



ORIGINAL ARTIGO

HEALTH CARE FOR PEOPLE IN ONCOLOGICAL TREATMENT*
ASSISTÊNCIA À SAÚDE DE PESSOAS EM TRATAMENTO ONCOLÓGICO
CUIDADO A LA SALUD DE PERSONAS EN TRATAMIENTO ONCOLÓGICO

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ABSTRACT

Objective: to analyze the legislation in force and compare it with the reality reported by health users, who perform cancer treatment in a health unit. **Method:** this is a qualitative, descriptive, exploratory study with ten people with cancer disease, admitted to a hospital unit. The data collection tools used were semi-structured interviews, field diaries and document analysis. The data was ordered, following the technique of Content Analysis in the category Analysis mode. **Results:** the following categories of analysis were listed: early diagnosis; UHS card modality and public network X private network in health. **Conclusion:** it is warned that there are significant gaps regarding health care in UHS, specifically regarding the initial diagnosis of the disease and access to treatment. **Descriptors:** Public Health; Oncology; Health Care Network; Health Services Accessibility; Regional Health Planning.

RESUMO

Objetivo: analisar a legislação em vigor e compará-la com a realidade relatada pelos usuários da saúde, que realizam tratamento oncológico em uma unidade de saúde. **Método:** trata-se de um estudo qualitativo, descritivo, exploratório, com dez pessoas com doença oncológica, internadas numa unidade hospitalar. Utilizaram-se, como ferramentas de coleta de dados, a entrevista semiestruturada, o diário de campo e a análise documental. Ordenaram-se os dados, seguindo a técnica de Análise de conteúdo na modalidade Análise de categorias. **Resultados:** elencaram-se as seguintes categorias de análise: diagnóstico precoce; modalidade cartão SUS e rede pública X rede privada na saúde. **Conclusão:** alerta-se que existem expressivas lacunas no que diz respeito à assistência à saúde no SUS, especificamente quanto ao diagnóstico inicial da doença e ao acesso ao tratamento. **Descritores:** Saúde Pública; Oncologia; Rede de Atenção à Saúde; Acesso aos Serviços de Saúde; Assistência à Saúde; Regionalização.

RESUMEN

Objetivo: analizar la legislación vigente y compararla con la realidad reportada por los usuarios de la salud, que realizan tratamiento del cáncer en una unidad de salud. **Método:** se trata de un estudio cualitativo, descriptivo, exploratorio con diez personas con enfermedad de cáncer, ingresadas en una unidad hospitalaria. Las herramientas de recolección de datos utilizadas fueron entrevistas semiestructuradas, diarios de campo y análisis de documentos. Los datos se ordenaron siguiendo la técnica de Análisis de contenido en la categoría Modo de análisis. **Resultados:** se enumeraron las siguientes categorías de análisis: diagnóstico temprano; Modalidad de tarjeta SUS y red pública X red privada en la salud. **Conclusión:** se advierte que existen lagunas significativas con respecto a la atención médica en el SUS, específicamente con respecto al diagnóstico inicial de la enfermedad y el acceso al tratamiento. **Descriptores:** Salud Pública; Oncología; Red de Atención a la Salud; Accesibilidad a los Servicios de Salud; Prestación de Atención de Salud; Regionalización.

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INTRODUCTION

It is known that public health in Brazil, after the 1988 Constitution, had a great advance through the Unified Health System (UHS), which was later materialized in Law 8.080 / 90.¹

This system was organized in a hierarchical and regionalized way, in a level of increasing complexity, so that, through social reality, it determines the health situation of each region. Uniqueness is allowed by the size of the Brazilian state, that is, UHS actions are planned to be carried out according to the needs of the local population. This system has as guiding principles, according to the same legislation, the universality of access to health, the comprehensiveness of care, the preservation of autonomy, equity, regionalization, hierarchy, popular participation, decentralization and single command.¹

Major changes were influenced by changes in the health context and also in reality. Brazil has come in recent decades, undergoing changes in the profile of causes for mortality and morbidity called epidemiological transition. This concept is said to refer to the various transformations in time related to health and disease patterns that occur in conjunction with other demographic, social and economic changes.² It is reported that in Brazil, there has been a decrease in mortality from infectious diseases and an increase in noncommunicable and chronic diseases, among which the diseases of the circulatory system, neoplasms and external causes are gaining prominence.³

