which represents one of the six most prevalent malignancies in the world. In Brazil, it represents the second most frequent type among men, with the stage of the disease being a determinant factor for treatment and for mortality rate, and within five years may reach more than 50%.^{2,3} Regarding the Southern region, a study carried out in *Porto Alegre* city, *Rio Grande do Sul* State, found that the second group of tumors most frequent in the studied population were those that compromised the head and neck (oral cavity, oropharynx, larynx and hypopharynx), ranking the first place among male patients.⁴ At a regional level, a survey conducted in a referral service for radiotherapy treatment in the central region of the *Rio Grande do Sul* State, found that cases of head and neck cancer

corresponded to the second type of neoplasm most treated in the aforementioned service.⁵

The main risk factors for head and neck cancer are smoking, alcohol consumption, family history, poor diet, unfavorable socioeconomic status, human papillomavirus (HPV) infections, exposure to chemicals, wood dust, soot, coal dust and ink vapors. Smoking and drinking habits establish a synergism between these two risk factors, increasing the risk for the development of this type of cancer by 30 times.¹

In order to reduce the impact of the disease, it is necessary to reduce, first, the prevalence of behavioral and environmental factors that increase the vulnerability and risk to the development of cancer. Therefore, it should be ensured that screening programs and treatment protocols are accessible, particularly in populations that are less assisted by health services.¹

Preceding the definitive cancer diagnosis, a person perceives himself to be ill by identifying changes in the functioning of his body, starting a journey in search of answers, guidelines, health care and treatment.⁶ This course is the therapeutic itinerary, which encompasses paths, flows and trajectories followed by individuals or groups in search of problem solving, preservation and recovery of health. It is a set of plans and actions that are sequential and also capable of merging or overlapping in order to deal with the illness.⁷

The idea of a therapeutic itinerary refers to a chain of successive events that form a unit, being the result of a certain course of actions, a set of plans, strategies and projects aimed at a preconceived object: the disease treatment.⁸ Concerning the itinerary of people with cancer, they have shown that patients have gone through various health services in an attempt to cure their problems, which sometimes postpones diagnosis and treatment.^{7,9-10} They also point out the weaknesses in health care services, as well as in the model of access and therapeutic itineraries in the oncology services,¹⁰ and also argue that these delays can be related both to the health professional's ability to detect the disease early, and to the time the patient takes to perceive his illness and seek professional assistance.¹¹⁻¹²

At the end of this trajectory, by the time that the diagnosis is established, the treatment phase begins. In some cases of head and neck cancer it includes radiotherapy, which aims to achieve a favorable therapeutic index, leading malignant cells to lose their clonogenicity and, at the same time, preserve normal tissues. It may be exclusive or in combination with other forms of treatment, such as surgery and chemotherapy.¹

By understanding the construction of therapeutic itineraries, it is possible to help the nursing professionals in the planning of care actions and allows analyzing the health/illness practices. The inclusion of these factors in health care allows the understanding of individual and collective behavior for the demand for health services, given that the choices are influenced by the social and cultural contexts in which people are inserted. Thus, studies that provide knowledge about the therapeutic itinerary of the patients served in the health services constitute an important tool to understand the context in which the experience of illness was experienced and the time in which the stages of the diagnosis/treatment process were developed.

Given the aforesaid, the present research has the guiding question, as follows: What is the therapeutic itinerary of patients bearing head and neck cancer that are undergoing radiotherapy treatment? The study's aim is to understand the therapeutic itinerary of people bearing head and neck cancer that are undergoing radiotherapy treatment.

METHODS

It is a descriptive-exploratory field research with a qualitative approach that was carried out in the radiotherapy sector from the *Hospital Universitário de Santa Maria (HUSM)*, located in *Santa Maria* city, *Rio Grande do Sul* State.

The participants of the study were nine families, composed of nine patients with diagnosis of head and neck cancer in radiotherapy treatment and nine family members, totaling 18 people. As an inclusion criterion, patients were defined as follows: people over 18 years old, which confers legal status to participate in the study, and presents clinical conditions. For the relatives, it was established that they should be recognized by the patients as such, that they had accompanied them at some point during the treatment and that they had cognitive conditions to participate in the interview. Exclusion criteria were considered, as follows: patients who were without a relative, had pain, dysphasia, aphasia, mucositis and/or have used tracheostomy. In relation to the relatives, it was considered as exclusion criterion, the patient's inability to respond to the interview. The number of participants was established through data saturation, in other words, when the study's objective was answered.¹³

Regarding the legal aspects, this work is part of a larger project that was approved by the Research Ethics Committee from the *Universidade Federal de Santa Maria* under *CAAE 0379.0.243.000-11*. All participants signed the Free and Informed Consent Term and in order to ensure their anonymity, the participants were coded with the letter E, when the interviewee is a patient, and the letter F, when the interviewee is a relative, followed by a cardinal number from 1 to 9.

