Therapeutic itinerary of elderly cancer survivors

Itinerário terapêutico de idosos sobreviventes ao câncer

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Abstract

Objective: To identify the therapeutic itinerary of elderly cancer survivors since detection of signs and symptoms until the end of treatment.
Methods: Qualitative research with four elderly cancer survivors (two prostate cancer and two breast cancer patients), two men and two women aged between 73 and 81 years. Data collection was carried out through interviews developed in five visits to the collaborator's households and with duration of 15 hours on average. Thematic content analysis was used.
Results: The journey experienced by the elderly starts with the discovery of signs and symptoms; the course towards the diagnosis in the Health System; the confirmation of cancer; surgery and chemotherapy and the inclusion of complementary and alternative practices in the itinerary.
Conclusion: The health care for cancer survivors demands intense articulation of the health system. In that sense, knowing the itinerary becomes a mechanism to qualify this assistance.

Resumo

Objetivo: Identificar o itinerário terapêutico de idosos sobreviventes ao câncer, desde a detecção dos sinais e sintomas até o final do tratamento.
Métodos: Pesquisa qualitativa com 4 idosos sobreviventes ao câncer (dois de próstata e dois de mama), dois homens e duas mulheres, com idades entre 73 e 81 anos. A coleta de dados foi realizada por meio da entrevista, com 5 visitas no domicílio e duração média de 15 horas. Foi realizada análise de conteúdo temática.
Resultados: O percurso percorrido pelos idosos vai desde a descoberta dos sinais e sintomas; a caminhada para o diagnóstico no Sistema de Saúde; a confirmação do câncer; a cirurgia e quimioterapia e a inclusão das práticas alternativas e complementares no itinerário.
Conclusão: A atenção em saúde para pacientes sobreviventes ao câncer demanda intensa articulação do sistema de saúde, nesse sentido, conhecer o itinerário torna-se um mecanismo para qualificar essa assistência.

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Introduction

In Brazil, research on health systems and on decisions that individuals make when they fall ill are still incipient. Currently, oncological studies have focused on biomedical processes related to the diagnosis and treatments and on the knowledge about adaptive reactions to diagnosis and treatments, with lower investment in post-treatment or survival phases. The paths traveled in the search for solutions to health problems are generally little known. This theme is not a priority in health, and it is rarely present in the concerns of researchers, managers and policy makers.(1)

Therapeutic itinerary refers to the journey patients experience in the search for treatment in which individuals or social groups choose, evaluate and adhere (or not) to certain forms of assistance.(2) Elderly people will define their path from an array of possibilities marked by distinct, individual or collective, and sometimes even contradictory projects.(3) Knowing these paths requires reconciling aspects of health care to the elderly, as well as identifying the cultural universe of these subjects experiencing a phase marked by complexity, diversity and transformation in which decision-making and choices are necessary.(4) To the extent health requirements of the elderly are intensified, it is essential that professionals who provide their care develop an attentive look towards the journey that the elderly need to pass in the pursuit of solving their problems within therapeutic itineraries.

In this context, the study aims to identify the therapeutic itinerary of elderly cancer patients from detection of signs and symptoms until the end of treatment. We believe that knowing the itinerary of elderly cancer survivors will allow a better understanding of health and illness processes and the building of relationships in time and space. This information may deepen the debate on the development of lines of care with more integral and humanized approaches that may strengthen individuals and guarantee the right to health.

Methods

This is a qualitative research focused on the method of thematic oral history. Oral history is defined as a social practice generator of changes, as it modifies the focus of the experience itself and reveals new issues and can overcome emotional barriers such as those found in the experiences of the elderly during and after cancer treatment.(5)

The research took place in a city in the west of Santa Catarina. Four elderly were the collaborators of the study: two prostate cancer survivors aged between 76 and 81 years, and two breast cancer survivors, one aged 73 and the other, 74 years. Collaborators were selected by the following criteria: residing in the city of the study; aged over 60 years; having evidence of cancer through biopsy diagnosed as breast cancer or prostate cancer; having knowledge of the diagnosis and treatment performed; having survived more than five years after completion of oncological chemotherapy, radiotherapy and/or surgery, without signs and symptoms of cancer recurrence. All were initially identified in medical records in the reference oncology outpatient clinic of the studied city and, subsequently, telephone calls were made to start the field work.

In-depth interviews were used as data collection instrument. This included guiding questions about the diagnosis of cancer; the first day of treatment; all stages of treatments performed and experiences that participants had throughout this journey; access difficulties to and the possibility of being under any kind of monitoring. Five meetings with each collaborator were held. The first meeting aimed at the initial approach; the second, third and fourth meetings consisted in the interviews; and the fifth meeting was held for validation of interviews. A total of 15 hours on average were necessary to complete each interview. Data collection was conducted from November 2014 to January 2015.