Thus, this study emphasizes cancer, popularly known as cancer, which today is considered a public health problem in developed and developing countries, accounting for over six million deaths each year worldwide.⁴ It is stated in studies by the National Cancer Institute that "the prevalence of cancer will continue to rise in developing countries and will grow even more in developed countries if preventive measures are not widely applied".^{5,26}

Faced with this current epidemiological context, cancer treatment was instituted by Ordinance 874, of May 16, 2013, by the National Policy for Cancer Prevention and Control in the Health Care Network of People with Chronic Diseases within the Unified Health System.⁶ The Ministry of Health has proposed a national policy to address the needs of the population regarding cancer prevention, diagnosis and treatment in the health care network. The aim was early diagnosis, as well as access to the medium and high complexity levels, so that treatment with a prospect of cure is possible, understanding that time for cancer patients is their biggest villain.

It is understood that, although there is legislation that guides the legal paths to access to

health, there are many realities throughout the Brazilian territory and many are the barriers that prevent what is provided by law to be met. Therefore, people are looking for various strategies and possibilities to achieve this service in order to guarantee the right to health. It is reported that these various possibilities, which escape the formality of the law, are the productions of care networks or "Living Networks" formed by the very people who produce movements, elaborate knowledge, build and share care and, in this context, the network is not formed, it will be woven according to the events.⁷

OBJECTIVE

- To analyze the legislation in force and compare it with the reality reported by health users, who perform cancer treatment in a health unit.

METHOD

This is a qualitative, descriptive and exploratory study using the technique of content analysis.⁸⁻⁹ As participants in the study, people with cancer disease admitted from December 2016 to January 2017 were surveyed. The number of participants was defined by the criterion of saturation of the responses, totaling ten participants, and of these, eight are men and one woman, all coming from the interior of the state, with ages ranging from 22 to 72 years old, all with their respective companions. It is revealed, however, that a companion participated in the interview effectively and, as his information was of fundamental importance, he was added to the study population. A ward that assists patients undergoing cancer treatment by the UHS of a large philanthropic hospital in the city of Salvador, which has several specialties in the health field, among them, the Oncology Service, characterized as Complex Oncology Care Center - UNACON, which serves the State of Bahia was chosen as a study place.

As a tool for data collection and production, a semi-structured interview was used in which the interviewee discusses the subject in question without being attached to the question formulated.⁸ During the interview, a tape recorder (Iphone 5S) was used to ensure the reliability of the speeches, as well as their confidentiality. It was also used, by the researcher, the field diary in which were written the experiences and situations lived at the research site and that were related to the thematic approached and, finally, a documentary analysis of the medical record in the institution's electronic system was performed in a complementary way.

Data collection was initiated through an active search of the profile of hospitalized patients, and the team later discussed the feasibility of

conducting the interview. Subsequently, contact was made with hospitalized people, as well as their families, and the research was presented and the invitation to participate was made. The Free and Informed Consent Term (FICT) was exposed, emphasizing the guarantee of anonymity and free choice to leave the research at any time. In addition, a copy of the document was left with the patient and, after the participant's consent, the interview was held at the patient's place of choice, thus maintaining confidentiality and comfort.

Data was ordered, following the technique of Content Analysis, in order to systematize them for analysis through a mapping, forming a matrix of thematic categories for all information obtained. The recordings were transcribed, and the informants' statements were reliably presented and literally transcribed, with the rereading of material from the field diary data and documentary sources. The data was classified in sequence, identifying the analyzers, and the empirical categories were elaborated. In the final analysis, the empirical data were articulated with the theoretical and methodological references of the research and documents, promoting the relationship between the concrete and the abstract, the general and the particular, theory and practice.

In order to maintain the anonymity of the research participants, the letters "P" (person) and "A" (companion) were applied, accompanied by Arabic numerals.

