

Dehospitalization in Cancer Care: a Debate about the Continuity of Family Care at Home

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A Desospitalização na Assistência Oncológica: um Debate acerca da Continuidade do Cuidado Familiar em Domicílio
Deshospitalización en el Cuidado del Cáncer: un Debate sobre la Continuidad del Cuidado Familiar en el Hogar

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ABSTRACT

Introduction: Dehospitalization in cancer care is a continuous patient-centered process of care and actions after hospital discharge. **Objective:** To understand the dehospitalization process in the perspective of the family and investigate how they are prepared to continue to provide care at home. **Method:** Qualitative study carried out in a reference oncological public hospital in the city of Rio de Janeiro, Brazil in the second semester of 2022, with a sample based on accessibility or convenience. The data were collected through a semi-structured interview with families of hospitalized patients who had clinical indication of hospital discharge and required referral to the health services network for continuity of care at home. The hermeneutic-dialectic technique was used in the data analysis, having as a reference the recommendations of the National Health System (SUS) and by authors of historical Marxist philosophy. **Results:** Two meaning units were found: "Planning and Management of Care in the Dehospitalization Process" and "Impacts of Cancer Treatment in Home Care". **Conclusion:** The health team must recognize that the efficacy of dehospitalization is contingent upon a joint network and organized multidisciplinary and intersectoral action.

Key words: patient discharge; medical oncology; continuity of patient care. caregiver; hospital to home transition.

RESUMO

Introdução: A desospitalização na assistência oncológica compreende o "desospitalizar" como um processo de continuidade do cuidado e ações de saúde direcionadas aos pacientes na alta hospitalar. **Objetivo:** Entender o processo de desospitalização pela perspectiva do familiar, e verificar como a família está preparada para prosseguir com os cuidados em domicílio. **Método:** Pesquisa qualitativa realizada no segundo semestre de 2022, em um hospital público oncológico, na cidade do Rio de Janeiro, RJ, Brasil, com amostra por acessibilidade ou conveniência. Foram realizadas entrevistas semiestruturadas com familiares de pacientes internados com indicação clínica de alta hospitalar que demandaram encaminhamento à Rede de Atenção à Saúde para continuidade do cuidado em domicílio. Na análise de dados, utilizou-se técnica da hermenêutica-dialética, tendo como referencial recomendações previstas em documentos do Sistema Único de Saúde (SUS) e de autores da tradição crítica e marxista. **Resultados:** Foram identificadas duas unidades de sentido: "Planejamento e Gestão do Cuidado no Processo de Desospitalização" e "Repercussões do Tratamento Oncológico no Cuidado em Domicílio". **Conclusão:** A equipe de saúde deve reconhecer que a eficácia da desospitalização dependerá de ações multiprofissionais e intersetoriais conjuntas e em rede.

Palavras-chave: alta do paciente; oncologia; continuidade da assistência ao paciente; cuidadores; transição do hospital para o domicílio.

RESUMEN

Introducción: La des-hospitalización en la atención oncológica entiende la "des-hospitalización" como un proceso de continuidad de cuidados y acciones sanitarias dirigidas a los pacientes en alta hospitalaria. **Objetivo:** Comprender el proceso de deshospitalización desde la perspectiva del familiar, verificando cómo la familia se prepara para el cuidado domiciliario. **Método:** Investigación cualitativa realizada en el segundo semestre de 2022 en un hospital oncológico público de la ciudad de Rio de Janeiro, RJ, Brasil, con muestra basada en accesibilidad o conveniencia. Se realizaron entrevistas semiestructuradas a familiares de pacientes hospitalizados con indicación clínica de alta hospitalaria que requirieron derivación a la red de salud para la continuidad de cuidados en la vivienda. La técnica hermenéutica-dialéctica fue utilizada en el análisis de los datos, teniendo como referencia recomendaciones previstas en documentos del Sistema Único de Salud (SUS) y de autores de tradición crítica y marxista. **Resultados:** Se identificaron dos unidades de significado: "Planificación y Gestión de la Atención en el Proceso de Deshospitalización" e "Impactos del Tratamiento Oncológico en la Atención Domiciliaria". **Conclusión:** El equipo de salud debe reconocer que la importancia de la efectividad de la deshospitalización dependerá de una acción conjunta multidisciplinaria e intersectorial, en red y de forma organizada.

