

Health and De-hospitalization Network: Challenges for Comprehensive Health Care after Hospital Discharge

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Rede de Saúde e Desospitalização: Desafios para a Integralidade do Cuidado em Saúde após a Alta Hospitalar
Red de Salud y Deshospitalización: Desafíos para la Atención Integral en Salud después del Alta Hospitalaria

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ABSTRACT

Introduction: This article is part of the research “Health and Oncology Network: the challenges of access to home care and health transport in the city of Rio de Janeiro”. **Objective:** To analyze the articulation process with the health network for patients at the neurosurgery clinic who live in the city of Rio de Janeiro and who need home care and/or health transportation services. **Method:** Based on exploratory and qualitative research, a case study methodological strategy was utilized. This is a single case study addressing the theoretical debate on the health network, de-hospitalization and comprehensive care, according to two key issues: home care and transportation for access to health. **Results:** After critical analysis, weaknesses were found in the articulation process with the health network in the context of home care and transportation for access to health. Delay in accessing services, a tendency to judicialization to access transportation, difficulty in the de-hospitalization process to carry out the continuity of the care and accountability of the family were found. **Conclusion:** Through a single case, it was possible to articulate the theory to the daily life of the caregiver and user, identifying weaknesses and strengths in the health network. The importance of future studies on this topic is highlighted.

Key word: health services; integrality in Health; home care services.

RESUMO

Introdução: O presente artigo é parte integrante da pesquisa “Rede de Saúde e Oncologia: os desafios do acesso à atenção domiciliar e ao transporte sanitário na cidade do Rio de Janeiro”. **Objetivo:** Analisar o processo de articulação com a rede de saúde para os pacientes da clínica de neurocirurgia que residem na cidade do Rio de Janeiro e que necessitem do cuidado domiciliar e/ou transporte sanitário. **Método:** Utilizou-se a estratégia metodológica de estudo de caso, elaborada por pesquisa exploratória e qualitativa. Trata-se de estudo de caso único que contempla o debate teórico sobre rede de saúde, desospitalização e integralidade do cuidado, a partir de duas questões-chave: atenção domiciliar e transporte para acesso à saúde. **Resultados:** A partir de análise crítica, verificaram-se fragilidades no processo de articulação com a rede de saúde no âmbito da atenção domiciliar e no transporte para acesso aos serviços de saúde. Observaram-se morosidade para acesso aos serviços, tendência à judicialização para acesso ao transporte, dificuldade no processo de desospitalização para efetivação da continuidade do cuidado e responsabilização da família. **Conclusão:** Por meio de caso único, foi possível articular a teoria ao cotidiano da cuidadora e usuária, identificando fragilidades e potencialidades na rede de saúde. Destaca-se a importância de estudos futuros sobre essa temática.

Palavras-chave: serviços de saúde; integralidade em saúde; serviços de assistência domiciliar.

RESUMEN

Introducción: Este artículo es parte integral de la investigación “Red de Salud y Oncología: los desafíos del acceso a la atención domiciliar y al transporte sanitario en la ciudad de Río de Janeiro”. **Objetivo:** Analizar el proceso de articulación con la red de salud de los pacientes de la clínica de neurocirugía que viven en la ciudad de Río de Janeiro y que necesitan atención domiciliar y/o transporte sanitario. **Método:** Se utilizó una estrategia metodológica de estudio de caso, basada en una investigación exploratoria y cualitativa. Se trata de un estudio de caso único que contempla el debate teórico sobre la red de salud, la deshospitalización y la atención integral, a partir de dos ejes fundamentales: la atención domiciliar y el transporte para el acceso a la salud. **Resultados:** A partir de un análisis crítico se encontraron debilidades en el proceso de articulación con la red de salud en el contexto de atención domiciliar y transporte para el acceso a la salud. Hubo retraso en el acceso a los servicios, tendencia a la judicialización para el acceso al transporte, dificultad en el proceso de deshospitalización para realizar la continuidad del cuidado y la rendición de cuentas de la familia. **Conclusión:** A través de un caso único, fue posible articular la teoría con el cotidiano del cuidador y usuario, identificando debilidades y fortalezas en la red de salud. Se destaca la importancia de futuros estudios sobre este tema. **Palabras clave:** servicios de salud; integralidad en salud; servicios de atención de salud a domicilio.

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INTRODUCTION

The central motivation for the elaboration of this study comes from the approximation with the neurosurgery clinic, in a multiprofessional residence, in a reference hospital in oncology, which brings particularities in the post-discharge period that impact the process of dehospitalization and access to the health network by users. Patients who develop difficulty in locomotion as a sequela, in some cases, depend on the guarantee of home care and sanitary transport for access to health as a public policy. However, the concrete demand for comprehensive care presents numerous challenges in professional daily life, which arouses concern¹⁻⁴.