We chose thematic content analysis as method for analysis of information. This was carried out in three stages: pre-analysis, material exploration and treatment of results and interpretation. The analysis unfolds in three phases: *pre-analysis* - phase of organization and systematization of ideas by resuming the initial assumptions and objectives of the research and developing indicators to guide the final interpretation; *material exploration* - raw material data are encoded into units of records to reach the core understanding of the text and a pre-categorization is proceeded; *processing and interpretation of results* - phase when analytical categories based on the surveyed information are developed, when the researcher proposes his inferences and conducts the his interpretation according to the theoretical framework and the proposed objectives, or identify new theoretical dimensions suggested by reading the material.(6) Collaborators self-identified themselves by adjectives related to coping mechanisms, as follows: Strength (76 years), Faith (81 years), Family (73 years) and Determination (74 years).

The research project was approved by the Ethics Committee of the Chapecó Region Community University (Unochapecó) under Opinion nº 909 718, of December 9, 2014.

Results

The figure 1 represents the journey experienced by the elderly in the search for diagnosis and treatment; initially, how they discovered the signs and symptoms, the search for diagnosis with consultations and examinations, the confirmation of the diagnosis, the surgery, chemotherapy, radiotherapy and hormone therapy, the impact of this treatment on their lives and their experiences with complementary and integrative practices in this process.

After analysis of the empirical material, summarized in figure 1, five themes emerged:

1- Start of therapeutic itinerary: discovery of signs and symptoms;

2- The journey in the search for diagnosis in the Health System: moves in the therapeutic itinerary;

3- Confirmation of the diagnosis of cancer: experiences in this stage of the therapeutic itinerary;

4- And now? Surgery, chemotherapy, radiotherapy and hormone therapy: complex stage of the therapeutic itinerary;

5- Alternative and complementary practices: part of the therapeutic itinerary.

Discussion

1- Start of therapeutic itinerary: discovery of signs and symptoms

The search for a therapy begins with the realization that something is not right, usually translated into physical manifestations that generate discomfort. At this stage, the individual and their families begin to reflect on what might be causing this symptom and seek ways to obtain the "diagnosis", starting the search for care and treatment. From that decision, choices are generally those that make sense for each person, they are anchored on previous experience, always provisional and under constant evaluation. At this point, there is no single path. Each subject makes choices within the possibilities they see. Paths are multiple and different.

The signs and symptoms were perceived by three of the four collaborators (Strength, Faith and Family). Among the signs and symptoms of breast cancer, the most common is the nodule (lump) in the breast, with or without pain at the site, as was the case of Family:

In October 2003, while taking a bath, I did breast self-examination, I felt a small lump in the right breast, it was very tiny, the size of the tip of a finger. So I thought it could be something more serious [...] although I was worried, I waited about 15 days, I kept it to myself, I did not tell anyone. (Family, 73 years).

The recognition of a body sign or symptom depends on the perception of individuals and on their previous knowledge. Before the fear of the disease and perhaps the lack of pain, Family did not take the detection seriously, she procrastinated searching for medical care - a frequent behavior among people, regardless of social class.(7)

As for prostate cancer at an early stage, this has silent evolution: some patients do not manifest any specific symptom; others just find it difficult to urinate or need to urinate more often during the day or night,(8) as it is the case of the collaborators:

In 2005, when I was 72 years old, I already lived in Chapecó, then I began to feel severe pain and diffi-

