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ORIGINAL ARTICLE

MODES OF CONSTITUTION OF FAMILY CAREGIVERS OF PEOPLE WITH CANCER IN PALLIATIVE CARE: A FOUCAULDIAN STUDY

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ABSTRACT

Objective: to analyze the modes of constitution of family caregivers of people with cancer in palliative care. **Method:** qualitative research, of the case study type, within the post-structuralist approach, with an approximation to Foucauldian Studies. Four family caregivers of people with cancer in palliative care, followed by the Interdisciplinary Home Care Program of a teaching hospital in Southern Brazil, participated. Data were collected in the homes through participant observation and semi-structured interviews. For data analysis, Foucauldian notions of subjectivation, power, and discourse were used. **Results:** the modes of constitution of the family caregiver subject are influenced by the illness of a loved one, the progression of the disease, the organization for carrying out care, as well as the relationships established in the hospital and home spaces – spaces with discursivities and practices that produce the functionality of caring for the other. **Final considerations:** problematizing the constitution of the family caregiver allows us to identify the productivity of the State's power relations over the bodies of those who care, which develops functionalities ranging from mediating the relationships between the patient and the health team, supervision, execution of care, to the management of time and bureaucratic issues.

Keywords: Caregivers. Home care services. Oncology. Palliative care. Qualitative research.

INTRODUCTION

The management of care and aging culturally involves a social and moral ethic that assigns mothers, wives, or daughters the responsibility of being caregivers. This role tends to develop within an asymmetry in which women take on almost all caregiving duties, while other family members—especially men—contribute only sporadically(1). Beyond cultural, ethical, and moral aspects, the formation of the caregiver is linked to the cognitive dimension, as one must learn caregiving activities. These previously unfamiliar activities become part of the caregiver's daily routine at home. Thus, adaptation is necessary(2).

Among the conditions that require adaptation and the presence of a caregiver is oncological illness, especially when it demands palliative care. A U.S. qualitative study(3) identified facilitating elements and barriers, from a socioecological perspective, that help integrate and support caregivers of cancer patients. Facilitating factors included the willingness to learn the skills needed to provide care, positive interpersonal interactions with healthcare teams, and an informal support network. The barriers reported were problematic communication with some professionals and patients, lack of response to phone calls, and difficulties in contacting services that could provide support.

A Brazilian qualitative study(4) found that the constitution of the family caregiver, within the context of primary care, occurs during the first experience of caregiving. The study encouraged participants to use their cell phones to photograph images that could inspire self-care reflections, demonstrating that this practice could, to some extent, relieve caregiver burden. Meanwhile, a qualitative study in Lithuania(5) showed that the formation of the caregiving role arises from the moral and cultural obligation felt by those who assume care for the ill person. This obligation is linked to bonds and roles established within the family—being a special duty of children and spouses—and to respecting the sick person's wish to remain at home. In the absence of other available family members, caregivers developed

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communication skills with professionals, emotional and supportive abilities for the family and the patient, as well as caregiving skills similar to those of nursing teams.

An Australian narrative review(6) revealed that family caregivers of people with terminal cancer feel unprepared to take on this role. Among the factors leading to becoming a caregiver are motivations related to family values, children's desire to reciprocate the care they received in childhood, and social pressure. Other factors include interactions with healthcare professionals linked to palliative care services; changes during the care process, such as the perception of declining health, increased dependence, and transformations in relationships and home environment.

Caregivers assume a dual role—as family members and as providers of care—requiring them, at times, to adopt behaviors that resemble professional conduct, which interferes with the level of intimacy and emotion within relationships. At the same time, the home is transformed, ceasing to be a place of love and privacy and becoming one of healthcare provision(6).

Given this context, the relevance of studies exploring the constitution of family caregivers in Brazil is evident, particularly those involving the monitoring of the caregiving transition across different settings, such as the one proposed in this study, which encompasses both the home and the hospital. To this end, Foucauldian theoretical notions are useful, especially those of subjectivation, power, and discourse. From this perspective, the subject is not substantial, as it is associated with a mutable position or function, according to the relationships established and the subjectivities produced through experiences grounded in discourse(7). Subjectivity involves truth with a historical and cultural bias attributed to the subject and to the experiences he has of himself(8). Power is related to the exercise of relationships that are also non-substantial, existing only in action, in interaction(9). Discourse—substantial—organizes, controls, and redistributes(10).

Recent public policies approved in Brazil, both the palliative care policy(11) and the care policy(12), are centered on the home and the caregiver. These policies produce discourses about what it means to be a caregiver in palliative care and subjectivate health professionals, who in turn establish power relations with family caregivers. Thus, understanding the process of constituting the family caregiver becomes relevant and urgent in order to problematize the relationships between professionals and the caregiving subject.

Accordingly, the research question was defined as: how does the constitution of family caregivers of people with cancer in palliative care occur? To address this question, the objective is to analyze the modes of constitution of family caregivers of people with cancer in palliative care.

METHOD

Qualitative research(13), of the case study type in the multiple cases modality. The choice of this modality was due to the possibility of deepening, replicating and reproducing theoretical reflections around similar, homogeneous situations that represent a recurring identified pattern.

Theoretically, it approaches Foucauldian Studies(14), as it does not aim to answer, know, and explain reality from a totalizing perspective in order to later prescribe measures or interventions to be followed and considered universal. Its applicability focuses on describing processes of social and cultural differentiation and hierarchization in order to problematize the ways in which such processes produce, or participate in the production of, individuals of a given type within culture. In the case of this study, caregivers of people with cancer receiving palliative care. The items of the Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed.