This article, an integral part of the research “Health and Oncology Network: the challenges of access to home care and sanitary transport in the city of Rio de Janeiro”, aims to analyze the process of articulation with the health network for patients of the neurosurgery clinic who reside in the city of Rio de Janeiro and who need home care and/or sanitary transport. It was developed from a single case study through a literature review, analysis of the medical records of female patients, accompanied by the neurosurgery clinic, and a semi-structured interview with the reference caregiver.

METHOD

The research was constituted in an exploratory and qualitative way, focusing on the deeper look at the relationships and processes within the health field. That is, research that “works with the universe of meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relationships, processes and phenomena [...]” as defined by Minayo⁵.

The methodological case study strategy defined by Yin⁶ was used as an: “empirical investigation that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and the context are not clearly defined”.

Also rescuing the definition of other authors, Gil⁷ states that the case study “consists of the deep and exhaustive study of one or a few objects, in a way that allows their broad and detailed knowledge”, and Mendonça⁸ describes that “the case study consists of a thorough investigation of one or more organizations or groups, aiming to provide an analysis of the set and processes involved in the fact analyzed”.

In this research, a unique case was chosen that dialogues with the theoretical debate of the studied theme, understanding that it makes it possible to “confirm, contest or extend the theory”⁶. Through the case study, it

strives to articulate the totality of the studied situation, observing the multiple dimensions that encompass the case and, from this, produce a critical analysis of it.

Paying attention to the necessary methodological rigor, the following techniques were used: 1) bibliographic research in a database of health publications – Virtual Health Library (VHL) and *Scientific Electronic Library Online* (SciELO), with the following keywords: dehospitalization, health care network, health transport and home care; 2) retrospective documentary analysis of the user’s medical record; 3) semi-structured interview with a reference caregiver, prospectively, “an essential source of evidence for case studies”⁶.

The content analysis technique was used, according to Minayo⁹, in the search to “go beyond the merely descriptive scope of the message, to achieve, through inference, a deeper interpretation” from qualitative or quantitative indicators obtained during the data collection process through semi-structured interview and/or medical record analysis. Subsequently, the categorization of the data was carried out, that is, the classification of the elements that constitute a set of groups with previously defined criteria.

This study presents as a theoretical-methodological reference the dialectical materialism, understood from Ianni¹⁰ as a method of approaching the apprehension of the real, from the dialectical movement, which requires a deep and complex critical reflection “which implies unveiling the real that in this case is the capitalist mode of production, dimensions, meanings, tendencies, which are definitely not given at the level of events seen as empirical facts”.

The research was developed in a reference hospital in oncology in the city of Rio de Janeiro, with a retrospective analysis of the first half of 2022, to choose the participants, following the following criteria: inclusion – reference person in the care of the patient, the latter residing in the city of Rio de Janeiro, aged 18 years or older, who needed to be hospitalized and was discharged from hospital within the analyzed period, accompanied at the neurosurgery clinic of the reference hospital studied, who presents restriction or difficulty in locomotion, requiring referral to home care and sanitary transport; and exclusion – patient referred to the palliative care unit, pediatric patients and those residing outside the city of Rio de Janeiro.

Three cases were observed that contemplated the theoretical debate involved, adapting to the case study. Of these, one chose not to participate in the research; the second chose not to follow up on the necessary referrals for home care and sanitary transport, not contemplating the objective of this study; and the third was the chosen case. Thus, the participant, from whom

free and informed consent was voluntarily obtained, is an elderly caregiver, female, mother of the patient accompanied by the neurosurgery clinic, resident of the city of Rio de Janeiro, who presented restriction and difficulty of locomotion during and after hospitalization, requiring articulation with home care and transportation to access health services aiming at the continuity of care, thus meeting the inclusion and exclusion criteria defined in the research project. The data collected respect and obeyed confidentiality, that is, they were anonymized. The research was only started after the approval of the Research Ethics Committee (CEP) under opinion number 5837966 (CAAE: 59564222.5.0000.5274), respecting the ethical principles of CNS/MS Resolution number 510/2016¹¹.

RESULTS AND DISCUSSION

Patient, female, 51 years old, white, with complete high school, social security bond (self-employed saleswoman), resident in the neighborhood of Realengo, in the municipality of Rio de Janeiro, diagnosed with grade I meningioma, benign tumor, which will be called Violeta, in order to preserve her identity, as well as her mother, named Margarida. The patient has a restricted support network. After hospital discharge, she began to live with her mother in a place that presented limitations for her clinical condition, as it was a second-floor apartment, without elevator. Margarida, his reference in care, is elderly, 74 years old, incomplete elementary school and retired. Family income was impacted, as Violeta did not obtain assistance for temporary incapacity (social security benefit of leave from work activities) immediately – about four months to grant the benefit – and dealt with large transportation expenses to the hospital unit.

According to a medical report, the patient presented hemiparesis, language initiation and repetition deficit, and conduction aphasia. She underwent microsurgery for long-term intracranial (deep) tumors, with bleeding and technical difficulty in resecting the tumor, with incomplete resection and significant manipulation, resulting in motor deficit and aphasia. During hospitalization, the ward team assessed the need for a full-time companion. The support of other family members and/or friends occurred sporadically, being prevented by issues related to work and the care of third parties, as well as by conditions of access and care due to the social situation and support network of the user, causing overload for Margarida. It is recorded, in hospitalization, in the post-surgical period, that Margarida presented questions to the team about home care. Prior requests were made for medical reports necessary for referrals guided by the social service, however, they were made available only at the time of hospital discharge.

