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Family caregivers of people with cancer: home and hospital palliative care

Cuidadores familiares da pessoa com câncer: cuidados paliativos domiciliar e hospitalar

Cuidadores familiares de personas con cáncer: cuidados paliativos domiciliarios y hospitalários

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Abstract:
Objective: to describe the transition to family caregiving in hospital and home environments. **Methods:** a qualitative case study, within the post-structuralist framework of Foucauldian studies. Participants were family caregivers linked to the Interdisciplinary Home Care Program of a teaching hospital in the city of Pelotas/RS, Brazil, in 2019, through participant observation and semi-structured interviews. The Ethnograph 6.0 program was used with problem-solving analysis. **Results:** the participants were four caregivers of people with cancer in palliative care. Two categories emerged: *Hospital Environment* and *Home Environment*. In the transition of family caregivers from hospital to the home, the discipline of the hospital institution is maintained at home. Although the hospital allows for more flexible entry for accompanying or caring for a hospitalized family member, the home provides more comfort to the patient and responsibility for the caregiver. **Conclusion:** in the hospital, the caregiver learns disciplinary techniques, which they will reproduce at home according to the established power relations.
Keywords: Home nursing; Caregivers; Palliative care; Hospitals; Neoplasms.

Resumo:
Objetivo: descrever a transição para o cuidador familiar nos espaços do hospital e domicílio. **Método:** estudo de caso qualitativo, na vertente pós-estruturalista dos estudos foucaultianos. Participaram cuidadores familiares vinculadas ao Programa de Internação Domiciliar Interdisciplinar de um hospital de ensino de Pelotas/RS, em 2019, mediante observação participante e a entrevista semiestruturada. Utilizou-se o programa *Etnograph 6.0 com* análise problematizadora. **Resultados:** participaram quatro cuidadoras de pessoa com câncer em cuidado paliativo. Emergiram duas categorias: *Espaço hospitalar* e *Espaço domiciliar.* Na transição dos cuidadores familiares entre o hospital e o domicílio, a disciplina da instituição hospitalar se mantém no domicílio. Apesar do hospital flexibilizar a entrada para acompanhamento ou cuidado de um familiar internado, a residência traz mais conforto ao paciente e responsabilidade para o cuidador. **Conclusão:** no hospital, o cuidador apreende técnicas disciplinares, as quais reproduzirá no domicílio conforme as relações de poder estabelecidas.
Palavras-chave: Assistência domiciliar; Cuidadores; Cuidados paliativos; Hospitais; Neoplasias.

Resumen:
Objetivo: describir la transición al cuidador familiar en los espacios del hospital y el domicilio. **Método:** estudio de caso cualitativo, en la vertiente posestructuralista de los estudios foucaultianos. Participaron cuidadores familiares vinculados al Programa de Hospitalización Domiciliaria Interdisciplinaria de un hospital universitario de Pelotas/RS, en 2019, mediante observación participante y entrevista semiestructurada. Se utilizó el programa *Etnograph 6.0 con* análisis problematizante. **Resultados:** participaron cuatro cuidadoras de personas con cáncer en cuidados paliativos. Surgieron dos categorías: *Espacio hospitalario* y *Espacio domiciliario.* En la transición de los cuidadores familiares entre el hospital y el domicilio, la disciplina de la institución hospitalaria se mantiene en el domicilio. A pesar de que el hospital flexibiliza el ingreso para el acompañamiento o cuidado de un familiar hospitalizado, el domicilio aporta más comodidad al paciente y responsabilidad al cuidador. **Conclusión:** en el hospital, el cuidador aprende técnicas disciplinarias, que reproducirá en el domicilio según las relaciones de poder establecidas.
Palabras-clave: Atención domiciliaria de salud; Cuidadores; Cuidados paliativos; Hospitales; Neoplasias.

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INTRODUCTION

Palliative care (PC) is an interdisciplinary approach for people with advanced or terminal illness and their families, aiming to promote quality of life, reduce suffering through symptom control, and ensure respect for values and beliefs[1].

In 2020, the majority of adults who needed PC worldwide had chronic diseases, such as cardiovascular diseases (38.5%), cancer (34%), and respiratory diseases (10.3%)[2]. Currently, cancer is one of the leading causes of death worldwide, and PC is used to alleviate suffering derived from symptoms, especially pain. Relief from physical, psychosocial, and spiritual issues through PC is possible for more than 90% of cancer patients, even in advanced stages[3].