The data collection was performed through an open interview, having as guiding question: Tell me about the illness, since the disease onset to the beginning of the radiotherapy treatment. The interviews, performed with the family dyad, took place in the meeting room of the radiotherapy service, were recorded and then transcribed. The analysis of the data had as reference the operational proposal for content analysis, thematic modality, which is composed of three stages: the pre-analysis; the material exploration and treatment of the results obtained and interpretation.¹³

RESULTS AND DISCUSSION

Regarding the profile of patients diagnosed with head and neck cancer, six are male and three female, within the age group from 49 to 77 years old. Concerning the marital status, four are married, four widowed and one single. Eight have children. Six live in urban and three in rural areas. About the schooling level, eight have incomplete elementary education and one have completed high school. In reference

to treatment, in addition to radiotherapy, seven performed chemotherapy sessions and three underwent surgical procedures. Regarding the pre-existing clinical conditions, four patients are hypertensive, three are smokers, three are ex-smokers and four are ex-smokers. Considering the degree of relationship of the family members involved, three were wives, two spouses, two children, a daughter and a neighbor.

From the interviews' analysis have emerged categories that were organized and grouped into four topics, as presented below.

Feeling sick and looking for home made remedies

The itinerary of people bearing head and neck cancer while they are looking for treatment has began with the recognition that they had a problem, a definition based on their perceptions, beliefs and previous experiences, which shows a long way between perceiving the appearance of the first signs and symptoms, and the search for solution, initially restricted to the field of possibilities in which they were inserted.

I started with the voice, which was normal. I went on a trip, the air conditioner turned on, it was a hot day, when I left my voice was gone. I thought it was cold, flu and I was taking medicine for the flu, but always hoarse. Then the children began to say, "father, you have to make an appointment with the doctor." (E1)

Although denying a possible association between the presented alterations and a more serious disease, the perception by the patients or their relatives that the alterations did not improve became the triggering factor for the search for other measures, starting with self-medication. The decision in the choice between the different types of possible care and treatments was influenced and validated by the family subsystem in which they surround the knowledge, values and beliefs accumulated during their lives.

Past experiences and personal and family beliefs support seeking different alternatives to solve their problems and improve health status. Thus, it is identified that the home measures were the first therapeutic choice, which were recommended by family and friends.

It was a colleague of mine who told me to make chamomile and mauve tea. And I made a lot of mauve tea for him to wash his mouth and then she told me that the chamomile was good. When we got here, they also showed me the camomile tea. (F2)

We put the mauve, which is the tea that most people use. Look, I think everything that has to do we should do, it is not getting worse, then should we go to everything. (E6)

The use of therapeutic measures based on popular knowledge is an empirical resource often used by people. Among these, the use of medicinal plants prepared in the form of teas stands out. The indications, the benefits and

the way of international preparation, among families, and through interpersonal relationships.¹⁴

Studies highlighting the role of integrating the family and social support network, such as friends and neighbors, as part of the solution solutions for more situations, such as illness, without context of their knowledge and beliefs.¹⁵ From this perspective, participants in the other forms of treatment by them, such as natural products, homeopathic medicines and ointments, which were indicated without aid or treatment of diseases.

I went to clear my throat with copaiba oil. I thought, "But there has to be something, and that came from copaiba oil. I had already done some research on copaiba oil, I took it and it was the one that cleaned it. (E5)

The treatment with alternative therapies was investigated in a research carried out with bearing cancer patients, which identified that they consider it as a valid form of care, with several possibilities of signification, such as: potentiating the allopathic treatment; increasing the chances of total cure of the disease; dealing with other dimensions considered important in the health-illness processes (mental, emotional, spiritual); and strengthening people both emotionally and psychologically.¹⁶

In this sense, it should be noted that from a sociocultural perspective, a person discusses or evaluates the possibilities of care of the disease based on their knowledge and experiences, using different types of care (informal, professional or popular) and following recommendations that make sense to her.¹⁷ In some communities, when people need help to alleviate physical or emotional discomfort, it is often sought out with friends and neighbors, using home-made formulas or self-medication. Self-treatment is based on lay beliefs about the functioning of the body and the nature of disease.¹⁷

Each person faces the disease in a singular and individual way, not having a single way to perceive himself sick and to seek help in the health services. It is observed that despite the perception of pathological symptoms and signs, many people avoid seeking health professionals as a way to deny their reality and to protect themselves from facing it.

