



THE THERAPEUTIC ITINERARY – THE SEARCH FOR HEALTH CARE UNDERTAKEN BY A PERSON WITH COLORECTAL CANCER

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ABSTRACT

Objective: Understanding, through the Therapeutic Itinerary, the search for care undertaken by the person with colorectal cancer and the Care Management mechanisms. **Method:** This is a unique case study with a qualitative approach, whose data collection was carried out through the Narrative Interview. To support the data analysis, the IRaMuTeQ® software was used. **Results:** Two Sub-corpus and five classes have emerged, through which it was possible to delineate the therapeutic itinerary and the care strategies from the perspective of the person allowed understanding that the production of care invades non-formal lines, enabling the treatment pathways that were within reach. It is unveiled the lack of a flow that guides the walk in a timely and safe time, with a feeling of insecurity and distrust. Thus, mediators move across and produce against flows in regulation, giving rise to live networks based on facing dead, disjointed and inoperative work. **Final thoughts:** The results made it possible to identify the disarticulation of services and the need to develop an oncological Care Line.

Keywords: Attention to health. Rectal Neoplasms. Continuity of Patient Care.

INTRODUCTION

The appearance of tumors located in the colon, rectum and anus usually develop from polyps that when it is removed early, there's reduction in the risk of malignancy because they are in the early stages, otherwise they can progress to colorectal cancer⁽¹⁻⁴⁾.

Sometimes, the delay in accessing the services of the Unified Health System (Sistema Único de Saúde - SUS) resulting from fragmented care models, associated with the disorganization of care flows, contribute to a late discovery, inefficient referrals and ineffective monitoring of the person affected by this disease⁽⁵⁾.

A survey conducted to evaluate the TI (Therapeutic Itinerary) of people affected by chronic conditions found the inefficiency of cases

in which the service is fragmented, with care provided by a non-resolving Health Care Network (HCN), thus compromising the quality and continuity of care⁽⁶⁾. In the same approach, another study identified that Primary Health Care (PHC) was not the gateway to SUS: in only 34% of cases PHC was the first service to be sought, while in 50% of them were diagnosed in specialized care, when they were already in an advanced stage⁽⁷⁾.

In this scenario, the Care Management (CM) tools, such as the Therapeutic Itinerary (TI) and the Care Line (CL) appear as alternatives to guide, reorganize, optimize, manage the relationships arising from this process, favoring a more comprehensive and fast user experience by the health system, contributing in turn to the observance of SUS principles^(5,8). Knowing the trajectory of users with colorectal cancer can favor

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the strategic improvement of HCN with regard to people with this chronic condition and even for the adoption of these CM tools, having in mind that there are still few studies that reveal the path of this user by SUS.

Given this context, the objective of this study was to understand, through the Therapeutic Itinerary, the search for care undertaken by the person with colorectal cancer and the Care Management mechanisms.

METHODOLOGY

It is a qualitative case study, which allows understanding complex social phenomena, in addition to providing retention of a holistic and real world perspective by observing individual life cycles⁽⁹⁾. Aiming to achieve the proposed objective, this research was based on the investigation of social management and health practices, having as main markers of meaning the singular ways of building networks of existential connections in the search for health care⁽¹⁰⁾. To unveil some forces related to formal and informal trajectories, in the assistance journey, some concepts were sought in cartographic studies⁽⁸⁾.

To choose the case of this study, the following inclusion criteria were established: having experienced a chronic or neglected disease; having passed through SUS; and being over 18 years-old and residing in one of the 19 municipalities belonging to the southern region of Mato Grosso. The participants with infectious diseases that were not part of the residents' care routine were excluded.

The participant was selected intentionally for having participated in the daily practices of the Multi-professional Residency Program in Adult and Elderly Health, an opportunity that provided a strong bond with one of the researchers in the daily care actions, in two specific moments: the first one, in the oncology clinic during the researcher's first year of residency; and the second moment, at the Specialized Assistance Service (SAS) during the second year of residence.