Palabras clave: alta del paciente; oncología médica; continuidad de la atención al paciente; cuidadores; transición del hospital al hogar

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INTRODUCTION

This article results from implications arising from the professional assistance intervention articulated with the theoretical methodological debates provided by the Multiprofessional Residency in Oncology, which, experienced with patients and their support network, provided indications about obstacles that families face in accessing the health network in the face of demands for home care.

It is considered that cancer treatment presupposes the integration of levels of health care, in order to ensure quality of life beyond the hospital environment, understanding that health needs are configured “in the whole of patients’ social life, in their way of working, in their particular ways of living; in their relationships with the family, with the social group, with institutions and with the territory where life happens”¹. Unison is the recognition of the importance of these interlocutions to meet not only the integrality of health care, but also to guarantee other social rights through social policies that must be guaranteed by the State. The central role of social policies in guaranteeing these rights is considered, according to article 6 of the Federal Constitution (CF) of 1988², which lists social rights such as education, health, work, housing, leisure, security, social security, protection of maternity and childhood, and assistance to the helpless; and according to article 194 of CF², which comprises social security as “an integrated set of actions initiated by public authorities and society, aimed at ensuring rights related to health, social security and social assistance”.

However, it appears that the implementation of a social protection system is a challenge, since economic policy prevails over social policy, and capitalist and market interests end up having supremacy over the interests of the population, compromising the guarantee of access to social rights, including full access to health. Thus, this article deals with the process of dehospitalization in cancer care, comprising “dehospitalization” as an act of continuity of care and health actions directed to patients within the scope of the programming and execution of hospital discharge³, thus surpassing the conception of a simple discharge after hospitalization period, so that organized and integrated health care is promoted, with coordinated care in a network during the care path³.

Thus, two questions arise: if on the one hand, there is a dehospitalization that corresponds to the ideopolitical management of bed optimization, cost rationalization and logic centered on the disease, on the other hand, dehospitalization is seen as the principle in which the care strategy links the patient’s right to family and community coexistence during treatment, without disregarding the responsibilities of the State in relation to health care⁴.

Regarding the managerial perspective of dehospitalization, for example, there is the following recurring discourse: a patient in their right to access the health policy in hospital care would be withdrawing the right of others to access the same policy. This would justify the defense of bed rotation, resolvability, and rationalization of costs in public health. It can be seen that this model tends to give patients and families a certain level of individualization and broader responsibilities that should be absorbed by the public health network. Such a management model thus assumes a familial bias of burdening care since it transfers responsibilities to families. However, in this study, it is argued that “the responsibility for social protection is not restricted to families and the solution goes beyond their individual possibilities”⁵, as it is understood that dehospitalization demands integrality and intersectorality.

Therefore, given the demands imposed by the dehospitalization process of patients who depend on assistance in the Health Care Network, the objective of this article is to identify the limits and possibilities that families of patients, hospitalized for cancer treatment and in the process of dehospitalization, face to ensure home care.

METHOD

Descriptive and exploratory field research, with a qualitative approach with a sample by accessibility or convenience, carried out in an oncology hospital, integrated with the Unified Health System (SUS), in the city of Rio de Janeiro, RJ, Brazil, in the second half of 2022. Data collection was performed with family members/caregivers accompanying patients over 18 years of age; attended and/or accompanied by the Social Work team during hospitalization; with clinical indication of hospital discharge; who required referral to the Health Care Network for continuity of home care. The following were excluded from the study: patients in exclusive palliative care; with pediatric cancer and/or hospitalized in the pediatric service (children and adolescents, according to current legislation); who were not attended by the Social Service during hospitalization. Five invitations to participate in the research were made and three family members accepted. It is noteworthy that the number of interviewees was not pre-established, considering that qualitative research responds to subjective and objective questions of a level of reality that cannot be quantified, that is, the object is captured in itself, in its hidden structure, deepened in the understanding of phenomena without concern for statistical generalizations⁶.