It was observed, according to reports in the medical record, that there was planning of punctual joint care due to the difficulty of understanding the family, with the objective of providing guidance on the care plan and dehospitalization. In the medical record analysis, it was verified that the patient was attended by professionals from medicine, nursing, social work, psychology, nutrition, speech therapy, physiotherapy and dentistry. In the social service, the conduct taken was: guidance and monitoring to resolve the social security situation, guardianship, sanitary transport through judicialization, home care through primary care, referral to the volunteer sector for loans of resources necessary for the care of the patient (wheelchair and hygiene, diapers, hospital bed, food bag), guidelines and telephone contacts for the elaboration of articulation with the service network (Basic Health Care, Public Defender's Office, among others), monitoring and seeking the expansion of the social-family support network.

In recent decades, there has been a change in demographic and epidemiological profiles, with an aging population and an increase in chronic conditions and diseases that, according to current data¹², are responsible for more than half of all deaths in Brazil. In the case studied, the patient was diagnosed with grade I meningioma, a benign and slow-growing tumor of the Central Nervous System (CNS)¹³. According to the National Cancer Institute (INCA)¹⁴, “brain tumors and other primary tumors of the CNS are a heterogeneous group of tumors, malignant and non-malignant, presenting different signs and symptoms, with variable prognosis”. The estimate, for each year of the 2023-2025 triennium, is 11,490 new cases in Brazil. In 2020, 9,355 deaths from CNS cancer were reported in the Brazilian territory¹⁴. Treatment is complex and can impact patients' living conditions and, in certain cases, result in sequelae that influence locomotion, orientation, communication and senses, thus bringing specific care demands that require comprehensive and continuous care to the health system, which translates into important planning at all levels of care of the Unified Health System (SUS). Thus, the dehospitalization process must be built collectively “considering the professional technical-scientific aspects and the needs of the user and the family”¹⁵.

According to Ordinance number 3.390/2013¹⁶, which establishes the National Hospital Care Policy, hospital discharge constitutes a “transfer of care” which requires the reinforcement of the autonomy of the subjects based on the socialization of information, with the patient and their families, about the follow-up of the treatment, as well as the need for articulation with the health service network to continue this care and the implementation of

“dehospitalization mechanisms, aiming at alternatives to hospital practices, such as home care”.

Based on the critical bias of this study, it is essential to understand hospital discharge as a result of a process of elaboration and continuous planning of care, throughout the trajectory of hospitalization. Thus, the case studied presents, already at the moment of the patient's first hospitalization, aspects that will permeate the hospital discharge process, such as bed restriction, absence of intelligible verbal communication, dependence on the care of others. In addition to these, there is also a need for understanding about essential care pointed out and expressed in a feeling of insecurity in home care by a family caregiver in the face of changes in the patient's condition. The caregiver's difficulty in absorbing the information in a short time was identified. Insecurities were expressed mainly in relation to the use of gastrostomy (GTT), present in the speech:

I was just so worried [...] about GTT. Then I found it very difficult [...] one day it was even like this, kind of... it seems to be inflamed [...] when she came, I say: 'For God's sake, I don't want her to go with this pet, not because I don't know how to take care of it, no'.

Given the difficulty of understanding the caregiver, it is clear that there was no articulation movement (team, family and user) planned and organized, but rather punctual in the face of a specific need. It is observed, in the report, that the skill of specific care is charged to the caregiver in a naturalized way, without considering the lack of skill as a limit to home care. In the aforementioned speech, the difficulty of the caregiver in relation to care with the TWG, which she refers to as a “bug”, expresses limitation in view of the information and guidance provided.

Another aspect directly related to the process of discharge planning and transition of home care is the socioeconomic issue. Insufficient and compromised family income, due to the delay in releasing the sick pay of the user, brought impacts and concerns with care planning, as shown by Margarida:

Look, it was kind of difficult because she had not yet received the money she leaned on, right, but then I always asked my son and I had saved a little money, then I paid Uber [paid transportation by app] to come [...].

Faced with the lack of social protection from the State, especially in relation to the caregiver, family members are forced to create strategies to develop resolutions for

unforeseen events. Thus, it is observed the difficulty pointed out by the caregiver related to urban mobility, present in the obstacles of the displacement to accompany the patient, causing her to express a desire to return home despite all the implications that involve the dependence on care. That is, the material and daily difficulties, in this case, impel and stand out from the fear of the challenge of home care, as presented below:

it's difficult for me, when I used to take the bus, I would stay more than two hours from there to here, [...]. I was already asking God for her to go home, for me to take care of at home. [...], with all the fighting, for me it was better, after she left.