I was avoiding because I knew what I had. The person knows! We were starting a partnership with friend and I was helping. I always kept saying that I could not consult, that I did not have time. Then he scored for me and left me no chance to get away from the problem, luckily. (E5)

We thought it was because of the air, which was connected directly in front of her, that she did not look good. That's when I noticed her throat that really scared me, because at the time I saw that it was nothing normal, everything swollen and just a little hole?! That's where I took her to a consultation. (F8)

Delaying the search for health services can be a way to deny symptoms, mask fear and reduce emotional discomfort

as symptoms have their importance diminished. Denial is considered a coping mechanism, in which not talking or thinking about the disease and the aspects involved in this process, protects and alleviates the suffering of the individual and their relatives.¹⁸

Faced with the patient's resistance to seeking specialized help, the family, while seeking to respect their decisions, also remains attentive to what is happening and often becomes responsible for "compelling" the demand for specialized care. Some relatives participating in the study have reported that they have been taking responsibility for triggering the therapeutic flow for the care of their relatives.

I have scheduled the appointment for him, but he did not go. Another day, he complaining, complaining, I went to do it over again! When the day came, he did not want to go! I got him into a car and we went after all. (F2)

A study carried out with the purpose of knowing and describing the feelings and emotions of patients in relation to the diagnosis of cancer, also identified that when they come into contact with the process of illness, negative feelings emerge, denial with emphasis on the resistance to the reality of fragility and dependence they are experiencing.¹⁹

In this perspective, the family seems to share this conception until a certain moment, when it begins to suspect that something really serious may be happening, which is reinforced when they do not perceive improvement on the part of the relative, even though the time of action of the measures adopted for recompose the health status pass. When the discomfort reaches the limit or the family manages to overcome the resistance of its relative, the health service is then pursued.²⁰ Therefore, the therapeutic itinerary proceeds in the health care service.

The search for the health care services

Examining what is happening is the starting point in the construction of the therapeutic itinerary, which occurs through the search of the professional system¹⁷ in the health care service. This is accessed, initially, through either the private or public service. It is identified that most of the participants used private consultations or health plans as a strategy to obtain answers to the concerns arising from the signs and symptoms presented.

I went first to the cardiologist, and then came others and others. Then the others sent it to others, and we're going. It's difficult! As the situation did not improve, we went looking for, over and over again... (E3)

After we paid particularly for the doctor to do the surgery, he forwarded everything. They were on strike here, so he tried to speed up, as soon as possible, because he could not wait any longer. (E9)

It was observed that the trajectory in the health services began by the search for help in the private system, due to the

delay in the service of the public service and because they cannot wait the time provided for the consultation due to the clinical picture of the disease. The scheduled appointments on the private service had immediate care, but from there patients went a long way between referrals and referrals to specialists. It can be observed that even paying for medical care, the participants found it difficult to arrive at the diagnosis, mainly due to the delay that occurred between the consultations and the examinations, often performed in public services.

The physician, who was private, indicated to come here. It's good here, but it was a lot of waiting. Then we went back there and he said to look for this doctor who attends here. We paid him to do everything and then he sent us here, because we could not afford to keep paying. (E6)

It can be stated by the testimony that the search for the diagnosis involved the journey through several medical offices until arriving at a confirmation that directed the treatment. This reality corroborates the results of a study that mentions the long journey of individuals and their relatives, among professionals of different specialties, as well as in different health services, even before diagnosis and treatment are established.²¹

Given the abovementioned, it can be inferred that the signs and symptoms referred by patients may be being devalued or even neglected, which leads to ineffective therapy. The lack of clinical knowledge that results in the lack of adequate guidance by the professionals. It makes people not knowing exactly who to turn to. This coming and going contributes to the delay of the definitive diagnosis and initiation of the early treatment.