RESULTS

The scenario of this research was chosen due to the experience lived in the hospital unit during the care of people in inpatient and outpatient units exclusively of UHS Oncology. Thus, it became possible the opportunity to welcome and guide many patients and relatives who told their life stories and barriers to access to cancer diagnosis and treatment. All of these include the difficulties with examinations, emergency care, waiting time for regulation, displacement for health treatment, and various barriers to achieving access to health. Three relevant categories of this process, namely, early diagnosis, the public network X the private network in health and the UHS card modality were highlighted in this research.

In the first category, early diagnosis, the various lines that bring the difficulties of access to preventive care and diagnosis of the disease were highlighted. The interviewees reported how symptoms appeared, with important health problems that led them to seek urgent care, and in the search for a diagnosis, some of them face the disease at an advanced stage, which often makes healing impossible.

Found out that [...]. I started with cough and vomiting, everything I ate, I threw it away, I didn't get anything in the stomach and also losing a lot of weight, so I went to the doctor there, a clinician; Then he passed some tests and a chest X-ray, when I did, I had a stain, then, with a short time, they told me to do nothing there, they said I was looking for a specialist and he sent it home. (P6)

It is noteworthy, during the research, the report of a patient who discovered the diagnosis during the seventh month of pregnancy and, after delivery, she had to be immediately referred for treatment of the disease, not being able to stay with her child and experience the problems in their first days of life.

After a pregnancy, from the seventh month of pregnancy, I had a USG of the abdomen and there was what I had. (P5)

It is noteworthy, given the interviewees' statements, the difficulty for local access to health services. It is also evidenced the fragility of care in emergency services, as well as in the basic health units.

[...] they did not admit, because there, to have emergency care, only if you have arrived with fever or vomiting, the rest sends home. (P6)

There we have no care [...]. (P9)

[...]Our Santa Casa is closed, so there was no way, the service, which we have most urgently, is a ECU, we have, and we have the IPE today, which ends up attending a little too that before was just to care for [...]. (A1)

But it's only for three months, four months [...]. (P9)

In the category, Public Network vs. Private Network in health, it is noteworthy that there are many reports that describe the difficulties for access to health care, as well as the great precariousness of care and the delay in diagnosis for the beginning of treatment; Therefore, to meet these needs, the participants of this study bring, as a strategy, consultations and examinations in private clinics to obtain a diagnosis sooner.

Then, I went to another unit, the post doctor referred to the pulmonologist I paid privately. [...] Then, in particular, he said that I had to have surgery, but there was not, to do surgery I did not do this surgery that I did at that time, then it passed to me, passed to me, I went through the surgeon there, to know if it was right here, right; there, I went there, to the surgeon, I paid private too. (P3)

[...]when it was fifteen days later I, before fifteen days, I started to have back pain and having a high fever and woke up all night drenched in sweat, the clothes could twist; Then I took another X-ray and saw that the stain had greatly increased during these two weeks; I paid for a private consultation, in fact, it's already

the second private consultation I had paid, where the doctor told me to have a resonance, see a pulmonologist. (P6)

All particular, X-ray, consultation, is, I did seventeen more blood tests, stools, urine, bronchoscopy, all particular. [...] the service was from the neighborhood, now, the exams, I had to pay. (P6)

[...]or regulation, so, as he was showing symptoms of pain, of discomfort, we could no longer wait, we had to resort to the private network. (A9)

It is clear that these people's lines are often full of commotion because it is a real battle to get to treatment and many are thrilled to tell of the various strategies they had to use to be there. It turns out that, for them, it is natural that those who have friends have everything; verbalize how they have the support of friends and acquaintances, who give the "way" because they are "comrades", and thus can more easily reach the treatment, because this was the way they found to make the health care network happen: is building a living network that fights for life.

I have a nephew that he is a candidate for councilman, right; then, through my respect, he took the federal deputy's office in Brasilia about me, then he said: "let's go now", then called [...]. (P1)

Along with Dr. A, Dr. A.'s wife said he was going to have surgery and such, that it would help me as it really helped me. (P1)

He came here, the doctor passed a report to look for, he gave a note to look for Dr. S.T's medical team, then he came from here like this, didn't come by the health department. (P3)

And finally, in the category UHS card category, it is noteworthy that due to gaps in care networks, especially regarding the agreement between municipalities, some respondents report complaints due to the delay in referral for treatment.