In Brazil, in 2024, the National Palliative Care Policy (*Política Nacional de Cuidados Paliativos*) was established, which sets guidelines aimed at expanding and universally accessing these services at all levels in the Health Care Network (*Redes de Atenção à Saúde* - RAS). This policy provides for the integration of palliative care into the healthcare network, ensuring that it is offered to people who require care at different points of care, including home care (HC)[4].

Home care intends to assist the comprehensive and equitable implementation of PC, as many countries have limited health resources and few institutional care options. Furthermore, dying at home is a common wish among patients at the end of life[5]. An analysis demonstrated the benefits of home care, including the availability of caregivers, the inclusion of patients in the care process, as well as improvements in dietary patterns and psychological well-being[6].

However, for home care to be possible, the presence of a family caregiver (parent, child or friend), who provides unpaid care and support to family members or friends in health conditions that require continuous care, is essential[7]. A study identified that caregivers have high physical, emotional, and financial demands; lack of support from the health system; seek to repay the patient for something from the past; and use resources such as religion, hope, and spirituality to cope with challenges; and feelings related to death are represented to themselves as something sad and devastating or as a relief for the patient[8].

Another study showed that, in a hospital setting, there is a prevalence of cancer patients in PC, and many caregivers say they do not know how to cope with the demands of care and report difficulty in accepting the role of caregiver[9]. Hospital discharge can be seen as an achievement, since the home was seen as a more peaceful space, but, over time, the home environment comes to be perceived as a place of isolation and insecurity due to the overload and responsibilities imposed on the caregiver[9].

Faced with the challenge of caring for another, initiatives are being developed to assist and guide family caregivers. A methodological study on educational technology for caregivers of cancer patients in home PC resulted in the development of a booklet divided into two volumes, with guidelines focused on the health of the caregiver and issues related to patient care. This initiative highlights the need for guidance and assistance for caregivers regarding the practice of caring for patients in palliative care, given the challenge of experiencing this reality[10].

Studies that problematize power relations are powerful in the field of HC and PC, especially because they focus on the transition of caregivers from hospital to home environment. These environments shape the perception and practices of care, and in the field of Foucauldian studies[11], it is possible to delve into the details, nuances, relationships, and create other ways of questioning to describe and analyze research objects. This article aims to describe the transition to the family caregiver in hospital and home settings.

METHODS

Qualitative research[12], of the case study[13] type in the multiple case modality, inserted in the post-structuralist approach with an approximation of Foucaultian studies[11], following the items of the Consolidated Criteria for Reporting Qualitative Research (COREQ) guide. The case study[13] allows a comprehensive and in-depth investigation of multiple cases in their real-life context, with the sample size not defining significance.

The study was conducted in the homes of participants linked to the Interdisciplinary Home Hospitalization Program (*Programa de Internação Domiciliar Interdisciplinar* - PIDI), which is part of the Home Care Service of the University Hospital of the Universidade Federal de Pelotas, a subsidiary of the Brazilian Company of Hospital Services (HE-UFPel/EBSERH).

The PIDI consists of two interdisciplinary teams that provide daily care to hospitalized cancer patients. Each team cared for 10 patients, making a total of 20 patients. The choice of this service is justified by the care of only cancer patients in PC and by requiring the presence of the family caregiver for inclusion and monitoring in the program. Eventually, it also occurred in the hospital setting due to the fact that one of the patients required hospital admission, requiring the caregiver's accompaniment.

Inclusion criteria were: being a family caregiver of a person with cancer in PC at home; being accompanied by a PIDI team; having accompanied the person under their care in at least one hospital admission; being 18 years of age or older; and exclusion criteria were: not being able to communicate verbally; not being able to communicate in Portuguese; being illiterate. The fieldwork lasted seven months, from April to October 2019.

Initially, contact was established with a health professional from each PIDI team, and subsequently, participation in the rounds took place. From these, seven participants who met the eligibility criteria were selected, thus constituting a convenience sample[14].

Subsequently, telephone contact was made with each of them, following the order of calls from patients and caregivers with the longest follow-up time by the PIDI team. During the phone calls, the research proposal was explained, and an initial meeting was scheduled with each caregiver according to their availability. Of the seven, there was one refusal, one patient's death before phone contact, and one case where phone contact was not possible, even after several attempts. Four caregivers were included and identified as CF01 to CF04.