It is noteworthy that these issues reflect the social, political, and economic crossings in the life of the user, from the point of view as a totality that implies the analysis of the social and biological process, in the complex process of production of health and disease, taking as a theoretical basis, the notion of social determination in health¹⁷.

Kuntz et al.¹⁸ specify some of these aspects, such as the caregiver's insecurity in providing care at home and difficulty in absorbing various information in a short period of time (especially at the first hospital discharge), socioeconomic issues that directly impact care, difficulty in understanding caregivers about the guidelines provided, lack of multiprofessional planning to provide the necessary guidelines and promote the transition of care, with timely planning in cases in which there is difficulty in understanding the family. In home care, these factors bring challenges to family members/caregivers who, in turn, do not have public policy support to guarantee this care as a category of law.

Care is defended as a category of law by different authors. Steps¹⁹ Miotto²⁰ and Guimarães²¹ dialogue about the care category, articulated with social protection, social justice, understanding it as an ethical principle that should lead life in society. Faleiros²² presents a critical analysis in relation to care, the author understands care linked to the historical needs of the subjects, and articulates care to the notion of right, in which “the foundation of care is human rights, as a universal norm of human dignity”. In addition, capitalist society reproduces values of deprivation of the rights of subjects, reinforcing individualism, competitiveness, and bureaucratic, pragmatic and immediate practices. In this sense, Faleiros²² states that the logic of care can be guided in a different sense, questioning these dominant values in the sociability of capital, “in a critical perspective of this society, [...] mediation between historical needs and rights, in a concrete and democratic way, [...] in a relationship of listening, welcoming, and shared interpretation of the situation”²².

Thus, care as a right does not occur only through attention to specific demands, it requires a critical point of view to meet the needs of the social being, from the perspective of reproduction and transformation of reality and the process of sociability.

In addition, there is a process of family accountability and the absence of the State expressed by the lack of public policies aimed at care that explain the neoliberal scenario. The concept of “familism” defines the degree of participation in the supply of patients’ needs and social well-being: the “family is responsible for the protection of its members, and must bear the burden of survival, assistance, care, socialization, among others. The State would be responsible for taking care only of those who have failed in these functions and have different problems”²³.

It is pointed out, in the case studied, a care that is carried out by the elderly mother of the patient, in view of the restricted social network presented, with people who take care of others or are unable for reasons of work and support of daily life to help her, leaving a support, when possible, of sporadic help from neighbors and family members. Regarding the organization of care, Margarida reports:

Planning at home, no one did any, because first of all, my family is small. My son has his family there, I couldn't come.

In this aspect, the overload and restriction of the care network are expressed by the conditions and circumstances involved in the family organization.

They [team] said they had to have someone to help because only I wasn't going to make it. [...] Then even my granddaughter said she was going to help, but my granddaughter has a small child [...] then she went to my house, then a neighbor appeared who helped me, right? [...] Sometimes I would go there, help give a bath, sweep my house, give a little help. That was it, you know? And I was the one struggling with everything. [...] I couldn't take the jolt, it's hard.

Regarding the role of caregiver assumed by the elderly person, Lemos²⁴ states that this occurs most often by circumstance and not by choice. That is, the elderly person is the one who is “free to care”, because the others need to continue with their work routines so that sustenance is guaranteed. For the author, this circumstance leads the elderly caregiver to “assume a burden without the possibility of questioning”²⁴, a situation expressed in Margarida’s speech about the difficulty of organizing the

care of the user and the difficulty of exercising this role alone. Within the generational aspect, the role of care assumed in old age “will directly imply the care that these people dedicate to themselves”²⁴, neglecting their daily and health needs.

In addition, there is the affection expressed by the caregiver, from the statement “I am the mother, I will take care”, which goes through the issue of affection and welcoming, and assumes an obligation imposed on her, for being a mother and especially a woman, emphasizing the issue of gender. This aspect highlights the dimension of organization of care, performed by the woman, in the face of the restricted support network and the task attributed to her, and makes other points of her life also affected and changed. The caregiver’s life is directed to the care of the family member affected by the disease, being restricted to “self-care”, that is, to “seek a space, a time to look at oneself, give oneself the ‘right’ to know oneself and feel one’s needs and, perhaps, allow one to fulfill one’s desires”²⁴. Thus, it is possible to identify the overload of care in the life of Violeta’s mother and also the importance of expanding the debate on the relationship of care and the issue of gender in the midst of a society that naturalizes the attribution of care to the female figure, holding her accountable, as the authors dialogue^{19,21}. The overload of care and the restriction of “self-care” are expressed in the following statement:

[...] I stay at home all day. There are days, there are weeks that don't even wash my head, I don't wash... It's just that I don't have time for anything, nor am I in the mood. Because we work so hard, we don't sleep well, we don't eat well, you know? [...] we can't leave the house anywhere [...] I never imagined that I would have to deal with a child as if it were a child.

As for the aspects involving the transfer of care between health services, as alternatives to hospital practices aimed at comprehensive care, this article discusses two main issues: home care; and difficulties in locomotion and access to adequate transportation for health needs.