Many times there is not because there are many who are waiting for regulation, but regulation there takes forever, I was regulated there myself and the business tightened and when we came running here, because if I had stayed I would not resist. (P6)

Given the above, another possibility was found by patients to obtain cancer care, which is the change of address on the UHS card for the municipality offering the service. The interviewees provide information on how they were able to make this change so ingeniously and naturally, without knowing that the ideal is that they would not need any of this; still others tell how they are staying in another municipality, with rented house, with the help of friends, because they needed to change addresses to access treatment.

Through my daughter, it was so much that our late place that my UHS did not serve here, was forced to take us another. (P1)

I had to get one here because it municipalized here, then I would not get treatment without taking this card from UHS here in SSA [...]. Friends like this gave us a house, we had to rent like this to get the UHS card. With the house contract, we took the UHS card. [...] the woman gave us the contract, we hit and went to the neighborhood post, then I got to take. (P5)

[...]you know, they know, so I came to question why as I was in need of treatment, then I talked about the card, then they: "Ah, you are carefree because there most people think they do too so they can take it here". (P5)

[...]it was that damn rush to get internment because my UHS card there, I had to change do with the address here, if I did not, could not. [...] with my sister's address. (P6)

Difficulties were found for regulation in almost all speeches and of the nine patients interviewed, six expressed having made the change of address to gain access to treatment, some advised by the health department itself.

DISCUSSION

According to the National Cancer Institute, cancer is named for a group of over 100 diseases that have in common the disordered growth of cells (malignant), which invade tissues and organs and can spread, causing metastasis throughout the body.¹⁰ Since the 1930s, cancer has become a public health problem and, because of this, a group of doctors, led by Professor Mario Kroeft, had the initiative to think about how to prevent and control the disease. It is pointed out, however, that an action in this sense only occurred effectively after the creation of the Unified Health System, regulated by Law 8.080 / 90, where regimental structures and guidelines were updated, as well as the actions were expanded in the scope of prevention and control of cancer.¹¹

In addition, currently the specific legislation in force is Ordinance 874, which established the National Policy for the Prevention and Control of Cancer in the Health Care Network of People with Chronic Diseases within the Unified Health System (UHS). It is revealed that one of the guidelines of this policy concerns prevention and early diagnosis, which is the detection of the disease at an early stage. These actions are included in the lines of care and comprehensive care that should be offered in a timely manner, allowing continuity of care.

Prevention at the primary and secondary levels of care is related to the incidence and mortality rate for cancer in Brazil: "The care lines are strategies for establishing the care pathway",

where the guarantee of care should be prioritized.¹²

The challenges for comprehensive health care are initiated by the work process in the basic network, which is thus added to the other care actions.¹³ They also state that most health problems can be resolved at this level of care, as well as the possibility of preventing serious problems that depended on hospital-level care; and as far as cancer prevention and early detection is concerned, the disease discovered early in life has a good chance of treatment and cure.¹⁴

INCA has established as a proposal for prevention and early detection of the most prevalent types of cancer, actions to control smoking and other risk factors, health education in schools, in the workplace, in care units and preventive periodic examinations.¹⁵ In addition, breast cancer campaigns (Pink October), which offer mammograms and prostate cancer (Blue November), in addition to consultation with the urologist. It is emphasized that these campaigns help to disseminate information and guidance, however, these isolated do not fulfill their main objective, which is early detection. Together with these campaigns, it is necessary that the population have access to the results of relevant examinations and referrals, if necessary.

Barriers to prevention and discovery of diagnosis are directly linked to public health barriers. The health system presents many weaknesses with regard to people's access to care, whether urgent or emergency or in basic health units. The study addresses the difficulties of access to health services for rural people in the US, similar to those of health services in Brazil. There are difficulties related to cultural and financial difficulties, restriction of service provision, doctors inside and longer delay for diagnosis and treatment.¹⁶

With regard to access and barriers in the health care of cancer patients, the findings of this study, which highlights the context of a person who also permeates public and private health services, are reaffirmed due to the deficiencies of the various care networks in which it should be inserted, Primary Care, Oncology and Stork Network, thus establishing the relationship between public and private health.