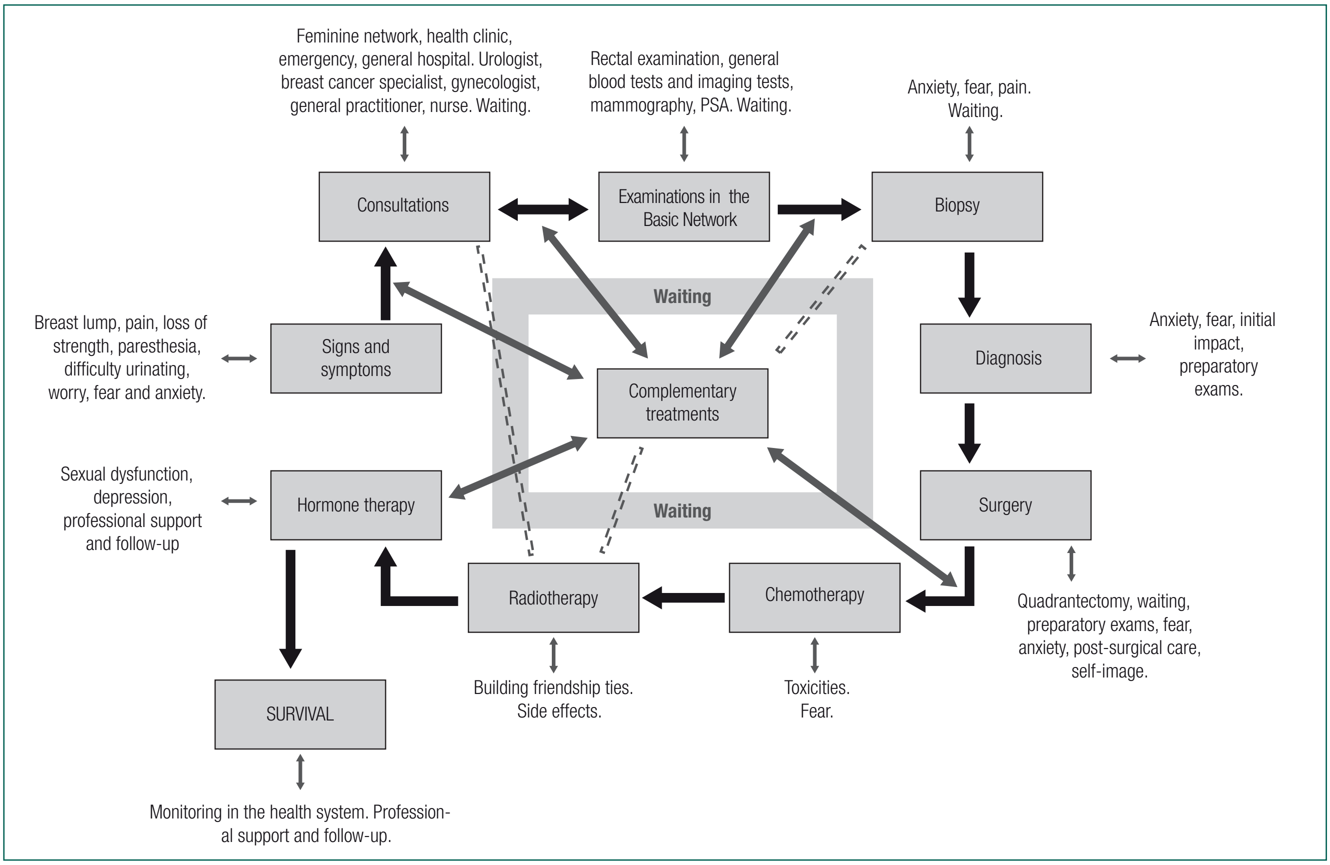

Figure 1. Path taken by the study collaborators while seeking care in the health system

culty to urinate; I would wake up four, five, six times at night, the urine would "stuck", I felt all those same symptoms the first time, I was very worried [...] (Faith, 81 years).

The study collaborators are elderly, and age is a recognized risk factor for prostate cancer - in fact, the only risk factor well established for development of this cancer. The incidence of prostate cancer is linked to the aging process. This has become the most common type of cancer among elderly men; approximately 62% of diagnosed cases worldwide occur in men aged 60 or older. With increasing life expectancy throughout the world, it is expected that the number of new cases of prostate cancer increase by nearly 60% by the year 2015.(8)

When the collaborators identified or felt something different, they took different paths to search for diagnosis. Along the way, the relationship established with health professionals can facilitate or not the acceptance, adhesion, adaptation and decision making regarding treatment.

In the case of collaborators of this study, we identified that Family, Faith and Strength sought aid in the Public Health System, while Determination choose annual monitoring in the private system. Identification of signs and symptoms and the initiative to seek care are part of the therapeutic itinerary, and this consisted in the way how each collaborator sought assistance and care.

2- The journey in the search for diagnosis in the Health System: moves in the therapeutic itinerary

Collaborators followed different paths in the run-up to diagnosis, marked by laboratory and imaging tests required in soon after the onset of signs and symptoms. The searching paths, production and management of health care undertaken by individuals and families follow an own logic and are woven in multiple health care networks, in order to ensure support during the experience of falling ill.(9) Reconstitution of the therapeutic itineraries of elderly cancer survivors presented in this research brings forth a reflection about the functioning of the health care network. The experiences of older people in the search for meeting their needs showed how services are organized to serve this population.