The production of the data took place in May 2018, at the end of the cancer treatment, through the Narrative Interview (NI)⁽¹¹⁾ performed in a single time and previously scheduled through telephone contact. Taking into account the

participant's preference, it was carried out at home and followed the script with the following questions: *"Tell me, how has your trajectory been since you've started to notice the disease? How have you sought help to take care of this problem, including the places you've been and the time to get the [needed] care you needed?"*. The interview was audio-recorded and transcribed in accordance with an educated standard of the Portuguese language to facilitate understanding.

The participant lives in the municipality of Rondonópolis, MT, where she has also undergone her treatment. This municipality was part of the Sul-Mato-Grossense Regional Health, a regional that is reference for 19 municipalities. According to IBGE, it has an estimated population for 2020 of 232,491 inhabitants, predominantly urban (81.9%)⁽¹²⁾.

The data analysis was performed using the IRaMuTeQ® software (R interface for Multidimensional Analyzes by Textes et de Questionnaires) version 0.7 Alpha 2, and using the Descending Hierarchical Classification (DHC) method⁽¹³⁾. The choice of the referred software allowed the classification of the segments of the texts, dividing them into classes based on the function of lexical items, which enabled the graphic representation of the corpus. The classes that emerged were named after interpretive processes⁽¹⁴⁾.

Data collection started after approval by the Research Ethics Committee of the Federal University of Mato Grosso with opinion n°. 2,571,546 / 2018, with the due signature of the Free and Informed Consent Term (FICT), and it was preserved identity of the participant, identified here with the fictitious name of Jasmim.

RESULTS AND DISCUSSION

A 72-year-old woman, retired, middle class, with incomplete higher education, diagnosed with colorectal cancer and who lives with a daughter, participated in this study. She reported that in the two years prior to the diagnosis she had persistent and severe abdominal pain, accompanied by colds and weight loss. During the period in question, she sought the Family Health Strategy (FHS) due to constipation problems, reporting that her complaint was not resolved.

After an increase in the intensity of pain and as a result of the failure to use medicinal plants, she sought private medical care, an opportunity in which she underwent abdominal computed

tomography (CT) and colonoscopy, enabling the diagnosis of colorectal cancer. The graphical representation of her trajectory is shown in Figure 1.

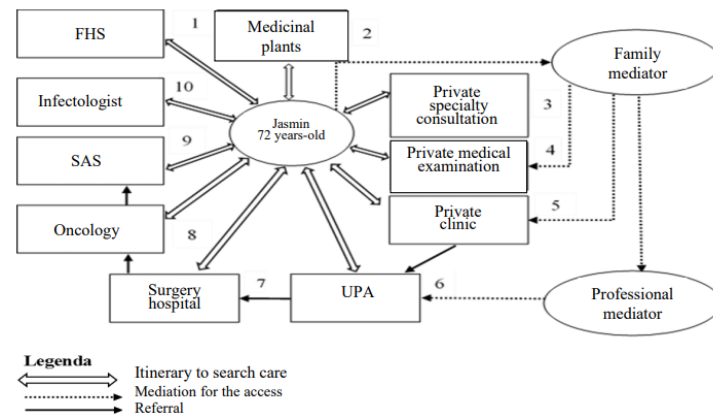


Figure 1. Graphical representation of the Therapeutic Itinerary undertaken by the participant-Rondonópolis, MT, 2018

During the course, it was identified that Jasmine had intestinal obstruction due to the advanced stage of a colon tumor. For this reason, she underwent rectosigmoidectomy surgery, having an infection at the postoperative site of the surgical incision, intensifying her search for care.

Parallel to the understanding of the case through the graphic representation of the TI,

the corpus from the interview was coded and analyzed by the IRaMuTeQ® software⁽¹³⁾. As a result of the textual organization, a general corpus with 85% of the text segments was obtained from the occurrence of 2,281 words - including 563 distinct ones - giving rise to five classes with two branches: Sub-corpus A (before diagnosis) and Sub-corpus B (after diagnosis), as shown in Figure 2.