The semi-structured interview was used as a data collection technique, a combination of closed and open

questions, which gives the interviewee the opportunity to talk about the topic. This interview was guided by a previously elaborated script to outline the profile of the interviewed family members and understand how they were prepared by the health team for hospital discharge, identifying the limits and possibilities in the implementation of home care in the face of demands imposed by dehospitalization. The participants were asked for permission to record the interviews, to facilitate the appropriation of the answers, as well as the ethical aspects of the study were informed and clarified. To avoid exposure, there was no identification of the names in the quotations of the speeches, the letter was used followed by numbering, ensuring secrecy and confidentiality.

For data analysis, the hermeneutic-dialectic technique was used to understand the meanings attributed by the subjects to their experiences in a given social and historical context. The study used as a reference recommendation provided for in SUS documents and by authors of the critical and Marxist tradition, which start from the data provided by concrete reality and examine the set of their historical determinations, observing the relationship between the particular and the universal beyond the phenomenal, immediate and empirical appearance⁷.

Following this perspective, the interviews were heard, transcribed, and read. For data analysis, the following steps were followed: 1. Organization of the data: with a survey of the empirical material and transcription of the interviews, rereading of the speeches and selection of the reports, aiming at understanding the speeches; 2. Data classification: the material was read and excerpts with relevant structures and central ideas of the interviewees' speeches were selected and classified by themes, grouped into empirical categories that allowed the construction of two units of meaning. The first contemplates the planning and management of care in the dehospitalization process. The second unit refers to the repercussions of cancer treatment on home care. The criteria for the inclusion and grouping of the speeches were recurrence, expressiveness, and relevance for understanding the object, either by homogeneity or by singularity; and 3. Final analysis: performed with articulation of the empirical material and the theoretical framework, from the intersection of different views and speeches, identifying convergences and divergences. Thus, "[...] the true circular movement occurs, which goes from the empirical to the theoretical and vice versa, between the concrete and the abstract, which seeks the riches of the particular and the general"⁷. Thus, the data analysis technique allowed contextualizing existing contradictions in the dehospitalization process, in which the institution, professionals, patients, family members and the Health Care Network are inserted.

The research was submitted to ethical standards involving human beings, according to the Resolution of the National Health Council (CNS) n°. 510/2016⁸ and approved by the Research Ethics Committee under opinion number 5673901 (CAAE: 60661722.1.0000.5274).

RESULTS AND DISCUSSION

The study consisted of three caregivers accompanying hospitalized patients; two were female. In relation to the family bond, they maintained a degree of consanguinity, being sister, daughter and father. Two were single, one a widower. None were engaged in economic activity and, among those who had some income, one was retired, and one was receiving temporary disability assistance by the Social Security Policy due to the absence from work due to health reasons. It is recorded that two of the interviewees reported the impossibility of performing an extra domiciliary activity because there was no one to take care of the patient while they were working.

As for the diagnoses, two patients had multiple myelomas and a neurological tumor, with functional losses, generating dependence to assist in activities of daily living. The difficulty of locomotion was pointed out as a major complicating factor both for access to the treatment unit and for the home itself. Regarding the housing conditions of the families, all patients lived in their own property, with basic sanitation and electricity, however, with architectural barriers that directly impacted the conditions for care, such as: presence of steps without alternative ramps to ensure access for wheelchair users, in addition to the absence of bathrooms adapted to the needs of patients.

In order to understand how the family is prepared for the dehospitalization process in oncology, in order to identify limits and possibilities for the continuity of patient care at home, two units of meaning were identified: "Care Planning and Management in the Dehospitalization Process"; and "Repercussions of Oncological Treatment in Home Care".

CARE PLANNING AND MANAGEMENT IN THE DEHOSPITALIZATION PROCESS

Care planning and management are characterized by a strategic set of intersectoral actions to ensure universal access to health, with equity and comprehensiveness⁹. When planning and managing care in the dehospitalization process is discussed, it is about the need to create mechanisms for articulation between the activities of the health team and other sectors involved to ensure care for patients outside the hospital environment.