Participants were family caregivers of people with cancer receiving palliative care, selected by convenience(15) from among those assisted by two teams of the Interdisciplinary Home Hospitalization Program (IHHP), linked to the Home Care Service of a public hospital. The choice of this service is justified by the fact that it attends only patients receiving palliative care for cancer and requires the presence of a family caregiver for inclusion in the program.

The inclusion criteria used were: being a family caregiver of a person with cancer receiving palliative care at home; being assisted by a IHHP team; having accompanied the person under his care during at least one hospital admission; being 18 years of age or older. These criteria were presented to the teams, and during the rounds in which the researcher participated, seven caregivers were identified who met the study's eligibility criteria. Subsequently, telephone contact was made with each of them, prioritizing calls to patients and caregivers with the longest time of monitoring by the IHHP team. During the calls, the research objectives were explained and a first meeting with each caregiver was scheduled according to his availability.

There was one refusal, one patient death before telephone contact, and one case in which telephone contact was not possible, even after several attempts. One of these was a male caregiver. Thus, four female caregivers participated in the study. No new participants were included because, as the meetings and interviews progressed, data saturation and convergence were observed regarding the participants' experiences. It is noteworthy that in multiple-case study designs(13), sample size is not considered a defining factor of the study's significance, since the researcher does not aim to enumerate frequencies, as occurs in statistical generalizations, but rather seeks to generalize a particular set of results to some theory, which constitutes an analytical generalization.

The fieldwork lasted seven months. Eighteen meetings were held throughout the data collection period, most of them in the caregivers' homes. In the case in which the patient needed to be hospitalized, one meeting was held in the hospital setting. With two caregivers, four meetings were conducted, and with the other two, five meetings. The mean duration of each meeting was 3 hours and 30 minutes.

Two data collection techniques were used in the home: participant observation(13) and semi-structured interviews(13). The participant observation followed a guide that included: how the relationship between the family caregiver and the patient unfolded; gestures and posture of the family caregiver in relation to the patient's care practices; gestures and postures during the meeting; characteristics of the home, space, and residents; organization and arrangement of objects, and the movement of people within the household space; and, in case of hospitalization, how this occurred in the hospital setting. For the interview, the guide included the following themes: caregiving experience; how the caregiver took on the patient's care; how care is provided at home; organization of care; who taught the caregiving practices; conversations with the patient about the illness.

In the situation in which data collection took place in the hospital environment, only participant observation was used. The meetings were recorded, and field notes were produced(16). Data production was carried out by a single researcher (a nurse, master's student in nursing, with experience in qualitative research through participation in other studies developed by the research group "core for chronic conditions and their interfaces").

Both the transcripts and the notes were organized in Word documents. For the composition of the empirical material, 73 pages of field notes and 168 pages of audio transcripts were generated, prepared by the first author, both in Word documents using Times New Roman, font size 12, single spacing. Considering the timeline for the research, which was part of a master's thesis, there was not enough time for member checking or for participants to review the material.

The first author compiled the material produced during data collection into text files and conducted an initial reading to identify possible thematic codes through an approach guided by the following problematizing question: What are the conditions for the subjectivation process of the caregiver? This question was broadly formulated in order to inquire into and examine the functioning and how things happen(17). This stage was accompanied and reviewed by the second author (a nurse, professor, and advisor), in which the following codes were defined: course of the illness; prior care; organization and life changes.

Subsequently, the documents were entered into The Ethnograph 6.0 software, demonstration version, the software most used by the research group during the period, for organizing and managing codes. In the software, the codes were problematized, based on the insertion of comments with the theoretical notions of subjectivation, power and discourse, proposed by Michel Foucault.

Subjectivation arises from the way we relate to discourses and experiences(8), and it is applied in the excerpts in which the caregiver reported changes in his role and the adoption of new attributes by the subject. Power is exercised in the midst of unequal and fluid relationships, which are not necessarily organized in hierarchies and structures, with a role of prohibition or redirection, but rather with a productive role[9], being operated in the excerpts that contemplated the relationship of the caregiver with the patient and with health professionals. Discourse is selected, organized, controlled and redistributed, to the point of conjuring powers and dangers in its random events. This means that you can't say everything to anyone and under any circumstances, only what is allowed[10]. This notion was used considering the hospital and home settings, since in the latter there is an institutionalization of this space with the entry of health professionals. This stage was also reviewed and monitored by the fourth author (nurse and teacher).

The Research Ethics Committee of the signatory institution (Opinion nº. 3,231,312) approved the study, and the identification of the participants was preserved, using codes, with C for caregiver, P for patient, and a number in sequence to designate an order.

RESULTS

To better characterize the caregivers, Table 1 presents some sociodemographic characteristics:

Participant	Family ties	Age	Education	Race/ Ethnicity	Income (minimum wages)	Occupation	Religion
FC01	Daughter	34	Completed High School	White	4	Nursing Technician	Catholic
FC02	Mother	68	Incomplete Elementary School	White	2	Retired	Catholic
FC03	Wife	54	Incomplete High School	White	1	Salesperson	Catholic
FC04	Wife	75	Incomplete Elementary School	White	3	Retired	Umbanda practitioner

Box 1. Sociodemographic characterization of the study participants.
Source: Prepared by the authors.

Next, we present the three categories developed: caregiver constitution, spaces and discourses that constitute the caregiver, and established relationships.