Faith, for example, sought help to solve his health problem in the Basic Health Unit (BHU) in his neighborhood:

[...] I went to the health center here in my neighborhood, where I used to go, but the doctor did not even look at me, he did not give me much attention, he asked blood tests and an ultrasound and told me to bring them to the specialist of the health secretariat, who was urologist. (Faith, 81 years).

What calls attention in the report is the lack of a welcoming and empathetic attitude of health professionals towards the user. In this context, we agreed that the welcoming hosting is not an isolated practice, but a set of actions that translate into attitudes that professionals adopt while interacting with their patients in health services.(10) In this perspective, the reception becomes a point of intersection between different subjects and care practices in primary care. It is clear that dialogue was not meaningful during the meeting between the collaborator Faith and the health professional. The need for dialogical hosting in health work is essential for providing an effective comprehensive care.

In the case of Strength, it is important to note that the hospital represented the public service sought by him and his family, according to his need of care:

[...] I felt a damping and loss of strength in the legs, was when I was in the bathroom shaving, then I could not move, I came from the bathroom crawling, and stayed on the couch waiting for my son. When he arrived, he took me to the hospital. [...] The next day I went to the health center in my neighborhood and there they referred me to see the urologist [...] (Strength, 76 years).

After entering the hospital emergency room, Strength was sent to a BHU. Many people return to BHU for lack of resoluteness and due to failures in the guidelines, to adopt a treatment, or even to carry out a proper assessment. (11)

Collaborator Determination followed a different path: ass she had a health insurance plan, she appointed a consultation directly with the gynecologist:

I did not try the primary care network, I did not look for SUS. At the time, as an employee of the state, I had health insurance plan, and I thought this was the fastest way because I was aware of many stories, many facts that there is a delay in setting up appointments and receiving care by the SUS [...]. On the mammogram, there was a lump in my right breast. In the first appointment with the breast cancer specialist, he actually said that there was something different, and even though I had no symptoms, we would have to investigate that; then he scheduled a biopsy. (Determination, 74 years).

The collaborator demonstrated a lack of confidence in the public health system. There are individuals who openly state they prefer using private medicine or health insurance plans because they believe their problems are solved more quickly and effectively in this system. They express a negative evaluation of the provision of care in the public sector.

For diagnosis of cancer, a biopsy is performed. During and after this examination, the collaborators reported different experiences and sensations. Strength felt pain and discomfort at the time of biopsy:

What I did not think was a good experience was this biopsy; at first it did not hurt at all, but then at the end, I felt a lot of pain. They took 12 pieces of my prostate, I could not take it anymore, I suffered, my vision blurred because of the pain. This stressed me a bit; no one likes to feel pain. I felt fear of pain, sadness for having to go through that, besides the concern, because it could be something complicated; if things were all right, of course I would not have be doing all those exams, all that mess. (Strength, 76 years).

The pain during the procedure is associated to two reasons: the input of a transrectal transducer and the needle penetration in the prostate capsule. Because of this necessary but painful procedure, it is important to make use of analgesia or anesthesia to reduce the discomfort and thereby increase the number of samples taken and the success of the procedure.(12)

For Family and Determination, this moment was marked by the search for definition of the disease and diagnosis:

As soon as I entered the room, she promptly asked me "Are you afraid of needles?" I said: "I do not think so." I felt a little prick, it hurt [...]. This medical expert examined, touched and felt the lump that was there, at that very moment she asked the ultrasound, took another piece to remake the exam, she herself sent it for biopsy *(Family, 73 years).*

I did this procedure [biopsy]; eight days after consultation, in a radiology clinic, I went with my sister to the biopsy, I felt pain, mixed with concern, fear, insecurity, uncertainty, sore [...] (Determination, 74 years).

The biopsy is the apex of the path taken towards the definition of the diagnosis in the therapeutic itinerary.(13) Patients showed signs of anxiety, anguish and helplessness. The period of diagnosis can be quite traumatic, especially if it is prolonged or ends with the confirmation of the disease.