In the participants' homes, participant observation[12] and semi-structured interviews[12] were used as data collection techniques. The interviews were recorded and conducted, as were the transcripts and field notes[15]. Both the transcripts and the notes were organized in a Word document. The interview included the following questions: *How is care organized? Who taught you the care practices? What was the hospital stay like? What are the differences and similarities between the hospital and home?*

Data production was carried out during scheduled meetings with family caregivers in their homes and in the hospital setting, in cases where the patient needed to be hospitalized.

For the composition of the empirical material, 73 pages of field notes and 168 pages of audio transcripts were generated, both in Word documents with Times New Roman font, size 12, single spacing. The material produced, in terms of content, was considered sufficient given the saturation of the data, considering the time available for conducting the research.

The set of material produced was entered into The Ethnograph 6.0 demo version program for data management and organization. Subsequently, an initial reading was carried out to identify possible thematic codes by approximation, considering the power relations of family caregivers with the spaces, with the person with cancer, and with health professionals.

With the codes in hand, the analysis followed post-structuralist studies[11], using the question: *How are power relations established in hospital and home spaces?*

Ethical aspects[16] were respected, with approval by the Research Ethics Committee, under Opinion No. 3.231.312 and the Ethical Presentation Certificate No. 08610919.5.0000.5317.

RESULTS

Sixteen meetings were held, of which: one for CF01, seven for CF02, four for CF03 and CF04. They lasted an average of 3 hours and 30 minutes, with a minimum of 2 hours and a maximum of 4 hours and 30 minutes.

The research involved four family caregivers of people in palliative care. CF01, 34 years old, a mix of sensitivity and strength, had a very busy routine, as she was the mother of a 10-year-old boy, a nursing technician, caregiver for her mother with cancer, and also performed cosmetic massages as a way to supplement the family income. Her mother passed away during data collection.

CF02, 68 years old, appeared "overburdened, resigned, and suffering." Her routine involved caring for her daughter, both at home and in the hospital, in addition to exercizing at a gym.

CF03, 54 years old, cared for her husband, who passed away during data collection. She presented herself as perceptive and understanding from the moment her husband was diagnosed with pancreatic cancer, as she understood that his life would be short, but she did not expect such a change, distancing herself so much from what she knew.

CF04, 75 years old, avoided saying the word “cancer”. She always presented an active, agile, questioning posture, like a whirlwind wherever she went, moving everything around, making necessary changes in her house to care for her husband. Chart 1 presents some sociodemographic characteristics of the caregivers.

Chart 1. Sociodemographic characterization of caregivers of patients in palliative care and with cancer. Pelotas/RS, Brazil, 2019.

Participant	Family relation	Age	Educational level	Race/ Ethnicity	Income measure in MW*	Occupation	Time of diagnosis
CF01	Daughter	34	Complete Secondary Education	White	4	Nursing technitian	2 years
CF02	Mother	68	Incomplete Primary Education	White	2	Retired	3 years
CF03	Wife	54	Incomplete Secondary Education	White	1	Saleswoman	2 years
CF04	Wife	75	Incomplete Primary Education	White	3	Retired	2 years

*** MW** - Minimum wages

From the interpretation of the interviews, the following codes emerged: *Difficulties in caregiving*; *Instrumentalization*; *Hospital space*; *Home space*; *Caregiver/professional relationships*; *Caregiver/patient relationships*; and *Professional support*, thus interwoven into two categories: *Hospital Environment* and *Home Environment*. Chart 2 presents the relationship between the thematic codes and the defined analytical categories.

Chart 2. Relationship between codes and categories resulting from the analysis process. Pelotas/RS, 2019.

Thematic codes	Analytical categories
Hospital space; Difficulties in caregiving; Instrumentalization; Caregiver/professional relationships; Professional support.	Hospital Environment
Home space; Instrumentalization; Caregiver/professional relationships; Professional support; Caregiver/patient relationships.	Home Environment

Hospital Environment

Since its medicalization, the hospital space has been a planned institution for the provision of healthcare. Therefore, its physical aspects, such as furniture layout and the total number of beds per ward, as well as its organizational aspects, such as scheduling and execution of specific procedures, are all coordinated to fulfill this function:

CF02 leads me to the ward, which has a capacity of four beds. There are two other women admitted with their respective companions. The patient's bed is located below the only window in the room, which, at the moment, allows sunlight to enter the patient's bed. The patient has a nasal cannula for oxygen therapy and is wearing a pink sweatshirt, which allows me to see, on the right side of her neck, a central venous catheter through which medications are infused from bottles attached to an IV stand positioned to her right. To the patient's left, attached to the side of the bed, is a urine collection bag. (Descriptive note, 7/05/2019, CF02)

There was a large window, cabinets to put things [personal belongings]*, a small table in the middle to put things on* [caregiver refers to the first ward where the patient was hospitalized]*. That one there won't do, it's too cramped. You have to keep moving here and there. And when they come and bring that covering screen for washing* [the patient]*, it gets even more cramped.* (CF02)

For "good coexistence" within the hospital environment, it is necessary to follow certain rules aimed at the safety of the patient under the institution's responsibility, as well as their well-being. This includes restricting and controlling the number of people or food items, for example, to prevent the entry of potential disease-causing agents or to avoid hindering the patient's physical recovery:

He knows a lot of people; so, in the afternoons, it gets a little crazy. One Saturday I had to go downstairs and tell them to hold back, not let anyone go upstairs, that their father was feeling unwell. At home, I talk to them out front, I see if they're very close people, we're trying to keep it to just relatives. Siblings, nephews and nieces [...]. *I'm very protective like that. There, at the hospital, there was no way around it, there was the card! When I looked, they were upstairs.* (CF03)

In the hospital, you can't bring food, only crackers. Nothing from outside. There are many things he can't eat. For example, he can't eat popcorn, lentils, or corn. He can't even eat beans; I used to blend them, and I started straining them, so it becomes a broth. Now I'm going to ask the doctor. (CF04)

In the hospital setting, the relationships established with the doctor follow a hierarchy, with the family caregiver needing to receive guidance or confirmation that the patient is doing well that day:

The doctor goes to the patient's bedside. [...] *CF02 positions herself at the foot of the bed. When asked by the doctor how she is feeling, the patient says that she feels better today compared to the previous day. The doctor gives instructions about the surgical procedure to be performed and that the date, yet to be defined, awaits the opinion of another colleague. He notices that CF02 remains attentive and smiling, with her arms positioned behind her body, listening to everything that was said without saying anything. The doctor remains in the room for about three minutes. When the doctor heads out of the room, CF02 follows, quickly going right behind the doctor. Outside the ward, CF02 says to the doctor: "She's doing very well today! Isn't she, doctor?". To which he nods and says that as soon as he has new information about the surgery, he will return to the room.* (Descriptive Note, 17/05/2019, CF02)

Upon entering the hospital setting, the family caregiver takes on a specific role. They may become a link between the team and the patient, facilitating the patient-centered therapeutic plan. The family caregiver cannot be considered merely a mediator in the relationship between the patient and healthcare professionals. Among the functions they perform in the hospital are carrying out tasks that are the responsibility of nursing professionals, such as "turning off the IV drip" and "flushing the feeding tube," as well as monitoring and supervising the team's work:

In the hospital, I'm the one who turns off the IV drip; when it's dripping too much, I reduce the flow; when it's finished, I close the valves and call them. The only thing I don't touch is the feeding, which is done with the machine. You have to know how many drops to give. I tell the nurse: "I haven't learned that yet; but one day I will." Every now and then, it starts beeping; then they have to come. [...]. *They ask me to turn it off: "When it's finished, either turn it off or call me!" But, since I'm already used to it, I turn it off. Then, when they pass by in the hallway, I say: "Oh! I already turned it off." "Ah, okay! Later, I'll go and put in another one!" When the feeding is low, it beeps faster; then, you have to put in a syringe with water and wash it; and then, add the other amount of milk. I'm mastering everything, I'm so hardened in the hospital.* (CF02)

Whenever I went there and asked, they would attend to me immediately: “Look! I’m going to attend to someone who isn’t breathing, but I’m on my way.” So, there was always someone there. One night, the patient wasn’t breathing properly, and I asked for nebulization. In my mind, nebulization would solve everything. I remember asking the nurse, and he said no, because it wasn’t on the prescription. It was something I thought was so simple, that would help the patient sleep better. The on-call doctor arrived and authorized nebulization, and the patient got better. That made me even sadder, more irritated, especially because it was something I thought was easy and it took so long! [...]. *Eleven* *hours after I asked, they spoke to the doctor. The doctor arrived at three in the morning. I got it right there; but, suddenly, I think – who knows – they thought I was being fussy* [...]. (CF03)