Caregiver constitution

The experience of caregiving was not new to some of the participants, since at other times in their lives they had been responsible for a sick family member. Having previously experienced caregiving contributes to the development of the family caregiver as a person permeated by security, affection, selflessness, and satisfaction:

> It is not the first time I have cared for someone who has been sick. If you need me, just call me and I will be there. [...] My husband was in the hospital for 16 days, and we were taking care of him day and night. In 16 days, he passed away. My sister was in [hospital X] for 3 months. My husband, we stayed with him for three months, and then he passed away (FC01).

> And around 2013, my father passed away, and I used to take care of him, I took very good care of him. So, my father was bedridden; and at that time, I was working. But I arranged for two caregivers to stay with him [...]. So, I organized things well, I would leave work. In the morning, I would go there, check on him, give him breakfast, come back, take a shower, and go to work. At eight o'clock, the girls [caregivers] would arrive, stay until seven, one caregiver would switch with the other, and I would leave work and go straight there. This went on for a long time [...] And my husband, who is sick now, he helped me a lot, he would stay; because, on weekends, we would stay there with my father, right? Since the caregivers had days off, we would take over (FC02).

> I am not afraid to face anything! Thank God, because I have already faced the illnesses of my mother, my father, my mother-in-law, a friend of mine, my aunt, and my godmother. I was the one who helped take care of them all (FC04).

> In terms of loving my neighbor, I've always been very selfless. I like having someone to care for, I like having children. Even at their age, I take care of them, I do little things they enjoy, I like taking care of their clothes. When my mother was alive, when I had young children, I was always the one who took care of her, the only one who lived here. I'm from Porto Alegre, there's only one child here and me: my other brother lives in Canoas and my sister in Porto Alegre. So, we've always lived here nearby, in the back of the house; then we bought this place, and we've lived here for about 17 years. So, it was closer,

> taking care of them, going to the physician, getting medicine, and that makes me feel very good: taking care of them. (FC03).

The caregivers cited monitoring the progression of the disease as a challenge in caring for their family members with whom they have established strong emotional bonds:

> It was because I am more calm than nervous. I'm tranquil. We get nervous because the person we love is there. On the very last day, the little sores started to open up, and that made me very nervous. The doctor said we had to give him water calmly because he could choke. So, we gave it to him with a dropper. The last day was quite complicated because my fear was that he would choke; but, thank God, my sister-in-law and my daughter were there that afternoon. So, we managed, even though he hadn't spoken for two days, and he asked for water! The main thing is to stay calm, and everything will be all right! And the girls are very helpful (FC01).

Caregiver FC02 nodded and told me that the previous night, while administering medication, she noticed her mother's nasogastric tube was blocked. As a nursing technician, she tried to unblock it numerous times without success. This caused her great concern and anxiety, as her mother requires continuous medication administered only through that route. Her anxiety was heightened by her inability to seek help from the IHHP professionals, as services are only available during the day. The caregiver stated that she called a private clinic requesting a home tube replacement; however, the professional who answered due to her home’s location refused the service. Under these circumstances, the caregiver took her mother to the private clinic where the tube replacement was performed. The caregiver commented that the procedure was quite expensive for her and that transporting her mother made the patient even more anxious (Descriptive note about FC01).

To take on the role of family caregiver, some women reorganized their work activities, while others opted to leave their jobs outside the home in order to dedicate themselves fully to caring for their husbands. These life changes led to adaptation to a new financial reality and uncertainties regarding the family's future financial security:

According to her, during the week, she works mornings in an Intensive Care Unit as a nursing technician and, on some days, in the afternoon, she works as a massage therapist in a room located in the city center. FC01 commented that, in recent months, she has organized her appointment schedule so that she can spend more time at home with her mother and be present at her medical appointments. Previously, her work pace was much more intense, but she chose to reduce it as soon as she noticed a worsening in her mother's condition and she began to need more help with activities such as moving around and bathing. According to FC01, even while working, she sees herself as responsible for organizing and administering medications. When asked about the presence of anyone else involved in her mother's care, she replied that it is only her and her father, as her siblings cannot help because they have their own lives, their families in other homes, and because they work (Descriptive note about FC01).

> [...] when I had his exam, I went to the hospital, and at work they gave me 15 days off. Then, when it ended, on my thirteenth day, I went back to the store and said, "I can't go back, I'm not going back, find someone else to take my place." That's how it is, I didn't want to do anything wrong either. So I said, "Fix me, and the only thing I want is to receive unemployment benefits and severance pay. I'll return the 40% so my boss doesn't lose out and she'll let me go, right?" Then I did not go back there anymore; I felt more at ease, one less worry [...]. In addition, when I found out about P03's serious illness, which was very serious, it was impossible to reconcile it with work. (FC03).

In contrast, FC02 managed to organize her daily life, maintaining valued social activities while caring for her daughter. The involvement of other family members in her care was important for this:

The caregiver mentions several times that, even though having her daughter sick is difficult, she manages to keep going because she knows she needs to move on with her life. She explains that, even though she goes to the hospital every afternoon to care for her daughter, she manages to share her responsibilities with other family members. When FC02 is not there, her grandson, son-in-law, children, and sister, according to each person’s availability, provide care. For her, it is important to maintain activities that make her feel good and give her energy, such as going to the gym, as she likes to always be active and moving. FC02 states that it is impossible to care for her daughter without taking care of herself. She highly values exercise, and on days when she does not go to the gym, she also does stretching and dancing exercises at home (Descriptive note about FC02).