In general, a flow is observed in the study collaborators that starts in the BHU, from the suspicion of cancer, and follows with referral to specialized services of medium complexity in the municipality patients live for diagnostic investigation, and then to Reference High Complexity Oncology Centers (CACON) to confirm the diagnosis, staging and treatment. In practice, we see that formally provided references do not always correspond to the actual network designed for users with cancer in their search for care. Other flows and new references appear as a way of overcoming the difficulties of access, as it was the case of Faith, who sought private care to solve his health problem:

I did the tests and after about twenty days, when I took them there [health secretariat], they told me that the urologist who would see me was on vacation [...] I would have to wait and I waited, I waited for almost one year, it was then that things got complicated, because the pain and the symptoms got worse too. It was like this: I would go there every three months to see if he had returned from vacation, and nothing, I went there and he was never there, he was a long time on vacation! I knew there was something wrong. During this waiting period I never mentioned to anyone about what was happening to me, I kept that just for myself; I would simply go by myself to the doctor. I would not tell anyone because I was ashamed, I did not want to bother, to bother anyone, but I was more for shame. I was in a very difficult moment, waiting, holding up all those symptoms [...]. It was then that I, I was very angry and I did it on my own, I went to the doctor's office, the urologist who operated on me the first time and that was the best thing I did, got tired of waiting! (Faith, 81 years).

The difficulties to access medium complexity services, that is, specialized consultations and examinations represent one of the great challenges of the SUS.(14) The resoluteness of primary care is associated with issues related to the physical structure of the services, processes and management of work and professional training, which, in turn, have repercussions on the demand for specialized services.(15) Hence the importance of knowledge and interpretation of the therapeutic itinerary; this help professionals and managers to become aware that the ways pre-established in service networks have not always been effective and they do not always work. The collaborators' search for the diagnosis shows that these needed to exercise the ability to elaborate coping mechanisms to overcome health disparities, not only in the sense of detecting them, but to overcome them in a context of large heterogeneities and inequalities within the health system.

3- Confirmation of the diagnosis of cancer: experiences in this stage of the therapeutic itinerary

Of four collaborators, three were informed of the diagnosis of cancer. One of them, Faith, did not received the information of his diagnosis: even being aware that he was undergoing treatments for cancer, he was not informed by health professionals neither by his family about his health condition. The impact of the diagnosis and the experiences in this phase will be explored below.

The collaborator Strength had mixed feelings when he received the diagnosis:

I got a bit scared, it was a shock because nobody wants to have this disease, but thought I had to go on, face this obstacle just as I have faced all in my life. Of course, deep down we feel fear, it was an unknown thing for me, but I never lose my balance for the problems of life, I was always the type that to goes forward without looking back. (Strength, 76 years).

Upon receiving the diagnosis of cancer, a disease that brings so much suffering and worries, it creates a deconstructive situation, not only for those who are for it affected, but for everyone around you, once you see surprised for a moment of great stress, which generates behavioral changes and puts the subject in front of a new stage of life, the unexpected beginning. We can assume that the diagnosis of cancer triggers various reflections and feelings, which, influenced by previous experiences and individual differences, result in unique behaviors of adaptation to face the stress and anxiety caused by this moment.(16) (Determination, 74 years).

The moment of diagnosis was very difficult, I thought it was something that would never happen to me, it was a mixture of fear, doubts about what would happen, on how would be the future, all came to my mind, and at the same time I wanted to show confidence for my family [...] so I tried to show that it was nothing, but inside, I had many fears, many fears! At the time I felt that fear of cancer, I am human [...]. The word cancer *scared a little my children and the other family members; it was very scary because I was always the strength in the family.*

When you receive a diagnosis of breast cancer, women face the prospect of an uncertain future, in which the fear of death and mutilation prevails. We experience a time of contradictory and intense feelings, in which fear, anger, uncertainty and even acceptance become part of the everyday life. Another important aspect to be discussed is how the diagnosis of cancer is released to the patients and their families by medical professionals:

The day of consultation had arrived, I was curious, I wanted to know the result, my chest was very tight. My older daughter, who always accompanied me in everything, she was with me; getting there, the urologist gave us the news that it was cancer, I would have to take some injections and undergo radiotherapy. (Strength, 76 years).

[...] So I said: "Doctor, do not tell me it's cancer!" And then she said: "Yes, it is cancer, but I do not know the type, I have to tell you, I cannot hide this from you." [...] My husband was out there waiting for me, I left the office frightened, giddy, could not feel the floor, got in the car, and he was worried, he asked me what had happened, I said: "Do you know what I have? It is cancer!" At that moment, we felt a mixture of fear, sadness, it seemed a nightmare. (Family, 73 years).

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Delivering bad news as the case of a diagnosis of cancer is an extremely complex issue and requires preparation and sensitivity.(17) So, planning how the disclosure will occur can make it easier for health professionals to provide the flow of information, as well as how to best do it. Revealing the diagnosis in fast manner and in a place that restricts the possibility of dialogue is far from being the most appropriate way to disclosing such information, as pointed the reports of the study collaborators.