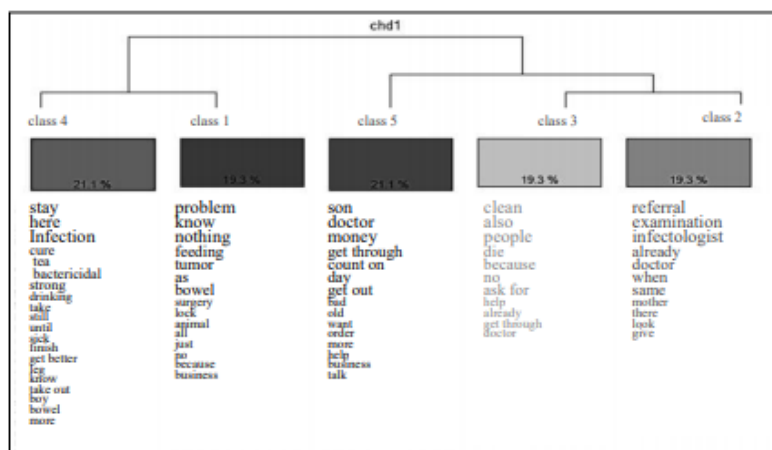


Figure 2.Dendrogram of Descending Hierarchical Classification – Rondonópolis, MT, 2018

Sub-corpus A had two ramifications: IV Class - “Integrative and Complementary Practices” and; I Class - "Trajectory before diagnosis and limitation of care in Primary Health Care". Sub-corpus B, in turn, was subdivided into three branches: V Class -

“Limitations on access to the Health Care Network and Mediators involved in the process”; III Class - "Absence of the Care Line: guidance and support" and; II Class - “Difficulty articulating with Specialized Care”.

The classes will be presented respecting their ramifications and within each one, the order of the largest text segment per breakdown is observed and sequenced from left to right.

Sub-corpus A/ IV Class - Integrative and Complementary Practices

Class IV evidenced the use of medicinal plants in search of relief from suffering at the beginning of the illness.

I stayed here drinking tea until my son got money to pay for the consultation; I was drinking tea [...] I knew that drinking tea was good for inflammation and infection in the intestine. For Crohn's disease, tea is really good, and many friends said it heals, it seemed like it was true[...] (**Jasmim**).

The use of medicinal plants is a very ancient treatment based on the accumulation of information by successive generations⁽¹⁵⁾. The use of these practices in the Jasmim's TI represents an attempt to control the disease externally to the health system, through the inactivity of a SUS that, in the patient's perception, did not work. In daily life, people build bonds and consume different types of care, producing networks of unforeseen connections and which escape the routine established by health services⁽¹⁰⁾.

The use of natural resources appears as a reflection of the lack of guidance from health professionals in the care of Jasmim, which highlights a complex situation that even contributed to the emergence of an infectious condition.

I cleaned it with aloe vera and put it in the anus, a little piece. I had difficulties, but it was worth it, because it cleaned with just three days. On the third day the infection exploded[...] (**Jasmim**).

Although the use of medicinal plants, in this case, has presented reactions (*"the infection exploded"*), they were perceived as beneficial to its treatment. Because they are part of their daily lives, people resort to herbs and medicinal plants, taking a new look at the health-disease process, which makes it possible to promote comprehensive care⁽¹⁶⁾.

In the micro-politics of Jasmim's TI, the use of these resources, added to the poorly resolute response of FHS, exerted contradictory forces with regard to access and conventional treatment.

The patient did not rely on the meeting with health professionals and, on the other hand, took advantage of other connections present in her social and cultural environment, sometimes based on her beliefs. People don't just use health equipment; in the face of institutional barriers and the need to overcome obstacles, as in the case presented, they act as nomads detached from the instituted⁽¹⁰⁾.