To discuss the management of health care, we take as a basis the dimensions that produce a complex network of

possibilities pointed out by Cecílio¹⁰, such as: individual, family, professional, organizational, systemic, and corporate. The author defines the individual dimension as “taking care of oneself”, that is, the autonomy that the individual has to decide how to live and to exercise their care from existing and accessible resources. The family dimension concerns the central social support network in care, and signals family members, friends, and neighbors, as well as contradictions and conflicting relationships existing as a consequence of the complexity of family ties and the burden of caregivers. The professional dimension is one that occurs in the encounter between professionals and users, being guided by technical competence, the ethical posture of the professional and the ability to build a bond with those who need care. The organizational dimension is carried out in health services, marked by the technical and social division of labor, with organization of the work process, definition of flows and rules of care and adoption of devices shared by professionals. From a macro-structural perspective, there is the systemic dimension that is defined as one that builds “formal, regular and regulated connections between health services, composing ‘networks’ or ‘lines’ of care, from the perspective of building the integrality of care”¹⁰, and the societal dimension that deals with how public policies are produced in general, in particular health, the latter being the broader dimension of care management, since, according to the author, “it is in it that one appreciates how each society produces citizenship, the right to life and access to every form of consumption that contributes to a better life”¹⁰.

Monnerat and Souza¹¹, in addressing the dilemmas of the integration of social policies in Brazil since the inscription of social security in the 1988 Constitutional Charter to intersectorality, indicate that the State’s counter-reform reached health through the propositions of restricting public funding; the dichotomy between curative and preventive actions, with the persistence of the prevalent endogenous conception and the biological paradigm still hegemonic in the field of health and which is expressed in the practice of professionals.

Thus, it is verified that, in the planning and management of care, it is essential to recognize the needs presented by patients and family members, which needs to be assumed by health professionals with a commitment to guide from the perspective of an integrated management, which presupposes articulation in the local care nucleus and between different sectors of the health system and involved subjects. Such aspects will point to the “micro space” of work of health teams, where care management is proposed and a fragmented and vertical organization is perceived, focused on the productivity of actions and

on the control and compliance with administrative rules, constituting obstacles to integrality in the “macro context” of the service network. Furthermore, as health intervention requires a combination of procedures, flows, routines and knowledge, care planning and management become indispensable and acquire even more centrality, especially when it comes to people undergoing cancer treatment who, at the time of hospital discharge, require prior articulated and integrated organization with different daily routines, family arrangements and levels of health care in the territory.

According to Coelho et.al.¹², dehospitalization can be defined as the deinstitutionalization of people hospitalized in a hospital environment, preventing unnecessary readmission, supporting primary care teams, ensuring agility in the process of discharge to home and reintegration of these people in alternative care networks to the hospital. However, the following report indicates the absence of collective organization strategies during the planning and management of care in the hospital discharge process.

They just called me saying she was going to be discharged. I could only come once a week and, the week I came, they said that there was no discharge forecast yet. Then they called me, like this, out of nowhere, telling me ‘tomorrow she’s high’. I had nothing planned, I just wondered what I was going to do when she was discharged, but prepare, prepare, I couldn’t prepare, I got caught in the scare (E2).

The multiple dimensions of care management, considered in the context of hospital discharge, point to aspects of the social reality of patients and their families, as well as health services in the current situation. In this sense, Olario¹³ defines the act of dehospitalizing as,

a tangle of complex actions and decisions that should begin during the hospitalization period and last until the continuity of care at home with the participation of the hospital, home team, family and others that may be necessary in the transition of care¹³.

Dehospitalization is understood as a care strategy, in which the patient and family/caregiver should be the center of attention. Thus, the concept and practice of dehospitalization must be present in the process of care, management, health education, involving comprehensive care, planning for discharge, humanization and protagonism of the patient. A process that should be addressed from the patient’s first contact with the public health system to their transition between the different

points of health care in the territory³. However, in the daily life of health services, there is commonly the production of an early hospital discharge, with exclusive responsibility of the family for the care, from the managerial perspective of dehospitalization and without an integral and intersectoral action.

In Brazil, the proposed organization of health care points in Health Care Networks is conceptualized as “an organized and arranged way of actions and interactions in health services, which comprises various technological densities that are articulated and integrated [...] with a focus on ensuring the integrality of care”¹⁴. However, for the debate proposed in this work, the network design goes beyond the focus on the Health Care Network, expanding to the service network in an intersectoral dimension, requiring a much more complex network articulation, composed of both other health services and other institutions.