Home Environment

The discourse of AD (Adult Education) circulates in different spaces and contributes to the constitution of the family caregiver subject. Progressively, individuals are touched and understand that it fulfills their needs and those of the patient under their care:

> *The girls there* [at the hospital], *the nurses, said: 'Now that you're going home, you'll see that everything is easier, the medication, you do it like this.' They always help. We got home around noon, I think it was about 2:30 in the afternoon, and the PIDI had already arrived. And the best part was the care from the PIDI girls* [nurses]*. At least once a day, or twice a day. So, it's like being in the hospital, they're always here, and that gives you security, peace of mind. Today, they came too, they checked. Checked blood pressure, things like that. All this support is what makes the difference for us, for God's sake! I don't know what we would do without this care. I'll have a lot to remember after all this is over, sad things, but beautiful things for me. We learn a lot in these moments, especially in times of pain, we learn more. More than when we're happy.* (CF03)

Home care for people with advanced cancer is considered an alternative to hospitalization. When included in such a program, the family caregiver has the possibility of remaining at home and having access to procedures for their loved one that are comparable to those offered in a hospital setting:

> *At home, everything is better. At home: if I take a nap, if I want to come here to do something, I'm home. My sister-in-law stayed in the kitchen; so, she made lunch. I spent more time with him. He always said, "I don't want to leave the hospital in pain." He was very afraid to come home because he spent a lot of time in pain, and we thought it was gallstones. Then, he had surgery. So, until the pain was well managed, we didn't come home. It was better at home because, without the PIDI, it would have been much more complicated; because there was a weekend when he was in a lot of pain, and we had to call them. I don't know if he was more nervous or if the medication wasn't working anymore. And then, she increased the morphine dose, but it was easier because we had that support, and they came morning and afternoon, every day. It's like they say, it's like being hospitalized, but at home. The person feels comfortable, and it frees up a bed.* (CF03)

> *We were very well taken care of. The dentist, the skin doctor, the nurse, the nutritionist, the psychologist. What more could you want at home? Even receiving IV fluids?! A vitamin! From the moment they arrive, they're all smiling, wonderful, they attend to you, kiss you, they arrive, theye grab a tangerine and feel at home! For me, it's wonderful. Thank God that this exists. I'm taking care of myself and doing my chores at home.* (CF04)

From the moment the caregiver/patient opens the doors of their home to home care, it becomes an institutionalized space. This change is reflected in the presence of healthcare professionals in the family environment and the physical presence of new elements, such as furniture and medical devices, which gradually alter its appearance:

The patient was lying on a double bed. Beside her was a bedside table positioned so that the patient could easily reach it. On it, I could see several bottles of medication and blister packs of pills. When she saw me, the patient, looking dejected, smiled, nodding her head, keeping her right hand on her opposite jaw. Her husband returned to the room and quickly connected a bottle of formula to the patient's nasogastric tube, then hung it on a small improvised hook located above the bed. CF01 then offered me a bench placed next to the bed and asked me to sit there to talk to her mother. The caregiver sat at the foot of the bed and remained there, stroking her mother's feet. CF01 told me that the two usually spent their afternoons like that. At that moment, CF01 and the patient looked at each other and smiled. After a few minutes, the sound of a car could be heard. It was the PIDI team's car. Immediately, CF01 got out of bed and went to meet the team professionals. The first professional to enter the house and meet the patient was the team chaplain, who, after asking permission, went to the room to greet the patient. I could see that, at that moment, the patient's dejected expression changed, becoming lighter. Upon seeing her husband, the patient asked him to lead her to the living room. He offered his shoulder for her to lean on while he lifted the bottle of the formula that was being infused. Upon reaching the living room, she sat in the armchair, and then I could see that there was a small hook placed on the wall, which her husband used as a support for the formula bottle. (Descriptive Note, 11/04/2019, CF01)

I changed the bed; there was no way to hang the IV drip. My son had to put a little stick in the door to hang it, he had to put a hinge on to adapt the IV drip. My son was there administering morphine to the stomach [patient shows photo]. *I had to move the kitchen table to get through, entering through the living room. We pulled the sofa to get in, we had to change the bed, change the bidets, the places for the medications, so everything would be close to her. I put everything in a large tray. I just kept looking at the folder! You're not going to change the patient's medication, just like when we were in the hospital. The food each patient ate had to be written down in a folder: one could only eat pureed food, another could eat everything, another didn't eat anything. That's why you have to put this in a folder to know how to deal with the patients.* (CF02)