Home care is the “modality of health care integrated with the Health Care Network (HCN), characterized by a set of actions for the prevention and treatment of diseases, rehabilitation, palliation and health promotion, provided at home, ensuring continuity of care”²⁵. Thus, the health needs of the user are not exclusive to the hospital environment, surpassing the hospital-centered perspective, and should be articulated with the health network so that the provision of care is carried out in the user’s own residence so that the need for comings and goings to the hospital is reduced. In this care planning, those who depend on specific transport (ambulance or

passenger car) to access health services in the municipality of Rio de Janeiro seek the “Elective Sanitary Transport” program, provided for by the Resolution of the Tripartite Intermanagerial Commission (CIT) number 13/2017²⁶, which is “intended for the scheduled displacement of people to perform elective, regulated and scheduled procedures”. The literature review on these two themes reveals some problems in the process of continuity of care.

In home care, the articles found expose the view of health professionals. Brito et al.¹ discuss the importance of home care for the materialization of comprehensive care, however, they highlight a “distance between theory and practice”, and state that it is necessary to look at issues not valued in the hospital context and that the existence of conflicts within the organization and care impact the work process, the great demand and the prioritization of bureaucratic issues in the face of comprehensive care actions. Within this debate, Maroco² talks about the effects on the service because of the work overload, the difficulty in managing the time to schedule visits, and the lack of training and qualification for professionals.

The user’s experience in relation to home care raises the debate about users’ lack of knowledge about the health network:

i had never needed to go to the family clinic, sometimes, I would take my blood pressure, right, then I don’t know, we arrive and don’t know how to express ourselves, they don’t care either.

The report presented demonstrates a restricted conception of health, expresses the difficulty of access, and reveals how the health service is seen and naturalized for/by the user population. Health in the neoliberal perspective, defending the idea that the SUS should be aimed at the poorest population, that is, those who cannot pay, brings the focused character, having as a guideline the reduction of the role of the State to those who really cannot afford to pay, in a precarious way and making society responsible for solving problems²⁷ in order to eliminate its public and universal character²⁸. The notes on the service raised by Margarida highlight the sporadic monitoring, not meeting the total needs of the patient who depends on home care, indicating the lack of comprehensiveness of the network and reinforcing the naturalization of care by family members:

the very good doctor, very fine people. [...] it took a few days, it was not soon [...] it must have been after a month. [...] the doctor went only once [...] then she appears there the girl, physiotherapist, nurse, but they don’t do anything, they just give an orientation and leave. Then I thought the physiotherapist was

going to do physiotherapy, but he doesn’t, he just goes there, then he says: oh you have to do it like this, you have to do roast [...]. I think it was twice.

When asking about the possibility of caring for the patient without needing the family clinic to be her home, Margarida affirms the importance of the service and presents the limitations, explaining the demand often for extra costs to cover medical needs due to the difficulty of access to the health network. The repercussions of the privatization movement in health in the lives of users are observed, which means that health is not offered totally free of charge, dismantling its universal and public character from the conformation of a complementary health system²⁷:

everything has to pay and everything is expensive [...] sometimes, I take her to the doctor [...] I spent money, a lot of money on her because she had a bowel problem, there was a day that I went to the proctologist, I paid 100 reais because at the family clinic it would take a long time, the medicine he passed, I spent 260, there goes 300 and a little. [...] with acupuncture [...] I spent 300 and little too and nothing [...].

Regarding the sanitary transport program, Brandt^{3,4} reinforces that, in Rio de Janeiro, public policies related to urban mobility for patients with chronic diseases are mainly limited to the free pass (Vale Social and Riocard Especial), which, however, is restricted to tickets limited to public transport for commuting between home and hospital, which does not cover the needs of patients restricted to bed and with difficulty in locomotion, while the program organized for this purpose – elective sanitary transport – presents a “tendency to the individualized treatment of the issue through its judicialization”. It is also noteworthy that such programs prioritize physical disability and end up not covering aspects related to chronic illness and treatment, such as fatigue, asthenia, dyspnea, presence of ostomies, symptoms such as nausea, pain, among others, which, in turn, impact and are crossed by the social sphere. Faced with the non-provision of this right, the user and his family end up having to bear the costs, follow the treatment in a precarious way, or abandon the treatment.

In the present case, the process to achieve sanitary transport was marked by many comings and goings to different addresses provided by the Health Dispute Resolution Chamber (CRLS) – a cooperation project between the Attorneys General of the State and Municipality of Rio de Janeiro, in addition to the State and Municipal Health Departments, the State and Federal

Public Defenders' Offices, and the State Court of Justice with the objective of promoting resolutions on health issues. The guarantee of transportation is understood as imperative and urgent for the monitoring of the patient's health, given the socioeconomic impacts and the need for adequate transportation for people restricted to bed. However, according to medical records, it took about nine months to guarantee the right to transportation based on a request made by a family member after the first hospital discharge, even if it was requested as a matter of urgency. Margarida, after a few trips to the Public Defender's Office, got the guarantee of three days of transportation, but soon after, transportation was no longer guaranteed:

i checked in there, but so far I haven't got anything. Well, the first time I checked in, I got it three times, they released transportation for me, but not now.