Despite the expanded understanding of health and networks, the interviews revealed the lack of strategies on the part of the team to promote actions that presuppose integrality of care and articulation with other health services. Absence that imputes to family members the concern for the organization of care, in addition to generating doubts and insecurities in the course of treatment, as can be seen below:

It's difficult, this thing of her depending on someone to take a shower, to clean herself because she wears a diaper, this has brought a very serious problem. She changed her diaper thirty times, which I never changed. I've never changed a diaper or a child. Something I never did in my life, I started doing with her. But at the same time it gave me despair because she was the one who took care of it, I said: 'damn, I'm not going to stand the snap, am I selfish?' (E1).

Everything worried me... why would it be? I was very worried because I wasn't prepared for it. Like, 'it's going to be like this, like this, like this'. They did not sit down to tell the right state of my mother, what is happening, what is not (E2).

Although the aspects presented point to the unpreparedness in relation to the planning of future care, some family members highlighted in the speech's guidance received from health professionals on prognosis, survival and level of dependence on care of the patients served. In the health area, difficult news can be defined as information that can negatively alter the individual's view of their future. Communication encompasses elucidations that will lead to changes and impact the lives of patients,

family and the entire health team involved¹⁵. Thus, it is expected that the health team, when communicating an oncological diagnosis or a worsening in the prognosis and dependence on care, as presented below, will be able to provide family members and patients with a space for listening, empathy and privacy.

Talked like that palliatively. About the care he has to do. That now there has to be a person to help, that I now have to stay 24 hours with him and watch him. [...] He called me in the hallway, told me the reality: 'look, your son has metastasized and has progressed. There is no way to do another surgery, the tumor has returned, it is resistant' (E3).

He [professional] spoke, but I didn't listen to what he said. He turned to me and said: 'look she's not going to walk anymore, she's not going to sit down anymore, she's not going to do anything else, do you understand?'. I stared at his face... (E1).

Corroborating this, the physical structure of the hospital does not contribute to the production of a welcoming and privacy environment, and the use of the ward corridor or bed in a shared room to pass on this news is recurrent, which makes it difficult for the patient and family to understand, sometimes generating exposure. In these statements, it can be noted that guidelines and information transmitted by the team, despite being directed to the patient's clinical situation, covered up other health needs such as articulation with other points in the health network and the social reality of family members who are often not prepared for care actions outside the hospital.

In the speeches in which the social worker was mentioned, immediate referrals are highlighted, via the third sector: supply of geriatric diapers, food bag, wheelchair, and hygienic chair loans. It is necessary to signal guidelines and referrals regarding the insertion in a home care program and/or access to transportation for displacements necessary for the continuity of outpatient treatment. Sousa¹⁶ points out the intervention of the social worker in the dehospitalization process in mediation and referral to the patient and family throughout the discharge work process.

Yes, they gave me a lot of support, like in terms of diapers, in terms of wheelchairs because before the other social worker had already commented that it was going to be necessary and such, that whatever was necessary she was going to support me, then they gave me the referral for transportation, to get a hygienic chair, wheelchair, diapers (E2).

Another social worker told me that, as I had another sick person at home, they had to see the issue of home care (I1).

During the interviews, it was noted that one of the major obstacles to the effectiveness of the dehospitalization process and continuity of home care is the difficulty of access to public policies related to urban mobility and home care, in addition to the difficulty of architectural accessibility and housing adaptations. Thus, several patients with favorable clinical conditions to continue treatment at home remain in the institution, as observed:

That's when the girl from the family clinic had it at home, she even apologized to me for the lack of return but said that she really didn't have the transportation to offer. I said: 'if she had to die, she was going to die because she needed to do a chemo Monday, she had a high Friday, and you were supposed to give me an answer and you didn't' (I1).

[...] her fear was to go home because she would not be able to go up, she was hospitalized for the longest time, because she did not have the ramp (E1).

It's more transportation because I'm through the INSS, but if I go back, I'll try to do everything to always be with her, but my biggest problem is only transportation, it's nothing else because I'm taking it out of hand as I'm able to solve it (E3).