Spaces and discourses that constitute the caregiver

For FC04, her husband's illness was initially recognized as something temporary, to be overcome with the adoption of antineoplastic therapies and the union of the couple. In our first meetings, the caregiver did not mention the word cancer:

> Here at home, it was like this: we found out, we were a bit shaken, but then we believed and went for it; and there you have it, he is cured! To speak for my daughter, and myself I can say that if the family comes together and gives support, I think the patient has more courage and recovers faster. [...] At the time, it was a shock. We spent a week, the two of us like zombies in the house, I did not know what to say, I did not talk, I said nothing. Then we said: "You know what, honey, let's face it, whatever God wants, let's do the tests and let's go." And we did, and he recovered! (FC04).

While answering questions related to her husband's illness, I noticed that the caregiver became somewhat uncomfortable, shifting on the sofa at times. She recounted the stages of treatment her husband underwent, including chemotherapy, radiotherapy, and surgery. However, she emphasized that her husband's illness was not malignant, never mentioning the word cancer (Descriptive note on FC04).

Regarding learning about caregiving, some caregivers report that it occurred through observing healthcare professionals in both home and hospital settings. The importance given to maintaining hygiene habits and performing wound care and personal hygiene, constantly applied in the hospital setting and then replicated in the home environment, is highlighted:

> No! I learned how to change diapers myself; just by watching them change them there, seeing how they put it on, turn it over, clean it, turn it to one side, change it, clean it; then turn it to the other side, pull the diaper, put it back in place. I am already used to it. [...] It was the physician who taught me. You learn. Slowly, you get there. You take that sign, put it in that plastic like that, you have to wash your hands with alcohol. Of course, now I know everything, that when you get to the hospital, the first thing to do is to put alcohol on your hands. (FC02).

> [...]I think it was a team that was studying, that was prepared to care for the patient in bed, that gave baths teaching that you have to wash the head in a basin, rinse and dry; and, to clean, there's the basin and you wash from here to here and not from here to here (demonstrates) [...]. Yes, from here to here with a cloth, here another cloth; then, they washed everything this way, one leg with a cloth and the foot; then, the seat; then, turn over, wash the whole back. Then, they dried everything, put on the sheet, turn the patient this way, and put the sheet over there. Now, the mobile that turns the patient is very good, a beauty. [...] I know, I know how to act! We will see what is right, what is wrong. We take care of how we have to act, always with delicacy, especially, and we will proceed calmly (FC04).

In the case of caregiver FC04, the training initiated in the hospital setting was insufficient for providing ostomy care at home, which needed to be supplemented by enrolling the patient in a specialized ostomy care service:

> It is normal; I had already taken care of him once. At first, it was difficult because you don't know how to put the bag on, the nurses have to teach you how to clean it. Now, he's washing himself; but, at first, it was all me, I had to clean him while he was lying down; then, I would take a little bag, empty it there, empty it in the toilet, so it wouldn't smell too much. There, at the hospital, the nurses were doing it. At first, I thought it was such a bad thing to deal with. Now, we find it normal. You go to the bathroom, sit down, leave it there, and wash with the showerhead, which we put warm water on. [...] They taught me a little; but, to really teach you, it is where the nurse is (specialized ostomy service), lay him down there, remove the bag, talk to him, and clean him. There, you really learn and they have the paperwork with all the measurements. (FC04).

Established relationships

The relationships previously established with the people being cared for reinforce, in the present, the process of subjectivation of the family caregiver, who, by looking back at past experiences, is able to attribute meaning to the situations faced today:

> When my mother passed away, I felt like I had lost my mother, but I still had my father, and he needed me very much. I took care of him, [...] I felt protected with him. That is what happened with P03:

> he was there sick, but I had him, he was there nearby, but that changed me; we always learn, we become more human, we certainly become motivated to do better, to help, to give of ourselves. People say: "Go there and do something." That person who goes there and reads a story to someone. Of course, the person who receives it is great, but the person who gives, the peace of mind of having done it with affection and nothing out of obligation: "Oh! It was my husband, I had to do that." No! I did it because I love him! I did it from the heart, I would do it all again. Well, I would take care of my husband; now, another man, I don't know, but I would take care of a woman, I took care of my mother, my mother-in-law, I took care of a lady when I was 19 years old. No other man [...] only "my darling," my husband [...]. I have the patience to take care of him. My mother-in-law, for example, was someone I had to bring her in, take care of her, sit her on the toilet, clean her, put her under the shower, on the little stool, scrub her all over, wash her hair, dry her a little, take her out of there, put her back here, I would dry her, dress her. How much time did I spend taking care of her? It took a lot of time. (FC03).

In the care provided to individuals with cancer in palliative care, the family is sometimes called upon to make decisions alongside the healthcare team. During her daughter's hospitalization, FC02, who had previously seemed resigned to the possibility of her daughter's death, expressed a desire to change that situation:

The caregiver says that the hospital staff talked about the possibility of keeping P02 sedated so that she would be more comfortable. Regarding this, FC02 said she was completely against it, as was her grandson, P02’s son, who is a physical therapist. According to FC02, it is better to keep her daughter awake so that she can see and talk with her family, even if she does not currently understand what is happening around her. The caregiver tells me that P02 does not speak openly about her illness or about the risk of death, but she feels that her daughter knows exactly what she has and how serious her situation is, as she is an intelligent and educated person. The caregiver then tells me that, once, her daughter told her that she does not want to die, that she wants to stay by her family’s side, and that it does not matter if, for that, she has to live with the sequelae of the disease. Her greatest wish is to remain alive, even if she can no longer get out of bed on her own; what matters is continuing to live with the people she loves. The caregiver told me that what remained now was to have faith and move forward, doing everything possible, using all available resources so that her daughter can stay alive, because that is her daughter’s wish and hers as well. (Descriptive note – about FC02);

> No, because from the waist down she is already “dead”; she has no sensation in the nerves of her legs, and she no longer has her feet. Her feet used to move, but they do not move anymore. She used to move her toes; now she does not move them anymore either. You can move them this way and that, you can press, pinch. My sister pressed, and I said, “You can press”, she does not feel it. From the waist down, it is as if she did not have legs or feet; they do not move. How long this will last, I do not know — we will see what the physician says, whether we will take her home or whether she will stay in a wheelchair forever. But I prefer her in a wheelchair, alive, rather than for her to die. That is my opinion (FCO2).

