

## (End of) Life spaces: an ethnographic study in Brazilian and French homes and medical-social institutions



*Espaços de (final de) vida: estudo etnográfico em domicílios e estabelecimentos médico-sociais brasileiros e franceses*

*Espacios de (término de) vida: estudio etnográfico en domicilios y establecimientos médico-sociales brasileños y franceses*

Franciele Roberta Cordeiro<sup>a</sup>   
 Maria Henriqueta Luce Kruse<sup>b</sup> 

### How to cite this article:

Cordeiro FR, Kruse MHL. (End of) Life spaces: an ethnographic study in Brazilian and French homes and medical-social institutions. Rev Gaúcha Enferm. 2019;40:e20190065. doi: <https://doi.org/10.1590/1983-1447.2019.20190065>

### ABSTRACT

**Objective:** To analyze the constitution of homes and medical-social establishments as possible spaces for the end of life in Brazilian and French scenarios.

**Method:** An ethnographic study in homes and medical-social establishments carried out in Porto Alegre and Grenoble, between October 2014 and October 2016. Participants were six people with end-of-life cancer and four family caregivers. Data was submitted to cultural analysis.

**Results:** We showed how the (re)configurations of the home space and the medical-social establishments occur to receive people at end-of-life stage by two categories: *"They don't know where I live": the home as a space for the end of life* and *"They are good here, but in another way": care in medical-social settings*.

**Conclusions:** The (re)definition of the space where we die takes place based on the culture, besides the social and economic conditions of the families to receive the person at the end of life. In both spaces, home and medical-social establishments, we found that sickness and the end of life are still cross-permeated and signified according to the knowledge of health, in such a way that it continues to medicalize death and the dying process, even outside the hospital.

**Keywords:** Anthropology, cultural. Nursing. Culture. Hospice care. Homebound persons. Homes for the aged.

### RESUMO

**Objetivo:** Analisar a constituição de domicílios e estabelecimentos médico-sociais como espaços possíveis para o final de vida nos cenários brasileiro e francês.

**Método:** Estudo etnográfico em domicílios e estabelecimentos médico-sociais em Porto Alegre e Grenoble, entre outubro de 2014 e outubro de 2016. Os participantes foram seis pessoas com doença oncológica em final de vida e quatro cuidadores familiares. Os dados foram submetidos à análise cultural.

**Resultados:** Foram elaboradas duas categorias: *"Eles não sabem onde eu moro": o domicílio como espaço para o final da vida* e *"Eles são bons aqui, mas de outra maneira": os cuidados em estabelecimentos médico-sociais*.

**Conclusões:** A (re)definição do espaço onde se morre ocorre com base na cultura, além das condições sociais e econômica das famílias para acolher a pessoa em final de vida. Mesmo fora do hospital foi possível identificar que se continua a medicalizar a morte e o morrer.

**Palavras-chave:** Antropologia cultural. Enfermagem. Cultura. Cuidados paliativos na terminalidade da vida. Pacientes domiciliares. Instituição de longa permanência para idosos.

### RESUMEN

**Objetivo:** Analizar la constitución de domicilios y establecimientos médico-sociales como espacios posibles para el término de la vida en escenarios brasileños y franceses.

**Método:** Estudio etnográfico realizado en domicilios y establecimientos médico-sociales en Porto Alegre y Grenoble, entre octubre de 2014 y octubre de 2016. Participaron seis personas con enfermedad oncológica terminal y cuatro cuidadores familiares.

**Resultados:** Se trató de demostrar cómo ocurren las (re)configuraciones del espacio del domicilio y de los establecimientos médico-sociales para recibir a personas en el término de su vida por medio de dos categorías: *"Ellos no saben dónde vivo": el domicilio como espacio para el final de la vida* y *"Son buenos aquí, pero de otra manera": los cuidados en establecimientos médico-sociales*.

**Conclusiones:** La (re)definición del espacio donde se muere ocurre con base en la cultura, además de las condiciones sociales y económicas de las familias para acoger a la persona al final de la vida. Tanto en el domicilio como en establecimientos médico-sociales se pudo constatar que la dolencia y el término de vida aún están atravesados y significados por los saberes de la salud, de tal manera que se sigue medicalizando la muerte y el morir, incluso fuera del hospital.

**Palabras clave:** Antropología cultural. Enfermería. Cuidados paliativos al final de la vida. Personas imposibilitadas. Hogares para ancianos.

<sup>a</sup> Universidade Federal de Pelotas (UFPel), Departamento de Enfermagem Hospitalar na Rede de Atenção em Saúde, Programa de Pós-Graduação em Enfermagem. Pelotas, Rio Grande do Sul, Brasil.

<sup>b</sup> Universidade Federal do Rio Grande do Sul (UFRGS), Programa de Pós-Graduação em Enfermagem. Porto Alegre, Rio Grande do Sul, Brasil.