It took too long! There were many uncertainties. We did not know what we had and nobody said it. One passed to the other. So it was very time consuming. (F3)

When he came to the specialist, he waited three months. He made an appointment and gave a drug for 40 days. If it did not improve I would go back. Then he came back, and he gave another, for another 40 days. As it did not improve, he said: it's not for me, I'm going to send you to another doctor. Since it took time to consult with him, we consulted with another, who did the same exam again and said that he would do the biopsy. Then he said: It's not for me; I'm going to send you to another one. (E1)

In the therapeutic itinerary of the study participants, it was found that after the tests and confirmation of the diagnosis, the patients were referred to perform the oncological treatment in highly complex service in the public health service, in other words, in the referral hospital of the region.

We took another way because it started to take a lot here. We went to the doctor at the clinic and he drove right

back and that was very fast. We paid an appointment to be sent here. (E9)

In view of the difficulties encountered in providing care in the public health service, the private services were sought as an attempt to shorten the waiting time for the diagnosis and also with the intention of being referred to the public health service where they would make the specialized treatment. This strategy can be understood as a result of the slowness of the public service, the long waiting times and the delay in scheduling consultations and examinations.

He is under treatment at the medical clinic because of his heart. From the medical clinic they went to hematology. There it showed that it was a tumor in the throat, from there it came to the radiotherapy. (F4)

We went to the physician by the health plan. Then, because of the complexity, he sent me here. There was no way we could do the private exams. So we came here and had to wait. (E5)

Having similar results, which corroborate the present investigation, a study carried out with people bearing cancer has identified that in the itinerary covered the patients faced several referrals for consultations and exams, with a long waiting period, which obliged them to decide for the payment of consultations aiming to speed up the health care service.¹⁵ This situation reveals the lack of commitment, accessibility and resolution verified in the *Sistema Único de Saúde (SUS)* [Unified Health System], since the success of cancer treatment may be directly related to early diagnosis, so the delay in obtaining the correct diagnosis leads to loss of time and disease progression.^{9,15}

Among the participants of the study it was possible to identify that the time passed between the symptoms' awareness, deciding to search for a health service and the beginning of the treatment, lasted for several months.

I went to a medical appointment and waited for the surgery. It took about eight months or more, so I had to go after it. I saw that it was not working, so I even went to the Forum to get it, otherwise I would never get it. (E7)

Although the public system is inefficient to meet the demands of the population in a satisfactory way, it can be seen that users, when they have knowledge of their rights as citizens, sought alternatives to accelerate treatment and find the solution to their problem.

Nevertheless, not all people have the economic conditions to address the inefficiencies of public service and pay for private care. They can only begin treatment months after diagnosis and referral to the specialized service, being conditioned to remain in this waiting period, without proper care and treatment. This reality converges to the results of other studies that highlight the lack of resolution of the Health System in the oncology area as a factor generating insecurity for patients and families,

because when the patients' needs are not solved in the local service, then the problems end up without a solution.²²

The physician asked for twelve thousand reais in order to do the surgery, but I did not have the money, I did not have the conditions, or even where to take it. I'm a salaried guy. (E9)

Universal access to comprehensive and quality care is not yet contemplated in the daily life of health services, even with all the legal and legal support of the *SUS* principles and guidelines. Yet, integrality in health care should be thought of as a process that involves people's lives, their histories, experiences, anxieties and expectations.²³

Therefore, it can be seen in the itinerary covered that patients seek both the public and private services, as evidenced in a study that found that the private service was accessed by the participants as strategies to minimize the waiting time for diagnostic tests, however, due to the costs of this service, they returned to the public system, then resulting in public-private mix access.²⁴

The delay in diagnosis and treatment

The delay in formulating the diagnosis and initiating treatment is corroborated by the choices made by patients who, when faced with something other than the normal, refuse to seek help, either from fear or from an erroneous interpretation of the symptoms, thinking that they can solve it alone. Considering that the perception of signs and symptoms and the interpretation of health status are influenced by social and cultural factors²⁵ the interpretation and individual experience of the illness process give different meanings to the situation experienced and may be aggravating factors in the delay of diagnosis.

It took me a while because I was late. We always thought it was because of the air conditioning that was in front of the box and it was connected right in front of me. (E8)

It took me a long time. I was raised without having to go to the doctor. (E9)

However, the delay in diagnosis is not a result of patients' behavior and difficulties in accessing the health system mentioned in the previous category, but also associated with the lack of instrumental resources and technical-scientific knowledge on the part of health professionals with regard to the neoplasms that affect the region of the head and the neck, and in how to detect them in its initial stage.