DISCUSSION

The ways in which the family caregiver is constituted occur as a loved one becomes ill, as the disease progresses, and as care is organized, as well as in the relationships established in hospital and home settings – with discourses and practices that produce learning for the caregiver's functionality.

For caregivers, caregiving is a function established "naturally," even more so when it comes to a sick family member, and is seen as something necessary. They reconcile this commitment with other daily practices, often without questioning it. Having previously cared for an acquaintance or family member becomes a condition of possibility for choosing a particular person to occupy the role of caregiver among the other family members.

The construction of the caregiver individual can be shaped by the conviction built through family experiences and the social value of the family. The position assumed within the family—typically that of a wife or daughter—results in a responsibility for caring for family members, whereby the gift of caring is attributed to women. Thus, there is a discursive relationship of naturalization in the process of becoming a caregiver that follows the moralization of ways of being(2). The discussion on gender inequalities and caregivers’ feelings points to the attribution of responsibility for caring for their relatives; that is, they were being compelled either by others or by themselves to assume caregiving duties, something that was causing them to become ill due to the demands inherent to the caregiving role(18).

One of the greatest difficulties for a family caregiver is witnessing the progression of a disease such as cancer, which deteriorates the body and generates dependency. The caregiver must meet the patient's needs and cope with physical changes, providing comfort even while knowing that a cure may not be possible and that the relationship may be interrupted at any moment.

In line with the above, a Chinese qualitative study(19) conducted with family caregivers of older adults at the end of life identified that recognizing signs of physical and psychological deterioration is a source of stress, powerlessness, and despair, due to the perception of loss of control, dignity, and personality, as well as the sense that the care provided no longer produces effects. Similarly, a Brazilian phenomenological study(20) conducted with family caregivers of people with advanced cancer found that they experienced an oscillation between avoiding and accepting imminent death, with participants reporting increased physical and emotional burden as the disease progressed and deterioration intensified.

The occurrence of a diagnosis of advanced cancer in a loved one forces the family caregiver to change certain aspects of his life, such as abandoning or stepping away from their job. These changes affect how his routine is managed and often lead to postponing his own desires and plans, due to the need to reorganize other areas of his life in order to fulfill the caregiving role. Thus, from the hospital onward, the caregiver shaped by this experience mobilizes himself to facilitate his adaptation to the new role.

For this reason, early palliative care monitoring—not only for patients but also for caregivers—may be an important strategy for health teams to adopt, especially home-care teams such as the one in this study. In this direction, a multicenter systematic review(21) aimed at synthesizing the impact of early palliative care on the quality of life of caregivers of patients with cancer (including those with advanced cancer) found that although this approach does not affect quality of life, it can significantly improve psychological distress, reduce anxiety levels, and enhance caregivers' perception of preparedness for care, thereby consequently reducing their sense of burden.

Faced with the event of a loved one becoming ill with an incurable disease, it is possible that other experiences will arise to affect and subjectify the family caregiver in other ways. Among these, there is the possibility of more productive experiences, without the total detachment from activities valued by the family caregiver. The widespread disruption of social relationships, resulting from the caregiver's daily activities, appears in almost all accounts as an inseparable factor, alongside the caregiver's overload and illness process. The inability to engage in leisure activities due to confinement in the constant care environment often leads the family caregiver to experience a greater sense of overload(22).

However, it is worth noting that sources of support for caregivers in Brazil, both governmental and non-governmental, are scarce, and the task of mobilizing people willing to help falls to the family. Thus, the availability to share care is a benefit for few family caregivers.

In the situation presented, the caregiver offered a possible reaction to her family member's cancer diagnosis, where the disease is framed by the discourse of hope for a cure, promoting a positive attitude. This movement may be related to understanding the cancer diagnosis as a call to war, in which victory requires the struggle and willpower of those involved. When the caregiver refuses to associate the cancer diagnosis with negative connotations, she exercises a form of resistance to the discourse of cancer as an incurable disease. This can occur through avoiding the word "cancer" and relativizing its degree of malignancy, in order to distance herself from its existence. Being touched by the discourse that it is possible to overcome cancer helps the family caregiver maintain her functionality, since the burden of understanding that her care did not produce improvement in the patient can be too heavy, making it difficult for her to cope with the strain of the new routine.

In this case, it is possible to assess how subjectivity, when directed toward certain themes such as those of medicine, can impact people's lives, given that it is common nowadays to avoid mentioning the word cancer, which would once have implied a death sentence—an association arising from society’s lack of knowledge about the disease(23). Cancer represents a significant threat to patients and can profoundly affect the well-being of those impacted, as there is fear associated with the diagnosis and treatment process, the disruption of daily life, and physical symptoms(24).

Thus, it can be observed that the use of metaphors related to cancer can subjectivize the way family caregivers constitute themselves in the face of the disease; that is, when confronted with a loved one’s illness, the caregiver may understand that without his support or enlistment in the battle, the patient has no chance of winning.