Family caregivers identified differences between the home environment and the hospital environment, which corresponded to the performance of certain practices, such as organizing and handling medications, and the presence of a greater quantity of personal items, among other things:

Doctor XX and XY [nurse] *were here for about two hours because it's quite slow* [the caregiver is referring to performing paracentesis at home]. *We did it right there in the room. They administered anesthesia, and he slept the whole time. I mean, for any exam, you don't need to leave home. It's the same thing we'd be receiving at the hospital, we're receiving at home. At home, I'm more demanding of myself because I'm more responsible. At the hospital, the medications weren't my responsibility; it was the nurses' responsibility. If I don't give a medication, I know it won't be good; I have to follow those schedules. There, it was easy; I knew that at six in the morning, the tray with all the medication would arrive.* (CF03)

DISCUSSION

The hospital remains a disciplinary institution, but in a more flexible way, as it allows one person to enter to accompany and/or care for a hospitalized family member. The control of hospital entries is assimilated by the caregiver, who then reproduces and controls who visits the sick person, and this also occurs at home.

For the team, especially doctors, the caregiver occupies a spectator role, but, depending on the patient's situation, they mobilize to request interventions from healthcare professionals. At home, which becomes institutionalized as a care space, there are indications that it is a better place for the patient to remain, and the responsibility for care is felt by the caregiver. Furthermore, the home is adapted in terms of its space and furniture for better organization of care.

The hospital, which is a disciplinary space, has a certain rigidity in its structure and operating dynamics – divisions that determine its space and protect everything inside – so that its function is fulfilled effectively.

In hospital wards, patients are placed in beds and share the space with other patients, companions, and/or caregivers, having in common being male or female and the accompaniment of a specific care team. Currently, the hospital allows people to enter to accompany someone in palliative care, and consequently, their discourses will be decisive in the formation of the family caregiver.

In the hospital space, discipline[17] can be perceived as the most evident technology of power, since it organizes, defines, and arranges places according to a certain logic, which creates complex and, at the same time, architectural, functional, and hierarchical spaces. This, in addition to ensuring the obedience of individuals to norms and rules, favors the economy of time and gestures.

A Brazilian study[18] with physicians and nurses in Intensive Care Units highlighted that daily practices – disciplinary strategies such as hierarchical observation, normalizing judgment, and examination – shape the relationships between nurses and physicians. However, both power and disciplinary mechanisms in the hospital environment should not be understood as good or bad. On the contrary, these elements should be analyzed from the perspective of the effects they produce on the structure and relationships that are established, since power is relational and manifests itself in discourses.

In this space, the family caregiver observes and learns care practices, regardless of the existence of training programs for transitional care. Regarding training, a Norwegian study[19] highlighted that family caregivers reported information overload in hospital training before returning home, making it difficult to select the most important information for each moment. However, a study[20] conducted in the United States with home care teams reveals support and appreciation for training programs for family caregivers, as they understand that better-prepared family caregivers ensure a safer environment.

To access the hospital space, it is necessary to be identified, categorized, and comply with the rules and permissions for circulation. The hospital's entrance marks the entry point into this space, as there is a person responsible for controlling entries and exits – the doorkeeper – classifying and identifying the individuals who enter the hospital. It is worth noting that the presence of caregivers within the hospital institution marks a possible conjuncture at this time, due to the understanding that the patient's proximity to their family can be beneficial for their recovery.

An integrative review[21] on family caregivers in the hospital identified functions that define their role within this space, such as: decision-making, becoming a mediator between the patient and the health team, as well as ensuring physical and emotional support for the patient.

In another study[21], it was found that family caregivers obey and reproduce the hospital rules, following the guidelines received from professionals, and take responsibility for ensuring the patient's well-being, defining who and when can visit the patient under their care. These rules are subsequently applied at home, considering the need to adapt to routine demands.

In the hospital setting, family caregivers bring food into the hospital as one of the elements controlled by professionals. The figure of the doctor in the hospital is culturally recognized as the highest authority within the institution. They define the conduct and therapeutic measures to be implemented, often without the active participation of other members of the multidisciplinary team, patients, or family members. The family caregiver occupies the role of observer of the doctor's actions, adapting their routine to be present at the bedside during the times when the doctor makes daily rounds with the patient.