Medicinal plants and phytotherapy are part of the practices incorporated into the National Policy of Integrative and Complementary Practices (Política Nacional de Práticas Integrativas e Complementares - PNPIC) of SUS, which in its guidelines highlights the need to develop strategies for the qualification of professionals for the management of PICS⁽¹⁷⁾. However, investments for training must go beyond new knowledge about the PICS: it must be able to enable the worker to predominantly use light technologies, as it is in the field of relationships that the different barriers can be broken to consolidate the access.

Outlining the therapeutic itinerary and the care strategies from the perspective of the person allowed us to understand that the production of care invades non-formal lines, thus enabling the use of the treatment routes that were within reach. This specific case demonstrates the use of medicinal plants from the perspective of popular knowledge and the network of contacts, since the "treatment" adopted by the patient was based on resources that were within her reach and that were suggested by friends and not exactly as a PICS indicated by health workers.

Sub-corpus A/Class I - Trajectory before diagnosis and limitation of care in Primary Health Care

In Class I of Sub-corpus A, CHD indicates the trajectory before diagnosis and the limitations of PHC. For Jasmim, doubts and concerns arise regarding the signs and symptoms of the disease.

[...][...] in 2016, a bowel problem started, it was difficult like that, it wasn't normal, but I have always been dried out and then I went, I should have received care before, because I was already dried out [...] (**Jasmim**).

The path taken by the participant with

colorectal cancer before diagnosis was marked by numerous barriers to obtain relief from her constipation. The logic of successive failed appointments reveals the micro-politics of work, in which an unconventional complaint made by Jasmim is minimized by the PHC team, which is limited to dead work, full of norms and rules for the provision of health care ⁽¹⁰⁾, without being offered to the patient to listen and appreciate the suffering reported by her. The effect of the described practice resulted in the user's subsequent resistance to seek the FHS.

I didn't go to the health clinic, because I knew it wouldn't work, because I went because of constipation and they didn't solve it. We get there and say it hurts, but [...] (**Jasmim**).

People, even when they have strong links with certain health teams, are not exclusive to these places and occasionally transpose and ignore known trajectories⁽¹⁰⁾. In this context, the fact that the user does not seek the FHS, due to the delay in diagnosis, is a problem that unveils the barriers she faces.

The expectation of the person when looking for health services is that their needs are met. In this sense, it is worth highlighting the perspective of the multidisciplinary work of the FHS that provides for integration and coordination of care, with actions for screening and early detection of colorectal cancer in its initial phase⁽¹⁸⁾. Most cases of colorectal cancer evolve from benign lesions that enable early detection and, therefore, the initiation of treatment, which results in greater chances of survival⁽²⁾. In the case reported, the user's withdrawal from the service offered by the FHS occurred as a consequence of not accepting her complaints from a service that did not provide her with the timely and resolute treatment that would awaken her confidence and security.

Although screening for colorectal cancer results initially from the verification of occult blood in the feces, that is, from a low-cost non-invasive test, with subsequent colonoscopy⁽²⁾ when changes are found, Jasmim was not submitted to any of these tests, even successive complaints.

In daily life, people are reduced to stereotypes built by different services and workers who can exercise their functions through logics that are not guided by practices that bring people together, generating disagreements and frustrations

regarding the importance of the problem brought by those who seek the service. When they repeatedly return in search of care ⁽¹⁰⁾, sometimes they also produce resonances in the team, making it difficult to meet that could raise new investments bilaterally.

Sub-corpus B/Class V –Limitations on access to the Health Care Network and Mediators involved in the process

Class V refers to the limitations on access to the Health Care Network and mediators that facilitated the journey undertaken in the search for care, acting as forces that enable access to different services.

Well, when I realized I was getting sick from weight loss, I talked to my son, who sent me money to see a private doctor. [...] (**Jasmim**).