Patient and family information reveals that regardless of the strategy used to solve the health situation, the first diagnosis and the proposed medical treatment was often not conclusive because it was not compatible with the actual disease. In this sense and also in view of the mentioned symptoms, some participants underwent dental, flu and tonsillitis treatments.

A year and a half ago he complained of pain, but he thought it was from the gum because he had extracted his teeth and the sheet was bruised. They did another and it was no use. He did three surgeries, because it had become a bit of bone, and then had a tooth root. Only he had his surgery and it still hurt. Then, they sent us here. (F2)

We went to a health clinic where we lived and gave medicine for the flu and that was what made me late in searching for the real problem. He said it was the flu I had, it was the flu. (E1)

I consulted with the doctor and said that I had a bacterial tonsillitis. He gave me a treatment, but it did not solve at all, not even the throat infection. (E3)

The misdiagnosis was a factor that contributed to the delay in the cancer diagnosis, because it was only when they realized that the therapy was not performing the expected effect, the patients were recruited or referred to another doctor. In this process, patients and family members hoped to receive clear and accurate information from the professionals who attended them and that they would provide safe answers to their afflictions, which was not always the case.

Going back and forth was delaying everything. I lost my patience with the doctor: you have the experience and I have a tomography and two endoscopies in my hand. If you are not going to have the surgery, you should give it to someone else. This delay was from August to December. (E1)

The first doctor was not very experienced, he was freshly graduated, and he said: I think we're going to do this, if it does not work then we do this. I told him: the doctor is new and I am much older and I have life experience. I work in construction. If you make a wall and it does not work, you make another, but a life is more complicated. Those two months were precious. (F4)

The relationship established with professionals and previous experiences, with other physicians in which the care was not decisive or was wrong, besides revealing the fragility of the clinical behaviors, compromises the trust in the other professionals and in the health services, generating feelings of insecurity also in relation to the future itself and the possibility of appropriate treatment and cure.

In this sense, results of a study that analyzed how families of people with cancer perceived the care provided by professionals of a specialized public service point out, as a condition for the formation of a bond of trust between patient and professional, the perceived sense of security during the care received, where this is related to the technical and attitudinal competence of the professional, who reveal through this medium the quality of the service and the professional that attends it. They also pointed out that the reference and counter-reference model was considered to be faulty by the

participants, since the time spent between the various referrals was too long until the diagnosis was concluded.⁹

The delay in obtaining care in the public service brings to light a critical point in the health system in which the process of seeking diagnosis and treatment for head and neck cancer is often long and tiring for patients, turning this period into an agonizing lack of definition about what is happening to you.

The diagnosis' confirmation and the treatment onset

In the therapeutic itinerary covered, the diagnosis' confirmation and the prognosis reveal the answer to the patients' questions. It is the beginning of a new phase. Nevertheless, confirmation of cancer has a negative impact on people's lives, causing them to feel fearful about their own life and future, helpless and fragile to mobilize and face the situation, especially since this disease is still seen as difficult to heal. In the reports one can identify that discovering oneself with cancer was a painful moment added to a path permeated by challenges that demanded alternatives that would contribute to overcome the difficulties experienced.

I got lost! I went out with the exam in hand, in the middle of the cars, it was a very bad stage. Then I called my husband and told him to come and get me, that I was not well. (E3)

I did not even think about it at the time. He wanted them to do whatever had to be done. I did not even think about it, I just wanted to be okay. Until these days I do not stop thinking. (E8)

The social perception of the disease reflects the association of cancer with a fatal disease, considered a synonym of death in which pessimistic feelings are cultivated. This thought, present in some of the interviewees' testimonies, is in agreement with a study carried out with cancer patients, which showed that, despite the hope in medical advances regarding the treatment and cure of cancer, the fear of death against the disease was expressed by all participants.²⁶

I thought: if it's cancer I will not operate, I will not let it. I will await death. She can come when she wants. What can I do? (E1)

The impact of the confirmation of the diagnosis is also revealed by the perspectives that come from cancer treatment and its possible side effects, since neoplasms can alter the quality of life of the individual, both by the disease itself and by the deleterious results of its treatment.²⁷ The approaches for cancer therapy, such as radiotherapy, are often aggressive and cause adverse reactions, as can be seen in the following reports.