The non-disclosure of the diagnosis produces discomfort and distress, as in the case of Faith (81 years):

Nobody told me anything, neither the doctor nor the family, I suspected something, because I thought "they are not doing all of this for no reason". The urologist did not tell me it was cancer, neither the radiotherapy doctor. They never told me anything. But I knew it because it was written there. It was a place of treatment for cancer... And then, I would see and talk to all the other patients undergoing treatment, radiotherapy, there were ninety or a hundred people there for treatment, and then everyone would speak of their problem [...]. I was anxious, I knew my diagnosis, I had doubts, but I did not ask anyone about it, I was always quiet, I *was raised that way. This doctor [the oncologist] said it was nothing, but I knew and he surely also knew that I had cancer, he knew it, he should have known, right ?!*

Often, even because of family pressure, a dilemma of telling the truth or not for the elderly patients takes place. This aims to spare them from suffering. In fact, the main issue is actually the most appropriate way of communicating the diagnosis, because, when there is no communication, patients do not have their right of autonomy assured. This refers to the right patients have to decide whether or not to perform a treatment indicated by the health professionals, except in cases where their cognitive function is impaired.

Elderly cancer patients cannot be mischaracterized, deprived of the information on their diagnosis, on the proposed treatment and the care needed at this stage of life. It is understood that open dialogue can strengthen the link between patients and professionals, besides dignifying the human being by recognizing their autonomy and power of decision-making about their own lives.(18)

Confirmation of the diagnosis of cancer can trigger suffering that tends to affect people's universe of relationships. It can lead them to become closer or to move away from those around them, as well as to face in different ways the coming treatment steps.(19) Even in times of sorrow, distress, and great stress generated by the waiting period and by the confirmation of the diagnosis - or even if the case of Faith who was prevented from learning the diagnosis as formalized news - none of the collaborators was undeterred or gave up face the next steps; all adhered to the forms of treatment proposed and, from that, they chose to give continuity to their itinerary.

4- And now? Surgery, chemotherapy, radiotherapy and hormone therapy: complex stage of the therapeutic itinerary.

At this stage, collaborators enter high complexity contexts and perform treatments in High Complexity Oncology Center (CACON) in the municipality where the study was conducted. With regard to cancer care, the high cost of treatment must be considered. It is known that most cancers in Brazil are diagnosed in advanced stages, which leads to greater concentration of interest in providing high complexity services and resulting in low patient survival.(14) Among the various ways to treat cancer are surgery, chemotherapy and radiotherapy. The way elderly survivors experience these therapeutic moments will mark their life story.(20)

Among the four collaborators of the study, the elderly who had prostate cancer were not submitted to surgery. As for the two women, after diagnosed with breast cancer, they underwent quadrantectomy. It is noteworthy that Strength performed transurethral resection of the prostate (TURP) with negative biopsy for cancer in the period before the diagnosis of cancer.

Oncologic surgery is a cause of much anxiety, uncertainties and fears,(16) as expressed in the following account:

Surgery was an important moment for me because I thought I could "die on the table". I couldn't wait to do the surgery; from that stage on, I got better, it seems that they had taken that "thing" out of me. (Family, 73 years).

Women who undergo mastectomy face a whirlwind of feelings such as fear, apprehension and concern, especially in the moments prior to surgery; all promptly mention the lack of information and awareness about the disease.(21) Another important topic to be discussed in this step of the itinerary is the waiting time for the surgery in the SUS (Family) and in the private network, by the health insurance plan (Determination):

Five months after discovering cancer, I had the surgery. (Family, 73 years).

[...] between the discovery and the surgery, it probably took thirty days. (Determination, 74 years).

Specifically in the case of breast cancer, among other recommendations, INCA indicates that treatment should begin as soon as possible and not later than three months after the confirmation of the diagnosis. To carry out the complementary chemotherapy or hormone therapy, the maximum period should be 60 days, and for radiotherapy, 120 days. Delay in the commencement of treatment increases the risk of local recurrence of the disease and decreases survival rates.(22) Delaying the start of treatment brings complications such as increased tumor volume and decreased life expectancy. For the collaborator Determination, who began the treatment process in the supplementary health system, the deadline set by public policy was fulfilled. In the case of the collaborator Family, SUS user, this did not happen.

Among the collaborators of the study, Family and Determination received chemotherapy: the first underwent treatment in the CACON reference of her city; and the second in a supplementary chemotherapy service provided by her health plan. On the experience of undergoing chemotherapy, both highlight the care provided by health professionals during the course:

My first consultation with the oncologist happened a month after surgery [...] I felt well with him, he explained me everything [...] (Determination, 73 years).