In this context, it is described that private service providers, often "in a double militancy between public and private", are also responsible for regulating access, that is, the professionals inserted in public services direct the patients to access the private service as a continuation of treatment, crossing the barriers found in the public service.¹⁷

This situation is believed to be an important contradiction that permeates health as a right of

all and a duty of the state because this system is in a neoliberal economic context, which emphasizes the minimum state and the growth of private enterprise. This context is thus discussed as the incentive of the public health sector before and after the UHS, reaffirming these contradictions that permeate this scenario between public and private health.¹

The scenario described here becomes the difficult reality of many citizens who seek in their daily lives to solve their health problems, seeking various survival strategies as an escape from the gaps found in the public health system. It is, in this sense, to discuss the "maps of care", highlighting the frequent use of public and private resources in the paths of these people, the different formats of the public and private mix that permeate the official care path.¹⁸

It was observed that users build true "maps of care", based on practical knowledge from their own experimentation and observation of how to get access to care that they evaluate as necessary, using the medical-hospital-ambulatory apparatus, whether public or private, in a creative and combined manner, depends on your capabilities and / or resource controls, such as having a health plan or personal contacts and knowledge, for example.¹⁸

It is demonstrated that another issue brought by the author and also quite significant in this research were the contacts and personal knowledge, since the conclusive diagnosis and treatment of cancer are at the high complexity level and involve surgical procedures, biopsies, chemotherapy treatment, radiotherapy, hospitalizations, prolonged use and even the use of expensive drugs; Therefore, it is the type of treatment of a long and very expensive period, which makes it difficult to keep it in private, as was seen before the strategy for the discovery of the disease. It is noted that this condition is also cited in another study, about cervical cancer, late diagnosis, difficulties to perform tests and biopsy are the main problems faced for access to health services.¹⁹

Given the context, another possibility presented by respondents to achieve access to health is presented, which was the support of well-known politicians; physicians who attend privately and who are aware of the patient's situation and, through "contacts", get care for them; help from friends and acquaintances with some kind of political influence.

Another discussion by Almeida and Lima, 2015, addresses health and the Brazilian territory, the challenges of regionalization in a federative country, with a large number of municipalities, with significant regional inequalities and care gaps. Also highlighted by the authors, in their research, the public and private relationship

within this health system and its relationship with regionalization.²⁰ Added to these are the characteristics of the Brazilian health system, which is made up of public and private entities that must be taken into account in shaping the regional system. It is understood that the determinants of the regionalization process go beyond the health sector and that other territorial structures and economic, social and cultural factors must be taken into account in the formulation of intersectoral and regional development policies that favor the strengthening of regions in health and the reduction of territorial inequalities.²⁰

It is necessary to reflect on this situation, since private health services, which should only be a complement to the UHS, are now seen as the “resolution” for those people who need a resolution as soon as possible, but due to the fragility of the system, the option is to look for a private health service, reinforcing the stigma that the UHS is for those unable to pay for health. Everything is validated in this context of sickness and race against time for these people when life is at stake.

With regard to the UHS card modality and the organization of the Unified Health System, it should be made available to the population in a regionalized and hierarchical manner, with single direction in each sphere of government and ensuring the integrality of the actions in an integral way. Regionalization, one of the UHS guidelines, is gaining greater bias, starting in the 2000s, when the Health Pact was launched in 2006, and later Decree-Law 7508 of 28 June 2011, where this principle becomes an important point on the managers' agenda.²¹ Thus, it is determined by Decree 7.508 / 11, that the UHS should be formed by a regionalized and hierarchical network and that the health care network must guarantee a set of actions and services articulated, at increasing levels of complexity, ensuring, thus, the integrality of health care.²²⁻²³

With regard to the treatment of cancer by UHS, it is evident that, for citizens to have access to care, they must be registered in one of the units for cancer treatment, which are classified in High Complexity Care Centers in Oncology (CACON), which offer specialized assistance for the diagnosis and treatment of all types of cancer; High Complexity Oncology Assistance Units (UNACON), which provide specialized assistance for the diagnosis and treatment of the most prevalent cancers or the High Complexity Oncology Reference Center, which are designated to perform the auxiliary role of UHS manager, in cancer care policies. Therefore, it is necessary that this person already has the conclusive diagnosis of the disease through the pathological examination.