The radiotherapy almost kills me. This is tough! It burned me! We cannot even eat. The throat swelled, they had to

place a catheter. That was really annoying. At first, we do not even suspect that this can happen. (E7)

Radiotherapy treatment for patients with head and neck tumors exhibits important oral complications including radiodermatitis, mucositis, xerostomia, cavities, loss of taste, secondary infections, osteoradionecrosis, and trismus.²⁸ In this perspective, head and neck cancer patients may present adverse reactions caused by the treatment, which may have a strong negative impact and affect their life quality. However, in addition to perceiving and suffering from the effects of the treatment, the interviewees were aware of the radiotherapy, knowing the need to perform it for their own good.

The radiotherapy was very complicated in my life. Good help on the one hand, but on the other, very difficult. (E5)

They say the radiotherapy is meant to kill the cells. So, you have to. That is it! (E7)

In the search for the disease cure, radiotherapy is considered a necessary procedure, even presenting toxic effects that cause physical and psychological suffering. Nevertheless, in the face of stressful situations and threats to life such as the diagnosis of cancer and the need to cope with radiotherapy, positive beliefs contribute to keep going the treatment, and also boost emotional support.

50% of the disease cure is the personal mindset. If the person is sick and enters depression begins to sink, there is no remedy that heals. If the person has the good spirit and self-esteem up there, he or she will overcome any illness. (F1)

The way the person stands in the face of the illness situation helps him to have a less tragic view of the future, giving an optimistic meaning to the experience. This way of understanding the health-illness process allows one to have faith and hope, to believe in oneself and to have a better quality of life during this trajectory.

In this sense, spirituality is considered a situation of comfort and courage in facing a difficult condition. It expresses the identity of each person, who seeks strategies that alleviate suffering and increase quality of life and survival.²⁹ In this way, they seek resources that strengthen them and help overcome the illness, favoring positive feelings based on faith and spirituality, depositing in their trajectory hope and trust in God.

In such a situation one has to hang to everything that comes, because if something does not work here, it can work over there. (E2)

Yeah, but one day I'll end this disease! You have to reach to God, because only Him can help you. (E8)

The feelings of loneliness and uncertainty arising from cancer sickness lead the person to seek resources to support, comfort and help overcome suffering, and spirituality and religiosity socially represent an external appeal when the inmates are scarce, since the faith represents an ally against the cancer.³⁰ For patients and their relatives, the itinerary towards the diagnosis of head and neck neoplasm has been permeated by many obstacles, delays, doubts, anxieties and indignation. Hope, faith and courage are the forces that sustained, helped and will help find alternatives and overcome difficulties.

CONCLUSION

The therapeutic itinerary consisted of the actions undertaken by the patients and their relatives from the moment they recognized a health problem and sought to solve it. They have used strategies coming from either the popular system or the professional system, which was based on whether getting or not clinical improvement.

The itinerary was marked, in addition to the long lines in the health services, by the sociocultural components that determine the choices and practices to be used. With that in mind, it was realized that there is no single path to follow since the possibilities depend on the perceptions that each person attributes to what is happening to him/her, and also if the resources are available and accessible.

Therefore, during the search for the head and neck cancer diagnosis, the patients and their relatives have come a long way to reach the appropriate therapy, which included both the public and private systems, trying to fill the deficiencies of each service. Initially, the demand was for the public service, but the delay in the service led them to look for the private service, which presented itself as an alternative to accelerate the process and give resolution to the health problem. Considering the high cost of this service and the impossibility of maintaining it, the return to the public service was generally reestablished for the accomplishment of specialized examinations and treatment.

Knowing the therapeutic itinerary of the patients constitutes an important tool that allows understanding what they have experienced over this trajectory and, considering the undertakings necessary to overcome the obstacles of this experience, it is also possible to develop care in a humanized way. In this sense, it is up to the professionals to recognize that each person, when arriving at the radiotherapy service, carries with him a particular baggage with histories and life experiences, being necessary to listen and to respect his conceptions and forms of care that, often, they influence in the form of and whether or not to adhere to the treatment. Thus, the nurse must plan actions that contemplate the needs of each patient, turning care into a practice that considers the singularity and history of each one.

Considering the limitations of the present study, regarding the sample and the specific sociocultural context, which restrict the possibility of generalization of the results, it is important to develop studies that address the therapeutic itineraries covered by patients and their relatives in the

resolution of health problems, since it can reveal both the quality and the access to the health system.

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