The figure of the doctor occupies a central status[23], as they seek to impose their truths due to the greater development of the scientific foundations of their practice, ensuring such imposition through the control they wield over access to health technologies. However, a study in Iceland[24] with family caregivers of people in palliative care identified that the relationship with doctors was weakened by the lack of communication and information about prognosis and that the role of nursing stood out for its welcoming, strengthening and sensitive presence.

The positioning at the bedside, in addition to favoring continuous observation of the patient, allows visualization of the work of the health team. The family caregiver can closely follow the care actions performed by health professionals and verify their efficiency.

There are overlaps between practices exclusive to healthcare professionals and tasks that can be performed by family caregivers. Healthcare professionals frequently delegate some of their responsibilities to caregivers, requiring them to perform complex tasks such as administering medication and handling intravenous therapy devices. A mixed-methods study in Portugal[25] identified that informal caregivers acquire technical terms and procedures through immersion in caregiving experiences, which trigger learning.

Home care emerges as a way to address chronic health problems, ensuring that the patient remains at home and receives care from a health team. From a medical perspective, it is understood that the patient is well cared for, as they maintain contact with qualified professionals. For family caregivers, the relationship established with the home care team is conducted as a safer way to treat their family member at home. This support ensures supplies, materials, and supervision.

In this sense, research[26] shows that permission for health professionals, as biopolitical agents, to enter homes is granted more easily, configuring itself as a biopolitical strategy that regulates both chronically ill subjects and family caregivers. A study[27] demonstrated that the caregiver is directed to accompany the care and capture the team's instructions so that they can perform daily care actions. In this sense, there is a prescription of conduct for caregivers of an educational nature and focused on the sick body.

From the moment the family member's illness begins to impair their functionality and makes them dependent on others for some of their daily activities, the caregiver faces the need for changes that favor specific care practices and that the team can easily visualize the necessary direction during the short period of the visit. Such as the tactical arrangement of rooms and furniture. A study[28] conducted in Toronto also showed that it was necessary to prepare the house, organize transportation, and establish healthcare providers within the home so that the patient could remain at home.

Among the aspects that make the home environment different from the hospital environment, in the view of family caregivers, the possibility of maintaining domestic tasks concurrently with patient care stands out. In both environments, the patient has access to invasive procedures, collection of laboratory tests, and medications, which, for family caregivers, is considered beneficial for themselves and for the patient, as it avoids travel to a health service or the need for hospital admission. In contrast, at home, the family caregiver tends to assume greater responsibilities for the patient's care, since they do not have the presence of health professionals to share the care full-time, corroborating other studies[26-27].

Therefore, in the home space, currently institutionalized, power is exercised in the relationships between caregiver, patient and health team. For Foucault[29], power is emanated at a certain point, not being substantial, occurring in a bundle of relationships that is more or less organized or coordinated. Another study[30] identified the establishment of power relations supported by a hierarchization of the care relationship, demonstrating that caregivers have difficulty expressing their opinions because they do not possess the same technical knowledge as the team, not feeling authorized to use their accumulated experience as caregivers.

CONCLUSION

This study made it possible to problematize the transition from family member to family caregiver from hospital to home settings. The hospital, a disciplinary institution per excellence, offers flexibility by allowing a family member of the hospitalized person to accompany them as a family caregiver. This family member learns both care practices and organizational measures to limit visits and food in the hospital setting. At home, discipline intervenes to organize the care space, which follows a certain hospital-like organization.

This study points out that, for both the family caregiver and the patient, the transition from hospital to home can be a complex process involving numerous fragilities, challenges, and potential for both. In this transition, the family caregiver learns/replicates in the hospital and, therefore, will receive demands, tasks, and activities that they will perform at home after discharge.

This process involves changes in daily life and at home, leading to greater responsibility for care and, consequently, an overload of functions. Therefore, it requires public policies that strengthen team training and caregiver support, of an informational, instrumental, and emotional nature.

As limitations, the study was conducted in a single home care service in a municipality in the southern region of Brazil, as conducting the same study in other services located in other municipalities could present different experiences. In turn, it describes the complexity in the transition of palliative care in people with cancer, pointing to the need for a better understanding of the hospital space and the home space.

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