Among the mediators, there are three actors: the son with financial support for the mother to carry out the consultation and exams; a friend of the family who managed to mediate the regulation process from the entry into the Emergency Care Unit (Unidade de Pronto Atendimento - UPA) to the hospital oncology service; and a health professional. In different situations, it is common for mediators to participate in TI in order to achieve conditions, inputs and facilitate flows, by enabling them to face the ineffective responses of services about the demands ⁽¹⁹⁾. Specifically, they tend to have financial and/or political strength to guarantee access and flow in the system.

The low resolution of the care received in the public system often culminates in the delay in carrying out consultations and exams. In view of this scenario and in the case now reported, the feeling of aggravation of the disease caused the TI lines to turn to the private service to shorten the waiting time for the diagnosis. The paths of seeking care are live productions, sometimes defined by services, sometimes by individuals and families through overlapping, singular and rhizomatic networks ⁽²⁰⁾. In the case of Jasmim, it was marked by comings and goings between public and private.

The bureaucratic logic produced by the public sector creates an institutionalized, whole and solid path. Breaking this logic highlights the fragmentary characteristic of the network, characterizing its weave by events⁽²⁰⁾. Jasmine's

tumor was discovered in the private service, and the need for surgical intervention was identified. With that, there was the mediation to return to the service by SUS, using the UPA entrance door for referral to the Oncology Specialty.

[...] my son asked for a referral to the doctor and called a friend who works at SAMU to ask for help. His friend asked me to go to UPA, there he got a referral to Santa Casa in the other day[...]
(Jasmim).

In the TI, the role of mediators - family members or health professionals - regarding access was evident, making it possible to perceive that, in the exercise of a routine activity, they act as experts in the different services⁽²¹⁾.

When Jasmim was hospitalized, she underwent the surgical procedure and was discharged. However, when she felt pain and different discomfort, she sought care from the SUS, where she found barriers in access and, not having her expectations met, she went to the private service. In this context, the professional who assisted her showed ease in moving between the public and private sectors and, acting as a new mediator, expanded her therapeutic possibilities and resumed her care through SUS.

[...]we went to see the doctor and the appointment would be only later, but I couldn't bear to wait: I talked to family members and my older sister sent me the money. On the same day, I sold a construction tool that I had at home and got more money to pay for the care I needed [...](Jasmim).

A similar situation is revealed in another study that even problematizes, in the light of the production of inequities, the passivity of the State, due to the double militancy of the professional between the public and the private. On the occasion, the professional who has the double regulation of access attributes to the private sector the logic of the best care, a situation from which the private nature becomes public (and vice versa), in a situation of inequality, producing privileges⁽²⁰⁾.

Throughout the trajectory referred here, it is possible to perceive the regulation exercised by the mediators, resulting in a reduction in waiting time. These movements also demonstrate the importance of mediation in facing the difficulties that arise in the illness process⁽¹⁹⁾.

However, another study about people with cancer describes a different experience in relation

to mediation, characterized by the opportunity for successive barriers to users who, having different access keys, position themselves between the key and the lock, necessarily making ways for obtaining care⁽²⁰⁾.

In Jasmim's TI, it is unveiled the lack of a flow that guides walking in a timely and safe time, thus allowing the emergence of feelings of insecurity and distrust. Thus, mediators go through and produce counterflows in regulation, giving rise to live networks based on facing dead, disjointed and inoperative work.

Sub-corpus B/Class III -Absence of the Care Line: guidance and support

The Class III evidenced the absence of health education processes for Jasmim and her family in an attempt to subsidize coping with the disease. This fact resulted in lack of knowledge and multiple and disordered accesses, thus suggesting the absence of the Care Line directed at the person with colorectal cancer, low guidance regarding the flow to be followed and lack of support. Faced with different challenges, services should enliven prohibited and unproductive situations, allowing the production of life⁽¹⁰⁾.

[...] when I had this surgery, I didn't know that he had removed a piece of my intestine. He didn't tell us, so I acted like I had nothing [...](Jasmim).