Thus, the main obstacles to the effectiveness of dehospitalization are housing with architectural barriers; difficulty in accessing effective public policies; and difficulty in the relationship with the reference and counter-reference network. Therefore, one of the solutions found by family members to the obstacles in ensuring the continuity of care of these patients is the recurrence of the judicialization of social rights, as explained:

I still haven't been able to go [there] to work it out because she can't be alone. So, this is making it difficult to solve this transportation case. I've already been informed that it opens at ten o'clock. So, for me to come here at ten o'clock and leave her with my partner... my partner gets an hour in the afternoon, there's no time for me to get home (E2).

Castro¹⁷ points out that the judicialization of social rights appears in contemporary times when a citizen does not have his/her right of access to the dispensation of medicines, to the vacancy of the hospital bed, to transportation for access to medical treatment, and to access to social security benefits. Thus, taking litigation

to the courts as a way to guarantee access to rights also highlights the phenomenon of judicialization as "a fetishized form of expression of capitalist relations of production"¹⁸, in which access to rights is achieved by an individualistic bias and which overshadows the irreconcilable antagonism of classes.

The search for the judicial system, to resolve demands aimed at the realization of social rights, transforms collective needs to face social inequalities into an individual search for the guarantee of legally foreseen rights, while strengthening the premise of an overlap of the Judiciary with the Executive Branch, contributing to the de-accountability of the State and depoliticization of the public sphere.

In view of the issues presented, the need for network articulation capable of guaranteeing rights in a timely manner to the family member/caregiver and the patient in the process of dehospitalization is reinforced. Keeping in mind that continuous care is the responsibility of the entire Health Care Network, through reference and counter-reference, the need for it to be articulated to enhance the integrality and continuity of care is reaffirmed. Thus, it is assumed that, if the dehospitalization process is not thought from the perspective of the law and the organization of the network, with guarantee of access to the services that compose it, there will be a predominance of the familial bias, of exclusive responsibility of families in the scope of care planning and management, as will be discussed below.

REPERCUSSIONS OF CANCER TREATMENT ON HOME CARE

The repercussions of cancer treatment mentioned here refer to the debate around home care and the modality of home care as possible facilitators of well-being and improvement of the patient's health. Home care is usually indicated for people who have temporary or definitive difficulties leaving the space of the house to reach a health service, or for people who are in situations where home care is the most opportune offer for their treatment¹⁹. This modality of health care aims to provide the patient with the most humanized care, close to the family routine, avoiding unnecessary hospitalizations and reducing the risk of infections.

However, for home patient care to be effective, it is clear that some premises are necessary, such as: a unique therapeutic project; monitoring by the primary care team and/or the Home Care System (SAD); Better at Home Program or Home Care Program (PAD)¹⁹; living in a home that offers hygiene and food conditions; having one or more responsible caregivers capable of understanding and executing the guidelines provided; in addition to the patient's desire and permission to remain at home.

When this occurs, it is possible to offer comprehensive care, promoting continuity of technical and drug support, associated with safety and home comfort. Thus, for the realization of home care in health systems,

the home, the individual and their family must be perceived as part of a context that is much more than a physical space, and must be perceived with a broader meaning, needing to consider that the home and its members have different realities, cultures, values and beliefs [...]²⁰.

Klock et.al.²¹, when treating home care, reported that it involves the family, its domestic life and its insertion in the political and economic dynamics of society, strengthening social ties, solidarity and community networks, while considering the importance of the family caregiver. It is necessary to emphasize that, within the reality of many sick people, there is an informal caregiver involved in the dynamics of care, since a large part of the population cannot afford the financial costs of care work, private *home care*, for example. It appears that the Ministry of Health defines caregiver as,

the person who provides care on a continuous and regular basis, whether or not it is someone in the family. Their attributions must be agreed between individual, family, team, and caregiver, democratizing knowledge, powers and responsibilities²⁰.

Thus, the caregiver is the person who will receive the guidance from the team of health professionals and who will assume the care of the patient, representing a link between patient, family, and health team.