In April 2004, I had my first consultation with the oncologist. The doctor said that treatment was necessary to survive and in order to stand chemotherapy, I would have to be very strong; the doctor was very kind to me. (Family, 74 years).

Proper communication in chemotherapy units provides comfort, soothes the mind state, relieves symptoms, and reduces anxiety of the unknown.(23) Conversely, the noise coming from poor communication causes fear, anxiety and other negative feelings. It is essential that health professionals understand and interpret the attitudes of people through the experience of illness, because this information offer a direction for decision making with regard to the care guidelines.(20)

The diagnostic process is the most difficult and distressing period for the elderly. However, after referred to hospitals for treatment of cancer, factors such as anxiety, pain and ignorance of the disease are problems that are far from properly addressed. The time between the first medical care, comings and goings to professionals and the arrival at the referral hospital for oncological care lasts months and generates various feelings of uncertainty, as denoted in the speech below:

Around 10 to 15 days after the first visit, I went to the first chemotherapy session, I was anxious just as the days before this moment, that, in fact, was filled with curiousity: "What would happen? What was that? How is it applied? How is it that I would take it? What reaction would I have? How long would it take?" I was full of questions, doubts and fears. (Determination, 74 years).

The waiting time is a factor that concerns cancer patients, reverberates psychically, accelerates the disease process and reduces the chances of cure.(24) All collaborators of the study underwent radiotherapeutic treatment and reported preparation, expectation and anxiety for starting such treatment, as recorded in the following report:

[...] before radiotherapy, I got a tattoo, I actually have three, which are some dots that I still have, one on each side of the hip and down from the waist, that was for them to know exactly where they should apply treatment and after a month of preparation I made my first application of radiotherapy [...] (Strength, 76 years).

It is understood here that the experience of oncological radiotherapy represents to these patients the need to undergo a form therapy with drug-poison characteristics. This causes fear, but it is necessary if the goal is to get cured or even survive cancer.(25) Generally, after passing this stage, patients have the impression that they are strengthened and won one more barrier and this, in turn, facilitates adherence to treatment.

After I finished the last application of radiotherapy, I had the impression that I had woken up to life; I remember I got home and began to see things differently, I asked my family, "Why haven't you painted this house anymore?!" It was like I had waked up! I returned to be Family! (Family, 73 years).

For Determination, moments experienced in radiotherapy led to occasions of support and of building new relationships:

Very interesting that when I finished the treatment of radiotherapy, I always had the impression that I needed to go for radiotherapy, needed to go at that time, needed to be with those people. I remember I had difficulties to leave those friendships I made during treatment. I think I felt this need because being with people in the same situation used to make me feel safe, they had the same problems, the same fears. I identified myself with them, for eight to ten days I wanted to go there, I still missed going there, something was missing. (Determination, 74 years).

Study that aimed to understand the meaning of oncological radiotherapy to ten patients of both sexes noted that the symbolism of radiotherapy is built little by little, as informants perform the treatment sessions. This process contributes to the understanding of all aspects comprising the process of falling ill, and those embodied in the experience of undergoing treatment, giving direction to the recovery of the individual and social body.(25)

The individual perception or the one of a group on the disease defines the search for care. In order to understand the health of individuals and the way they face the disease, it is necessary to analyze their practices from the context in which they take form. From the perspective of authors, the demand for care is conditioned to attitudes, values and ideologies, as well as to the profile of the disease, the economic access and the availability of technology.(4)

In this study, even if the radiotherapy had assumed the form of an aggressive moment, collaborators remained active and adhered to the therapy. The decision to stick to treatment came from the construction of such networks and the search for therapeutic care to address their health problems. Hence the importance of social support networks to deal with daily problems, especially regarding the search for health care and the individual's ability to mobilize such resources.

All collaborators of the study underwent treatment hormone therapy. The collaborators Strength, Faith and Family kept under follow-up in CACON, where they continued this treatment considered highly complex. Apparently, collaborators have no difficulty in acquiring the medicine:

In the middle of the radiotherapy treatment I was directed to the treatment with injections in the stomach [anti-hormone therapy]. The radiotherapy doctor referred me to chemotherapy, he gave me a referral order and I went there; and then after two weeks they called for me to see the oncologist. I made eight applications, one per month, always the same, that little prick in the stomach, but it did not hurt much. (Strength, 76 years).

When I reached the middle of the radiotherapy treatment, the doctor referred me to take the shots in the stomach; I waited around ten days for them to call me for this treatment. (Faith, 81 years).