In this regard, figures of speech—such as euphemism and metaphor—are identified as subjectivating techniques, acting as a force that shapes the subject’s subjectivity. Subjectivation(25) occurs through actions upon individuals’ subjectivity, that is, through an established power relation. In this study, the caregivers’ power relation is exercised through such metaphors.

It is essential that the family caregiver make things happen—that she make it possible for the patient to remain at home. As for the healthcare team, it is its role to invest in the training of its members, who become the focus of constant educational strategies adapted to the reality. Little by little, the behavior of team members is regulated by the health team, which, by enabling the continuation of its actions through new actors, contributes to the interests of the State.

The statements of family caregivers reveal the need to feel supported by healthcare professionals so that appropriate interventions can be planned, allowing family members responsible for providing care to carry out their tasks properly. Some participants remained uncertain about their ability to meet the needs of their older relative within the new care environment.

It is also interesting to observe the movement made by the family caregivers themselves in seeking to acquire the knowledge necessary for care at home. The experience in the hospital setting gives rise to curiosity about how care considered ideal is carried out within a formalized health environment. Observation becomes an educational resource sought by the family caregiver herself when she realizes that, in a short time, she will find herself alone at home, performing the same actions as health professionals, and that her ability to reproduce these actions will be put to the test, analyzed, supervised, and recorded by the Home Care professionals.

Considering the care needs of a chronically ill patient, the period of hospital stay may be considered insufficient to prepare the family caregiver to fully meet the demands presented at home. In general, this phase occurs concurrently with the diagnosis of the family member's illness, which may compromise the process of assimilating the information passed on by the health team.

Physiologically, the body of a patient with advanced cancer tends to experience a decline in its functions, with less participation in self-care and activities of daily living. In this condition, life expectancy varies between four and 24 months, with the disease prognosis considered intermediate or poor(21). Thus, in addition to the learning initiated in the hospital setting, the family caregiver must adapt to new, often unexpected situations, without the company of healthcare professionals. Furthermore, it is an adaptation to finitude, to the loss of someone with whom she most likely had affectionate relationships and bonds throughout her life. It is then up to the caregiver to use her resources, from the most diverse sources, to find solutions to the demands and transformations with which she begins to deal.

The personal meaning attributed to what it is to be a caregiver is one of the indicators that health professionals use to assess whether the transition process is progressing satisfactorily. Analyzing the meanings through which family members perceive themselves within the context of caring for another person indicates how they characterize and perceive themselves in this process, since in some cases the patient believes that the family member is not fit for the responsibility of being a caregiver(26). Attitude, dedication, initiative, and availability were the main characteristics identified by the families in the study as necessary for a family member to satisfactorily perform the role of caregiver. The nurse is seen as a facilitator in this process, establishing bonds, providing guidance, and offering the training required in this new phase(27).

When comparing the multiple events involved in the illness of family members, differences are perceived in the relationships established with the people whom the individuals have cared for before—differences in affections and in the goals present in each relationship. Regarding subjectivation, for Foucault(7), we are constituted by truths that modify us and begin to guide our moral conduct; in other words, there is an action(25) upon the individual's subjectivity. Such action involves force and power; therefore, it is believed that, in the case of these women, caring for a man is acceptable because he is their husband, and not in another situation, since they were not objectified by an educational system in the field of health.

The experience of accompanying the progression of the patient's illness produces in family caregivers movements that oscillate between small daily improvements and worsening situations that place them face to face with the proximity of the final outcome: loss. Loss, in this case, refers to death, as it represents defeat in the face of cancer and the insufficiency of all efforts made on behalf of the patient to keep him alive.

Although experiencing an emotionally difficult moment, it is the caregiver's role to provide support by supplying information to the health team so its members can decide on care measures and treatments. This action is stimulated by the discourse of palliative care, which is based on minimizing the suffering of patients affected by serious illness and on integrating the family into the process.

The surface of family caregivers' bodies is permeable to the discourses of the spaces they occupy. In the hospital, traversed by discourses of health restoration and life maintenance at the cost of using invasive measures and technological apparatus, caregivers may be tempted to resort to them, aiming to reverse the condition of their family members. This can lead to divergences with the intentions of health professionals, who, touched by the discourses of palliative care, tend to suggest measures that do not prolong the dying process and that avoid therapeutic obstinacy.

Shared decision-making via family caregiver and health professionals is essential for patient-centered care, especially in situations where there are therapeutic preferences and when the patient has not had the opportunity to make his choices(28). Family caregivers are presented with different experiences, which build a new subject, who will develop certain functionalities: mediation of relationships between patient and health team, supervision and execution of care, in addition to time management and bureaucratic issues. Thus, the family caregiver can be influenced and modified according to what is permitted.

FINAL CONSIDERATIONS

This multiple case study based on Foucauldian theory allowed us to identify the discourses and relationships that produce functionalities in family caregivers through the mediation of relationships between patients and healthcare teams, the supervision and execution of care, and the management of time and bureaucratic issues.

The constitution of caregivers in this study was permeable to the onset of illness in a loved one, previous caregiving experience, and, during the process, the organization and learning of care that occurred in hospital and home settings with patients and healthcare teams.

Among the limitations, the choice of two data sources stands out, restricting the triangulation process, which is important in case studies. Regarding practical implications, Foucauldian studies are not intended to prescribe, but rather to problematize attention to the relationships established with family caregivers and their needs. For policies, this type of study allows for the observation of nuances in the relationships involving family caregivers, both in the healthcare network and in access to social support services. For health agendas, the contribution of this study encourages the inclusion of this population, since there are few Brazilian structures for promoting various types of support for family caregivers.