She also reports on the bureaucracy of the process, requiring a specific and detailed report to request transportation. In a documentary analysis of medical records, it was found that family members had difficulty in obtaining specific reports. Regarding this process, it is worth mentioning some points: access through judicialization does not solve the collective need; cases are individualized; late knowledge about the procedures in question makes access to the law difficult. It is necessary for health professionals to know about the process to guarantee the right, in order to facilitate the availability of documents necessary for articulation with the network.

Regarding transportation, the particular dimension of each situation is recorded. When Margarida is asked if she believes it is possible to offer care to the patient without the need for guaranteed sanitary transport, she answers:

It's because it's not always. [...] Now if it were frequent, every month, once a week, then it would be difficult because for us, when my son is there he brings it, but when he is not there, he has to pay Uber, I pay for me to come and go [...] I pay about 110, 120, you know?

In this scenario, the patient did not need daily trips to the hospital unit, as in the case of patients undergoing radiotherapy, but even with spaced appointments, access to transportation occurs in a difficult and slow manner, transferring responsibility exclusively to the family.

The case study presented also problematizes aspects that deal with the articulation with the health network. Through reports in medical records and during the interview, it was possible to identify guidelines and referrals necessary for access to the health network provided to family members by the social service. Based

on the studies of Cecilio et al.²⁹, it is understood that access to the network has different regimes and that "the regulation of access and consumption of health services, much more than a bureaucratic-administrative activity, of the governmental sphere or competence, is a social production, resulting from the action of a multitude of social actors"²⁹.

In the case studied, the presence of the government regulation regime is observed, that is, the articulation with the network from the formal referrals via guidelines and directions by professionals and institution, but mainly the lay regulation is identified, that is, the one that occurs from the service user (in the case presented, by the reference caregiver), who assumes the role of protagonist who, from strategies, creation of bonds, strategic contacts, builds a movement in the face of the limits and difficulties of the instituted systems, understanding that this movement arises from pain, suffering, illness and the need for health.

All these points of analysis are articulated and cross the lives of the subjects, bringing direct impacts on the health and care process. The reality experienced by the caregiver reflects the Brazilian socioeconomic conjuncture, marked by neoliberalism in its most aggressive phase – called ultraneoliberalism²⁸. In the field of health, the ultra neoliberal objective is privatization, the de-characterization of the principle of universality and the bureaucratization of access. This movement seeks to achieve the "public, universal, democratic and decentralized character, fundamental for guaranteeing the rights to health, social security and social assistance, as well as preventing the construction and incorporation of new social rights"²⁸. This context brings repercussions to the daily lives of users who, in turn, find it difficult to access services and programs that involve the integrality of health care.

The case presents the right in its reverse character from the contradictions between the current legislation^{30,31}, which state that health constitutes a social right bringing the public and universal aspect, and the reality, which exposes daily difficulties for access to basic issues related to care and the ability to come and go for monitoring and continuity of health treatment.

CONCLUSION

In the present single case chosen, it was possible to produce a critical analysis based on the studies on the theme discussed here, cooperating to verify aspects of the dehospitalization process and the articulation with the health network in order to meet the objective of the research.

It was not possible to identify articles about the user's perspective in relation to home care. The limitations

presented are from the perspective of the health professional, and expressed by the distancing of theory and practice from the integrality of care, issues that impact the work process, such as the volume of demands and the prioritization of bureaucratic issues, difficulty in managing the time to schedule visits, and lack of training for professionals.

There was a trend towards judicialization for access to transportation, reinforcing the individualization of the scope of the law, as well as the lack of knowledge of professionals about the process for preparing the necessary documentation.

The naturalization of the care capacity and the accountability of the family are perceived, given the lack of social protection policies, in the dehospitalization process. There is also an overload of care in the reference caregiver, an elderly woman, raising the debate of gender and age in the role of care.

The protagonism and importance of users are observed, in the face of illness and health needs, in the process of articulation with the network, in the face of the limits and challenges of the established systems that are characterized by the slowness and bureaucratization of access.

This article was produced with the purpose of preparing work to complete a multiprofessional residency course. The importance of future studies on this theme is highlighted, understanding that research produces more than answers, but also arouses new concerns and doubts during the process. From the perspective of critical analysis, there is the movement that allows us to evaluate what was revealed and what was hidden throughout the research. Therefore, interest in the elaboration and research on other issues is stimulated, such as: the impacts of familism in the field of care from a gender perspective, attributing the responsibility of care to women; the process of rephilanthropization, transferring the responsibility from the State to society in the sphere of problem solving through the lack of public policies related to care; the strategies of caregivers amid the scarcity of social protection policies and slow access to services for permanence and continuity of care; and the impacts of the symptoms and sequelae of chronic diseases – whether oncological or not – in addition to physical disability, in the lives of users and in the possibilities of care, given the precariousness and dismantling of Brazilian health policy. These are just some questions to search for new studies, in order to broaden and deepen the horizon on the theme of health and care from the perspective of the SUS, for the benefit of the user population.