After the anti-hormone Tamoxifen, the collaborator Determination returned to the public health system to receive another anti-hormonal, Arimidex (Anastrozole):

After five years, when I finished Tamoxifen, I started taking Arimidex, which I used for five years, but this one at the time would cost around R$ 400.00 each box. It was when the health plan oncologist explained me that I could receive this medication by SUS. He referred me to the Health Secretariat with a high cost drug request, and soon after, the reply came informing that I should go to the hospital's oncology clinic. This process took about two or three months, and after this time I started to go to this clinic to receive Arimidex, thus, the first boxes I bought and then it was fine, I would get them monthly, always respecting the date they determined. (Determination, 76).

The situation experienced by this collaborator was also reported in another study, whose subjects had difficulty accessing medicines in the supplementary care network, with the need to seek the SUS to give continuity to their treatment. According to the authors, this seems to be one of the main limitations of private health plans regarding the treatment of breast cancer.(26)

A study on therapeutic itineraries observed that patients move between the public and private systems to access health care and many difficulties are present in the coverage of health plans, with eventual need to seek the SUS for medication.(1) In the view of these authors, several arrangements are established in the everyday life of users when they seek, through their own choices or strategies, to overcome the gaps in the access and in comprehensive care. This condition has been also observed in this study, when the collaborator Determination had to move between the public and private health systems.

More comprehensive assessments of care models established for users in the current Brazilian daily care routine are needed to qualify the health care.(20) The investigation of the therapeutic itinerary of the elderly with cancer showed the difficulties experienced by patients in the search for care, starting from the discovery of the disease and extending to the end of the treatment carried out in health services. Often these difficulties are exacerbated with the limitations imposed by age and disease, producing pain to the user and to the family nucleus. In this perspective, they could pursue different strategies and ways to overcome such phase, among them, the complementary and integrative health practices that emerge in the therapeutic itinerary.

5- Alternative and complementary practices: part of the therapeutic itinerary

Complementary and alternative practices (CAPs) are a group of diverse medical and health care systems that are not considered part of the conventional medicine such as homeopathy, Reiki, chiropractic, acupuncture and meditation.(27) These therapeutic approaches point to a view of health understood as broad welfare, which involves a complex interaction of physical, social, mental, emotional and spiritual factors. In this perspective, the human body is understood as an energy field from which different methods can act.(28)

The collaborators of this study sought the application of medicinal mud, Reiki and medicinal teas and supplements in their health treatment during the therapeutic itinerary.

At that time I used to drink lots of tea... and I had faith that things would improve and solve. (Strength, 76 years).

At the end of radiotherapy I was tired, I wanted to be alone, I would come pretty stressed, angry, they had to leave me alone and quiet, so I always took tea to improve digestion; to tell the truth, I had tea all the time, chamomile, lemon balm, fruits; my daughter and my husband would prepare it to me, it helped me and calmed me down. (Family, 73 years).

[...] I did lots of Reiki, Reiki relaxed me a lot [...] (Determination, 74 years).

In order to ensure comprehensiveness in health care, the Ministry of Health created in 2006 the National Policy on Integrative and Complementary Practices (PNPIC) in SUS. This aimed to support, incorporate and implement experiences in the public network, such as acupuncture, homeopathy, herbal medicine, and others.(29)

In addition to the therapies prescribed by health professionals, it is common for patients to seek other care strategies when facing a disease. This search is intended to complement the health care needs and is focused on cultural beliefs directly influenced by individual and family choices.(30) The collaborators emphasized welfare and decreased stress during and after the use of complementary practices, a factor to be taken into account when establishing a health care planning for this population.

Conclusion

During the therapeutic itinerary, the elderly of this study transited between the private and the public health sectors, with more frequent use of the latter, especially of medium and high complexity services. Their reports showed that primary care is not structured to provide care at the stage of survival, which brings forth the need to discuss the organization of health care to patients with cancer before and after cancer treatment, with a view guarantee comprehensive health care in this phase, minimizing human suffering. The health care for cancer patients demands intense articulation of the health system and work of a wide range of services and professionals for the production of comprehensive care. The need for the comprehensive work of the articulated health team towards the patient's families becomes evident.

Elderly cancer survivors faced difficulties in accessing health services when they sought diagnosis and treatment in the public sector. The long waiting times for examinations and consultations are one example. In this scenario, the need to rethink health care for this population seems to be necessary. Investments not only in technological resources and infrastructure but also in human resources and in the organization of work processes are needed, as well as a support network to back up the actions of health teams, not only in the therapeutic course, but after that period, in the survival phase.

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Collaborations

Brustolin A and Ferretti F state that contributed to the conception, analysis and interpretation of data, article writing, relevant critical review of the intellectual content and final approval of the version to be published.

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