In health services, families have often been called in this role of caregiver, in order to instrumentalize it under the bias of accountability in the work of care, understood in this study as “*care*”²², which “is configured in an activity of unpaid work, without labor rights”²². In addition, the focus of this care is on women and occurs due to unequal sex relations, based on the sexual division of labor that delegates precarious and unpaid work to women²³. The research highlights the prevalence of female family members as the main caregivers in cases of illness, since the figure of women is interpreted socioculturally as a precursor of care, as highlighted in the following speech:

Me, while I’m at home, I don’t stop. I already get up with her in the morning, she goes to the bathroom, I already put water on the fire, I bathe her... I already give her coffee; my life starts at six o’clock in the morning when she takes the first medicine. Me and her only.’ From the time we get up to the time we go to sleep (E2).

It is also noted that the function of primary caregiver at home is an arduous and exhausting task, which can interfere in the daily life of the private sphere and work, as well as in the quality of life of all family members, “especially the one who centralizes care, as it is common for the caregiver to give up their activities (leisure and employment) to dedicate themselves to the task of caring”²⁴, as identified below:

Oh, I knew I was going to have to stop my life because of it, right, in terms, to stop my life I say, if I want to solve something, I have to have someone, I knew it would be a little difficult (E2).

In addition, the care activity becomes continuous and repetitive when performed at home due to the need for full-time care and carries an overload due to the impossibility of sharing care with more people. Important changes in daily life are perceived, such as: physical and emotional fatigue, stress, and health problems, as signaled by Chaves²⁴ and ratified in the following statements:

I sat on the curb and cried like a child, I got into such a big outbreak, I said: ‘my God in heaven’, I had already cursed everything (...) (E1).

Because I’m so tired, you know when you’re so tired that you don’t even want to walk on the street, you just want to stay at home (E2).

In this way, families are entrusted with care without the State providing them with subsidies, while at the same time promoting a reduction in public services. With the lack of responsibility of the State in the implementation of public policies, a familial logic of accountability and continuity of care of hospitalized patients over their families is imposed²³. In this socio-cultural context of accountability of families, it is clear that they feel insecure, present fears, anxieties, and judgments in the face of the dehospitalization process, as explained below:

[...] the fear was that she would go home because she couldn’t climb the stairs, I was afraid of something snapping, breaking, then the doctor said: ‘it’s not like that either, it doesn’t happen like that’. So, this process was difficult (E1).

The interviewee’s speech reveals a close relationship of real unpreparedness of the technical nature of this care, since family members usually do not have the knowledge as health professionals, in their specificities, and the care is often exercised by affective retribution or legal responsibility²⁴. This aspect also reveals a conception of the family as the first instance of socialization, creation of values and provision of care, with women by definition

as the main responsible for the function of caregiver. In addition, it was possible to identify the incumbency of the family in the provision of fundamental rights that should be provided by the State.

CONCLUSION

Factors that contributed with important implications for the process of dehospitalization and return home were presented, since this process is something complex that depends on relationships between health professionals, patients, and family members. The following stand out: unfavorable socioeconomic situation of patients and family members; residence in neighborhoods distant from the hospital unit or other municipality, difficulties in transportation to continue treatment; difficulties in accessing public policies; feeling of insecurity related to the technical unpreparedness of the family member; lack of structure of the property to receive patients with difficulty; and the fragility of proposals, by the health team, for more concrete actions in view of the needs presented in the dehospitalization process that pointed out the integrality of care and articulation with other health services, corroborating the accountability of family members, especially women, for the organization of home care.

The content apprehended in the research also demonstrates the need to develop actions, plans and strategies to carry out a hospital discharge that recognizes patients and family members in their entirety, without disregarding the difficulties encountered by the health team itself, given the issues of the current social, economic, and political structure and its repercussions on health services and other public policies.

Thus, the importance of care management planning by health professionals is considered, expressed in acts of care in the daily life of public services, as well as in its micro and macro-societal political dimension, so that it fosters a critical reflection and in search of alternatives in defense of the right to health, in its expanded conception, with potential for the elaboration of public policies in the field of care that contribute to the improvement of the quality of care provided and the necessary uninterrupted care, in view of the repercussions that are presented in the lives of people in the course of cancer treatment.

CONTRIBUTIONS

All the authors contributed to the study design, acquisition, analysis and interpretation of the data, wording and critical review. They approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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