CONTRIBUTIONS

Carolina Cardoso Tricarico contributed to the design, planning of the study, analysis, and interpretation of data,

as well as writing and review. Erika Schreider and Ana Raquel de Mello Chaves participated in the writing and critical review. All authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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REFERENCES

1. Brito MJM, Andrade AM, Caçador BS, et al. Atenção domiciliar na estruturação da rede de atenção à saúde: trilhando os caminhos da integralidade. *Esc Anna Nery*. 2013;17(4):603-10. doi: <https://doi.org/10.5935/1414-8145.20130002>
2. Maroco MFP. Limitações e potencialidades da visita domiciliar como ferramenta assistencial na saúde da família [monografia]. Conselheiro Lafaiete (MG): Universidade Federal de Minas Gerais; 2014.
3. Brandt DB. Transporte sanitário eletivo: a (i) mobilidade urbana das pessoas com deficiências e/ou doenças crônicas no RJ. In: 16º Congresso Brasileiro de Assistentes Sociais [Internet]; 2019 out 30-nov 3; Brasília (DF). Brasília (DF): Associação Brasileira de Ensino e Pesquisa em Serviço Social; 2019 [acesso 2023 jan 10]. Disponível em: <https://broseguini.bonino.com.br/ojs/index.php/CBAS/article/view/894>
4. Brandt DB. Mobilidade urbana, transporte e saúde na cidade do Rio de Janeiro. *SER Social*. 2017;19(41):439-58. doi: https://doi.org/10.26512/ser_social.v19i41.14950
5. Minayo MCS, organizador. *Pesquisa social: teoria, método e criatividade*. 17. ed. Petrópolis (RJ): Vozes; 1994.
6. Yin RK. *Estudo de caso: planejamento e métodos*. 2. ed. Porto Alegre (RS): Bookman; 2001.
7. Gil AC. *Como elaborar projetos de pesquisa*. 4. ed. São Paulo (SP): Atlas; 2002.
8. Mendonça AW, organizador. *Metodologia para estudo de caso: livro didático*. Palhoça (SC): UnisulVirtual; 2014.
9. Minayo MCS. *O desafio do conhecimento: pesquisa qualitativa em saúde*. 9. ed. São Paulo (SP): Hucitec; 2006.
10. Ianni O. A construção da categoria. *Rev HISTEDBR on-line*. 2011;11(41e):397-416. doi: <https://doi.org/10.20396/rho.v11i41e.8639917>
11. Conselho Nacional de Saúde (BR). Resolução nº 510, de 7 de abril de 2016. Dispõe sobre as normas aplicáveis a pesquisas em Ciências Humanas e Sociais cujos