The Care Line is related to the assistance flows guaranteed to the person, in order to meet their health needs. Therefore, it is essential to unify preventive, curative and rehabilitation actions⁽²²⁾, thus enabling the correct use of services when properly directing the person in all their TI. This interconnected action of life production, shaped by the principle of integrality, is only possible if care is organized in networks⁽²⁰⁾. Jasmim was submitted to surgery and, even showing signs of postoperative infection, she was discharged from the surgeon and, only after the oncologist's evaluation, she was referred to the infectologist.

I had surgery and after three days I got an infection: I had to clean it. I was also in a lot of pain; I thought I was going to die and the situation only got worse. We went to the infectologist, he said it could be a bacterium; it would necessary to clean it[...]
(Jasmim).

The Care Line becomes different from the referral and counter-referral process, because despite including them, it transcends the idea of established protocols, by recognizing that service managers can agree on flows and reorganize the work process when observing the particularities each reality⁽²³⁾. An oriented action becomes a producer of safe paths, technically assertive and favors the construction of bonds and autonomy.

Sub-corpus B/Class II -Difficulty articulating with Specialized Care

Class II showed the difficulties in articulating the HCN, after hospitalization and surgical complications due to infection at the incision site, when Jasmim needed care with an infectologist. Instead of returning to the FHS - for monitoring and coordination of the care to be offered after discharge, reassessment of the case, supervised management of the case or safe referral to other services - the user received guidance and referral to the hospital to directly seek the SAE. However, even though it is a practice of ambulatory and hospital services accessed in that municipality, the non-inclusion of the FHS generated a counterflow in the regulation system, a not agreed or foreseen situation by the HCN.

Thus, the post-surgical outpatient return was scheduled by Jasmim. However, the priority of the service in the face of a complication was not guaranteed, a situation that would lead to a delay of approximately one month for access due to the constant queue. Thus, the search for a private service was once again the option found: on one hand, tensioned by the urgency of care for the infected lesion, and on the other hand, by Jasmim's failure history in seeking access to SUS.

After all this walking, three months of walking and suffering, I needed the infectologist. I didn't do it in SUS, because it was going to take a long time[...] I was very unwell, very bad, but I couldn't do it: I looked for another way [...](**Jasmim**).

For not having accessed the service through PHC, the formal logics of access were not exercised, which hindered the assistance path, contradicting the HCN proposal, which, in turn, was formulated to respond to demand, to produce a key to the service lock when the access is not guaranteed. In this way, the lock remained and the barrier created movements and actions to

overcome reality⁽²⁰⁾ in the search for the service in the private sphere.

The communication difficulties of the various points of the HCN, together with the human resources not available for assistance in a timely manner, generate weaknesses that prevent the establishment of bonds and the observance of the doctrinal principles of SUS. For this reason, coping and efforts need to be directed towards the promotion of comprehensive, coordinated and user-centered care, with guaranteed access⁽²³⁾.

In this context, Specialized Care must be integrated with points of care and inter-communicating, capable of ensuring that the CL is articulated with all other units of the HCN and thus providing the user with an adequate response. Chronic conditions demand an articulation of assistance through a dynamic and connected network, with proactive, continuous and integrated responses, which break the logic of fragmentation in the care network⁽²⁴⁾.

The present study has the limitation that it is a single case study, with all the particularity of the context in which it is inserted. However, it was enhanced by the use of NI, which enabled detailed exposures of the situation experienced, giving visibility to determinants that can be considered in situations that have similarities.

FINAL THOUGHTS

The results of this research showed that the participant's TI was concentrated in the specialized and hospital service, without co-participation of the PHC, to which the coordination of care is deposited. The weakened link with the FHS determined limitations on access to other services in the SUS care network, with a consequent search for the private sector, a situation marked by successive crossings and regulated by people who had political, technical or financial micro-power.