MODOS DE CONSTITUIÇÃO DE CUIDADORAS FAMILIARES DA PESSOA COM CÂNCER EM CUIDADOS PALIATIVOS: ESTUDO FOUCAULTIANO

RESUMO

ObjetivO: analisar os modos de constituição de cuidadoras familiares da pessoa com câncer em cuidados paliativos. **Método:** pesquisa qualitativa, do tipo estudo de caso, inserida na vertente pós-estruturalista, com aproximação dos Estudos Foucaultianos. Participaram quatro cuidadoras familiares de pessoa com câncer em cuidados paliativos acompanhada pelo Programa de Atenção Domiciliar Interdisciplinar de um hospital escola do Sul do Brasil. Os dados foram coletados nos domicílios mediante observação participante e entrevista semiestruturada. Para a análise dos dados, utilizou-se as noções foucaultianas de subjetivação, poder e discurso. **Resultados:** os modos de constituição do sujeito cuidador familiar são influenciados pelo adoecimento de um ente querido, pela progressão da doença, pela organização para realização do cuidado, bem como pelas relações estabelecidas nos espaços hospitalar e domiciliar – espaços com discursividades e práticas, produtores da funcionalidade do cuidado do outro. **Considerações finais:** problematizar a constituição do cuidador familiar permite identificar a produtividade das relações de poder do Estado sobre os corpos dos que cuidam, a qual desenvolve funcionalidades, que vão desde a mediação das relações entre paciente e equipe de saúde, supervisão, execução de cuidados até a gestão do tempo e de questões burocráticas.

Palavras-chave: Cuidadores. Serviços de assistência domiciliar. Oncologia. Cuidados paliativos. Pesquisa qualitativa.

MODOS DE CONSTITUCIÓN DE CUIDADORAS FAMILIARES DE LA PERSONA CON CÁNCER EN CUIDADOS PALIATIVOS: ESTUDIO FOUCAULTIANO

RESUMEN

Objetivo: analizar los modos de constitución de cuidadoras familiares de la persona con cáncer en cuidados paliativos. **Método**: investigación cualitativa, del tipo estudio de caso, insertada en la vertiente postestructuralista, con aproximación a los Estudios Foucaultianos. Participaron cuatro cuidadoras familiares de persona con cáncer en cuidados paliativos acompañadas por el Programa de Atención Domiciliaria Interdisciplinario de un hospital escuela del Sur de Brasil. Los datos fueron recolectados en los domicilios mediante observación participante y entrevista semiestructurada. Para el análisis de los datos, se utilizaron las nociones foucaultianas de subjetivación, poder y discurso. **Resultados**: los modos de constitución del sujeto cuidador familiar están influenciados por el proceso de enfermedad de un ser querido, la progresión de la enfermedad, la organización para realizar el cuidado, así como por las relaciones establecidas en los espacios hospitalario y domiciliario - espacios con discursividades y prácticas, productores de la funcionalidad del cuidado del otro. **Consideraciones finales**: problematizar la constitución del cuidador familiar permite identificar la productividad de las relaciones de poder del Estado sobre los cuerpos de quienes cuidan, la cual desarrolla funcionalidades que van desde la mediación de las relaciones entre paciente y equipo de salud, supervisión, ejecución de cuidados hasta la gestión del tiempo y cuestiones burocráticas.

Palabras clave: Cuidadores. Servicios de asistencia domiciliaria. Oncología. Cuidados paliativos, Investigación cualitativa.

REFERENCES

1. Renk VE, Buziquia SP, Bordini ASJ. Mulheres cuidadoras em ambiente familiar: a internalização da ética do cuidado. Cad saúde colet. 2022;30(3):416-423. DOI: https://doi.org/10.1590/1414-462X202230030228

2. Silva YC, Silva KL. Constitution of the caregiver subject at home care:

psycho-affective, cognitive and moral dimensions. Esc Anna Nery. 2020;24(4):e20190335. DOI: https://doi.org/10.1590/2177-9465-EAN-2019-0335

3. Reblin M, Ketcher D, Vadaparampil ST. Care for the Cancer Caregiver: a Qualitative Study of Facilitators and Barriers to Caregiver Integration and Support. J Canc Educ. 2022;37:1634-1640. DOI: https://doi.org/10.1007/s13187-021-02001-6

4. Santos Junior JRG, Oliveira SG, Tristão FS, Ceolin T, Zilli F, Sousa JHD, Cardoso MB. Constitución del cuidador familiar a partir de fotografías: experiencias para el cuidado de sí. RUE. 2020;15(2):1-17. DOI: https://doi.org/10.33517/rue2020v15n2a1

5. Kuznecovienė J, Butkevičienė R, Harrison DW, Peičius E, Urbonas G, Astromskė K. What does it mean to be the main caregiver to a terminally ill family member in Lithuania?: A qualitative study. PLoS ONE. 2022;17(5):e0265165. DOI: https://doi.org/10.1371/journal.pone.0265165

6. Ongko E, Philip J, Zomerdijk N. Perspectives in preparedness of family caregivers of patients with cancer providing end-of-life care in the home: A narrative review of qualitative studies. Palliat Support Care. 2023; 27:1-11. DOI: https://doi.org/10.1017/S1478951523001013

7. Foucault M. O cuidado com a verdade. In: Ditos & Escritos V: ética, sexualidade, política. 3a. ed. Rio de Janeiro: Forense Universitária; 2017. p.234-45

8. Foucault M. As técnicas de si. In: Motta MB. Ditos e escritos IX: Michel Foucault genealogia da ética, subjetividade e sexualidade. Rio de Janeiro: Forense Universitária, 2014. p.264

9. Foucault M. Sobre a história da sexualidade in: Foucault M. Microfísica do Poder. 18a ed. Rio de Janeiro: Paz e Terra, 2025. p.363-406

10. Foucault M. A ordem do discurso: aula inaugural no Collège de France, pronunciada em 2 de dezembro de 1970. 19a ed. São Paulo: Loyola, 2009.