- procedimentos metodológicos envolvam a utilização de dados diretamente obtidos com os participantes ou de informações identificáveis ou que possam acarretar riscos maiores do que os existentes na vida cotidiana, na forma definida nesta Resolução [Internet]. Diário Oficial da União, Brasília, DF. 2016 maio 24 [acesso 2022 nov 24]; Seção 1:44. Disponível em: <https://conselho.saude.gov.br/resolucoes/2016/Reso510.pdf>
12. Ministério da Saúde (BR), Secretaria de Vigilância em Saúde, Departamento de Análise em Saúde e Vigilância de Doenças Não Transmissíveis. Plano de ações estratégicas para o enfrentamento das doenças crônicas e agravos não transmissíveis no Brasil 2021-2030 [Internet]. Brasília (DF): Ministério da Saúde; 2021 [acesso 2023 maio 10]. Disponível em: https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/svsa/doencas-cronicas-nao-transmissiveis-dcnc/09-plano-de-dant-2022_2030.pdf
 13. Brum CAI. Meningeoma: histologia e expressão do ki-67 e do p53: estudo de 114 casos. [dissertação]. Niterói (RJ): Universidade Federal Fluminense; 2012.
 14. Instituto Nacional de Câncer. Estimativa 2023: incidência de câncer no Brasil. Rio de Janeiro: INCA; 2022 [acesso 2023 jan 12]. Disponível em: <https://www.inca.gov.br/sites/ufu.sti.inca.local/files//media/document/estimativa-2023.pdf>
 15. Olario PS. Desospitalização em cuidados paliativos oncológicos: reconfiguração da gestão do cuidado para atuação multiprofissional [tese]. Rio de Janeiro (RJ): Universidade Federal do Rio de Janeiro; 2019.
 16. Ministério da Saúde (BR), Gabinete do Ministro. Portaria n.º 3.390, de 30 de dezembro de 2013. Institui a Política Nacional de Atenção Hospitalar (PNHOSP) no âmbito do Sistema Único de Saúde (SUS), estabelecendo-se as diretrizes para a organização do componente hospitalar da Rede de Atenção à Saúde (RAS) [Internet]. Diário Oficial da União, Brasília, DF. 2013 dez 31 [acesso 2022 nov 23]; Seção 1:54. Disponível em: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2013/prt3390_30_12_2013.html
 17. Garbois JA, Sodré F, Dalbello-Araujo M. Da noção de determinação social à de determinantes sociais da saúde. Saúde Debate. 2017;41(112):63-76. doi: <https://doi.org/10.1590/0103-1104201711206>
 18. Kuntz SR, Gerhardt LM, Ferreira AM, et al. Primeira transição do cuidado hospitalar para domiciliar da criança com câncer: orientações da equipe multiprofissional. Esc Anna Nery. 2021;25(2):e20200239. doi: <https://doi.org/10.1590/2177-9465-EAN-2020-0239>
 19. Passos RG. “Entre o assistir e o cuidar”: tendências teóricas no Serviço Social brasileiro. Pauta (Rio J., Online). 2017;15(40):247-60. doi: <https://doi.org/10.12957/rep.2017.32725>
 20. Mioto RCT. Cuidados sociais dirigidos à família e segmentos sociais vulneráveis. Brasília (DF): UnB, CEAD; 2000. (O trabalho do assistente social e as políticas sociais, mod. 04).
 21. Guimarães R. Deficiência e cuidado: por quê abordar gênero nessa relação? Ser Social. 2008;10(22):213-38. doi: https://doi.org/10.26512/ser_social.v10i22.12983
 22. Faleiros VP. Desafios de cuidar em serviço social: uma perspectiva crítica. Rev Katálysis. 2013;16(Spe):92-100. doi: <https://doi.org/10.1590/S1414-49802013000300006>
 23. Teixeira SM, Silva RNLM. Política de assistência social: entre o familismo e a desfamíliação. Emancipação. 2020;20:1-18. doi: <https://doi.org/10.5212/Emancipacao.v20.2013115.012>
 24. Lemos NFD. Idosos cuidadores: uma realidade não desvelada. Mais60: estudos sobre envelhecimento [Internet]. 2018 [acesso 2022 nov 22];29(72):8-25. Disponível em: http://www.mpsp.mp.br/portal/page/portal/documentacao_e_divulgacao/doc_biblioteca/bibli_servicos_produtos/bibli_boletim/bibli_bol_2006/Mais-60_n.72.pdf
 25. Ministério da Saúde (BR), Gabinete do Ministro. Portaria n.º 825, de 25 de abril de 2016. Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS) e atualiza as equipes habilitadas [Internet]. Diário Oficial da União, Brasília, DF. 2016 abr 26 [acesso 2022 nov 23]; Seção 1:33. Disponível em: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2016/prt0825_25_04_2016.html
 26. Ministério da Saúde (BR), Gabinete do Ministro, Comissão Intergestores Tripartiter. Resolução n.º 13, de 23 de fevereiro de 2017. Dispõe sobre as diretrizes para o Transporte Sanitário Eletivo destinado ao deslocamento de usuários para realizar procedimentos de caráter eletivo no âmbito SUS [Internet]. Diário Oficial da União, Brasília, DF. 2016 abr 26 [acesso 2022 nov 22]; Seção 1:54. Disponível em: <https://www.in.gov.br/web/dou/-/resolucao-n-13-de-23-de-fevereiro-de-2017-20815526>
 27. Dicionário da Educação Profissional em Saúde [Internet]. Rio de Janeiro: Fundação Oswaldo Cruz, Escola Politécnica de Saúde Joaquim Venâncio; c2009. Rizzotto MLF. Neoliberalismo e saúde; [acesso 2023 fev 26]. Disponível em: <http://www.sites.epsjv.fiocruz.br/dicionario/verbetes/neosau.html>
 28. Silva RR. A dinâmica da neoliberalização e os ataques à seguridade social no Brasil. In: Mauriel APO, Kilduff F, Silva MM, et al., organizadores. Crise, ultraneoliberalismo e desestruturação de direitos. Uberlândia (MG): Navegando; 2020. p. 129-58.
 29. Cecilio LCO, Carapineiro G, Andreazza R, et al. O agir leigo e o cuidado em saúde: a produção de mapas de cuidado. Cad Saúde Pública. 2014;30(7):1502-14. doi: <https://doi.org/10.1590/0102-311X00055913>
 30. Presidência da República (BR). Lei n.º 8.080, de 19 de setembro de 1990. Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização

e o funcionamento dos serviços correspondentes e dá outras providências [Internet]. Diário Oficial da União, Brasília, DF. 1990 set 20 [acesso 2022 dez 12]; Seção 1:18055. Disponível em: http://www.planalto.gov.br/ccivil_03/leis/l8080.htm

31. Presidência da República (BR). [Constituição 1988]. Constituição da República Federativa do Brasil de 1988 [Internet]. Diário Oficial da União, Brasília, DF. 1988 out 5 [acesso 2022 jan 12]; Seção 1:1. Disponível em: http://www.planalto.gov.br/ccivil_03/constituicao/constituicao.htm

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