According to regionalization, as well as the pacts between the various municipalities, those who do not have the necessary care in Oncology or other specialties need to refer patients to be treated in the nearest and agreed municipalities. It is clarified that the UHS card is the instrument used to identify the citizen and the domicile location so that it is regulated to have the necessary care. The legislation foresees that the health care network in UHS guarantees health care in a decentralized, intersectoral and integral way, with relevant services and procedures to ensure the resolution and comprehensiveness of citizen assistance.²⁴ Decentralization should be directly related to early diagnosis and prevention, understanding that this principle facilitates the internalization of actions and must still occur in the municipality of origin of this person.¹¹ However, “as we travel through the cancer network of the State of Bahia, we realize that the processes of building this network produce a series of barriers that impose on users the production of their access keys”.^{17: 94.}

It is found in research conducted in another context that there were also results very similar to the reality described here, because people sought the same strategy, in this case, to achieve all cancer treatment (Radiotherapy and Chemotherapy) in the same municipality; the case describes the situation of a mother contacting a particular association looking for someone to give her the local address through a water bill or voter registration procedure to be able to follow treatment.¹⁷ It is noticed that the behavior adopted by these people is very common due to the fragility of the system and the gaps that exist due to the poor resolution of health problems.

It is inferred from the various reports described that there is the creation of a network that is not formally foreseen, but that enhances lives. It is believed that, although there is a formal organization of the health care network, there are also encounters, affects, interferences that create other possibilities for walking in this network, showing that these networks are alive⁷ and, although not recognized, is a path possible access: “Networks are in fact produced and re-signified at all times”.^{17:97}

Therefore, it can be said that there are formal networks and “living networks”, the latter formed by the various circumstances, extrapolating what was established by law “not in overlap, but in a singular, rhizomatic and constant construction”.¹⁷ It must be considered that there is the production of a living region, which requires the recognition that not only managers and providers establish regionalities, but that different actors produce them, far beyond the formal health regions.¹⁷

It is warned that the situations described here are elements to think about the way the health

care network is organized, its weaknesses, the gaps that make people seek various strategies in search of health care or could even even say survival. It is understandable to hear these stories, which are true pilgrimages, that the daily life of these people is very far from what is foreseen in ordinances and laws, as there are many paths taken, all of them with many stones that must be overcome one by one to reach the ultimate goal: a health treatment with the hope of healing.

CONCLUSION

It is inferred, considering all that was addressed in this article, that there are major gaps with regard to health care in UHS, specifically regarding the diagnosis and treatment of cancer of people living in the interior of the state, and that, despite If there is organized legislation, it has not yet been implemented.

It is pointed out that when cancer is discovered in the early stages, the chances of cure are much higher, however, in this research there were reports of people who discovered the disease when there was already a severe and disabling symptom due to difficulties of access to health.

In addition, there are many problems for access to health in primary care, which is of fundamental importance for early diagnosis, and even at high complexity levels, such as emergencies and emergency units, there is no careful care, as symptoms are treated, but there is no diagnostic investigation.

It is analyzed that there are several barriers faced by people with cancer, from diagnosis to treatment, and they, fighting for life, have time as their biggest villain. For these, survival strategies are sought, among them the “living networks”, leaving the formality of the law and informally seeking access to health.

The prevention and control of cancer is needed from a comprehensive and decentralized health care network that is effective at all levels of system complexity, promoting health promotion, prevention and recovery, however, it is possible to understand that the daily lives of these people are far from what is foreseen in ordinances and laws. There are many paths for these people, all with strategies that seek only one goal: access to health and the possibility of cure.

This article sought to contribute to elucidate the need for improvements of this system with regard to its effectiveness. It is understood that, through studies, it is possible to add knowledge and illustrate the reality of health. Thus, there are subsidies to fight for the improvement of public health in the country.

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