11. Brasil. Ministério da Saúde. Portaria GM/MS Nº 3.681, de 7 de maio de 2024 [online]. 2024 [citado em 24 out 2024]. Disponível em: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2024/prt3681_22_05_2024.html

12. Brasil. Presidência da Reública. Lei nº 15.069, de 23 de dezembro de 2024. Institui a Política Nacional de Cuidados [online]. Diário Oficial da União, 24 dez 2024, Seção I [citado em 18 out 2025]. Disponível em: https://www.planalto.gov.br/ccivil_03/_ato2023-2026/2024/lei/L15069.htm

13. Cardano M. Em defesa da pesquisa qualitativa: desenho, análise de dados e textualização. Minas Gerais: Unimontes, 2024.

14. Meyer DE. Abordagens pós-estruturalistas de pesquisa na interface educação, saúde e gênero: perspectiva metodológica. In: Meyer DE, Paraíso MA, editoras. Metodologias de pesquisas pós-críticas em educação. 3a ed. Belo Horizonte: Mazza Edições, 2021. p. 49-63.

15. Campos CJCM, Saidel MGB. Amostragem em investigações qualitativas: conceitos e aplicações ao campo da saúde. Rev Pesqui Qual. 2022;10(25):404-424. DOI: https://doi.org/10.33361/RPQ.2022.v.10.n.25.545

16. Bernard HR. Research Methods in Anthropology: Qualitative and Quantitative Approaches. 2a ed. 1995.

17. Paraíso MA. Metodologia de pesquisas pós-críticas em educação e currículo: trajetórias, pressupostos, procedimentos e estratégias analíticas. In: Meyer DE, Paraíso MA, editoras. Metodologias de pesquisas pós-críticas em educação. 3a ed. Belo Horizonte: Mazza Edições; 2021.

18. Andrade LM, Reis LA, Peixoto LCP, Carvalho PAL, Meira EC, Sena ELS. Ser mulher e familiar cuidadora de pessoas com

doença de Alzheimer. Rev Recien. 2022;12(40):24-35. DOI: https://doi.org/10.24276/rrecien2022.12.40.24-35

19. Wong EL-Y, Lau JY-C, Chau PY-K, Chung RY-N, Wong SY-S, Woo J, Yeoh E-K. Caregivers' Experience of End-of-Life Stage Elderly Patients: Longitudinal Qualitative Interview. Int J Environ Res Public Health. 2022;19(4):2101. DOI: https://doi.org/10.3390/ijerph19042101

20. Benites AC, Rodin G, de Oliveira-Cardoso ÉA, Santos MA. "You begin to give more value in life, in minutes, in seconds": spiritual and existential experiences of family caregivers of patients with advanced cancer receiving end-of-life care in Brazil. Support Care Cancer. 2022;30:2631-2638. DOI: https://doi.org/10.1007/s00520-021-06712-w

21. Agustina R, Ispriantari A, MPhil KDK, Lin MF. Impact of early palliative care on the quality of life in caregivers of cancer patients: A systematic review. Worldviews Evid Based Nurs. 2023; 20(2):178-190. DOI: https://doi.org/10.1111/wvn.12629

22. Omiya T, Kutsumi M, Fukui S. Work, Leisure Time Activities, and Mental Health among Family Caregivers of the Elder People in Japan. Healthcare. 2021;9(2):1-13. DOI: https://doi.org/10.3390/healthcare9020129

23. Soares NM, Vieira JA. Metáforas e a constituição discursiva – uma análise crítica. VERBUM. 2022;11(3):103-123. DOI: https://doi.org/10.23925/2316-3267.2022v11i3p103-123

24. Fereidouni Z, Abnavi SD, Ghanbari Z, Gashmard R, Zarepour F, Samani NK, Sharma AR, Ghasemi A. The Impact of Cancer on Mental Health and the Importance of Supportive Services. Galen Med J. 2024;13:e3327. DOI: https://doi.org/10.31661/gmj.v13i.3327

25. Rose N. Inventando nossos selfs. Rio de Janeiro: Editora Vozes, 2011.

26. Sousa AMBD, Sousa CF, Nogueira MJC, Oliveira MSB. Atenção Familiar no Cuidado em Saúde Mental: Quem Cuida do Cuidador?. PsicoFAE [online]. 2022 [citado em 28 out 2025];11(1):59-70. Disponível em: https://revistapsicofae.fae.edu/psico/article/view/395

27. Bernardi MB, Gonçalves AS, Barbosa SGR, Bernal SCZ, Plantier GM, Rodrigues TFCS, Radovanovic CAT. Vivência de cuidadores informais na transição de papéis após o processo de desospitalização. Cienc Cuid Saude. 2022;21:e6182. DOI: https://doi.org/10.4025/ciencuidsaude.v21i0.61823

28. Albuquerque A, Antunes CM. Tomada de decisão compartilhada na saúde: aproximações e distanciamentos entre a ajuda demissional e os apoios de tomada de decisão. Cad Ibero Am Direito Sanit. 2021;10(1):203-223. DOI: https://doi.org/10.17566/ciads.v10i1.621

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