For not having her health needs met, between consultations, the patient used medicinal plants without professional guidance, referring to the need to value the services of the different ways of producing care.

Observing the TI allowed analyzing the health system in an unconventional way, making it possible to visualize the disconnections between the points of care; this resulted in increased

suffering with the person's journey between public and private services. The results of this study showed the fragility of the right to health, the urgency of articulating the various points of the HCN, as well as the urgency of developing an oncological CL to organize the service and thus to direct the person and his family, thus promoting assistance centered on the subject and their health needs. In this perspective, health work structured by the construction of CL articulated through the HCN would contribute to a different itinerary,

less permeated by loneliness, suffering and (un) welcoming.

It is suggested, therefore, that new multiple case studies be developed in order to evaluate interventions aimed at the development and implementation of CL designed for users diagnosed with colorectal cancer and who wander through health services, in order to meet the needs so unique and legitimate of this population, thus allowing greater density to the findings.

ITINERÁRIO TERAPÊUTICO – A BUSCA PELO CUIDADO EM SAÚDE EMPREENDIDA POR PESSOA COM CÂNCER COLORRETAL

RESUMO

Objetivo: Compreender, por meio do Itinerário Terapêutico, a busca pelo cuidado empreendida pela pessoa com câncer colorretal e os mecanismos de Gestão do Cuidado. **Método:** Trata-se de um estudo de caso único de abordagem qualitativa, cuja coleta de dados foi realizada por meio da Entrevista Narrativa. Para subsidiar a análise dos dados utilizou-se o software IRaMuTeQ®. **Resultados:** Emergiram dois Subcorpus e cinco classes, por meio dos quais foi possível delinear o itinerário terapêutico e as estratégias de cuidado na perspectiva da pessoa permitiu compreender que a produção do cuidado invade linhas não formais, possibilitando as vias de tratamento que estavam ao seu alcance. É desvelado a inexistência de um fluxo que oriente o caminhar em tempo oportuno e seguro, surgindo sentimento de insegurança e desconfiança. Assim, os mediadores atravessam e produzem contra fluxos na regulação, fazendo surgir redes vivas calcadas no enfrentamento de um trabalho morto, desarticulado e inoperante. **Considerações finais:** Os resultados permitiram identificar a desarticulação dos serviços e a necessidade de elaboração de uma Linha de Cuidado oncológica.

Palavras-chave: Atenção à saúde. Neoplasias retais. Continuidade da assistência ao paciente.

ITINERARIO TERAPÉUTICO – LA BUSCA POR EL CUIDADO EN SALUD EMPRENDIDA POR PERSONA CON CÁNCER COLORRECTAL

RESUMEN

Objetivo: comprender, por medio del Itinerario Terapéutico, la busca por el cuidado emprendida por la persona con cáncer colorrectal y los mecanismos de Gestión del Cuidado. **Método:** se trata de un estudio de caso único de abordaje cualitativo, cuya recolección de datos fue realizada por medio de la Entrevista Narrativa. Para auxiliar el análisis de los datos se utilizó el software IRaMuTeQ®. **Resultados:** surgieron dos Subcorpus y cinco clases, por los cuales fue posible trazar el itinerario terapéutico; y las estrategias de cuidado en la perspectiva de la persona permitieron comprender que la producción del cuidado va más allá de aspectos no formales, posibilitando las vías de tratamiento que estaban a su disposición. Se percibe la inexistencia de un flujo que oriente el caminar en tiempo oportuno y seguro, surgiendo sentimiento de inseguridad y desconfianza. Así, los mediadores atraviesan y producen contra flujos en la regulación, haciendo surgir redes vivas basadas en el enfrentamiento de un trabajo muerto, desarticulado e inoperante. **Consideraciones finales:** los resultados permitieron identificar la desarticulación de los servicios y la necesidad de elaboración de una Línea de Cuidado oncológico.

Palabras clave: Atención a la salud. Neoplasias del Recto. Continuidad de la Atención al Paciente.

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