## ■ INTRODUCTION

The notion of space is etymologically associated to three possible situations. The first one corresponds to the nature of the space, the position of an object/materiality; the second one consists in its substantiality; and the third one deals with the concept of space as a metric structure<sup>(1)</sup>. While thinking about end of life possible spaces, we consider the first and the third possible concepts as relevant. In other words, we think about end of life spaces as physically delimited structures – places sheltering objects related to other objects producing certain possible ways of dying during the current time.

In that respect, we found out that possible spaces to shelter end of life and death have been a topic in public health policies worldwide and also a recurrent subject in health research<sup>(2-3)</sup>. We would like to clarify that when we mention the expression ‘end of life’, we consider the period from six to three months since the onset of a life-threatening disease diagnosis which does not respond to the modifying treatment until death<sup>(4)</sup>.

In Brazil, since 2003, with the institution of the National Humanization Policy, which has ambience as one of its priority guidelines, with the Better at Home Program, which aims to favor hospital discharges seeking to optimize bed occupancy, with Administrative Rule No. 4.279, dated December 30, 2010, which aims to organize the Health Care Network and with Administrative Rule No. 825, dated April 25, 2016, which redefines Home Care, there is a concern of the State with the possible spaces for the healthcare of the population.

Regarding end of life, the above-mentioned public policies prioritize the residence as the space to deliver assistance to people affected by diseases that no longer respond to the treatment intended to modify them. Recently, Resolution No. 41, dated October 31, 2018, which deals with the palliative care arrangement on Brazilian ‘Unique Health System’ (SUS), emphasizes the importance of using spaces other than hospitals for palliative care development, especially residences, highlighting that a hospital must be requested when symptoms are ‘uncontrollable under another level of assistance’<sup>(5)</sup>.

In France, considered a pioneer country in the structuring of services, laws and public policies addressed to people at the end of their lives, there is development of strategies considering the home as a space of care since 1986, following the publication of Circular DGS/3D, which deals with the organization of care for terminally ill people and the accompaniment of sick people in terminal phases. The health system organization itself, comprising family/generalist doctors and nurses who move between their medical

offices and patients’ residences, shows the centrality of this space in French health public policies. In this scenario, palliative care plans are triennially developed, determining priorities in health financial support and investments. Its latest edition<sup>(6)</sup>, it emphasized residences and medical-social offices – ongoing care clinics, long-term care institutions for dependent and non-dependent elderly patients – as priority spaces to activities of French health public entities.

Therefore, it is observed that health care models, programs and public policies are conceived focusing on a bounded site; but the groups move and the culture globalizes. Such a movement results in the sharing and dissemination of methods of care, institutional models, and laws that aim to standardize and regulate specific means of governing the population. As previously mentioned in the literature<sup>(2-3)</sup>, a growing number of studies investigate people’s preferred place to end their days. In those studies<sup>(7-9)</sup>, end-of-life experiences at the hospital and at home are verified, the preferences of rural residents as compared to urban residents, all indicating that the house is the least stressful and the most dignified environment to experience end of life and death. Additionally, primary health care and home care services are considered powerful settings for developing the principle of palliative care and for people’s follow-up until death, because they are incorporated into everyday life, thus facilitating the governing of people and favoring the effectiveness of public policies for end of life care<sup>(10)</sup>.

Thus, we advocate for the importance of analyzing the organization of health care spaces – the home and medical-social institutions – set forth in public policies for people at the end of life in Brazil and France. These countries exhibit differences regarding economic, social and cultural aspects, but show similarities with regard to the development of strategies to help cope with current health care demands.

Entering, describing, and analyzing these spaces may provide grounds for the design of action strategies directed either to family members, who are the main responsible for end of life care in Brazil, or to health care professionals working directly in patient care at social or health care facilities, who take on this role in the French scenario<sup>(11)</sup>.

Given the foregoing, the following questions are raised: What are the conditions of the homes and medical-social institutions for people to experience end of life and death in Brazil and France? How are relationships developed in these spaces? In order to discuss these questions, the aim of the present study was to analyze the establishment of homes and medical-social facilities as possible sites for the provision of end of life care in the Brazilian and French scenarios.

## ■ METHOD

This paper describes some results of a doctoral thesis presented in 2017<sup>(12)</sup>. This is an ethnographic study linked to the field of post-structuralist cultural studies. In ethnographic studies based on this theoretical perspective, subjects gain concreteness through a discourse or institutional practice. In other words, habits, customs, and behaviors are incorporated into subjects' physical bodies, but the focus of analysis is on the discursive and non-discursive practices that go beyond these physical bodies and establish them into subjects of a given time. Therefore, ethnographic studies conduct an analysis of relationships developed in small spaces, within a given culture, from a historical *a priori* point of view<sup>(13)</sup>.

The immersion time in the field, in France and in Brazil, was 24 months, between October 2014 and October 2016. The study's scenarios were two Palliative Care Units (PCU), the homes of people with oncological disease at the end of life, in the cities of Porto Alegre, Brazil, and Grenoble, France. In relation to hospitals and palliative care units, in Brazil, the hospital was large, with 815 beds, and a teaching institution. In the period when the study was developed, the Brazilian palliative care unit had seven beds for hospitalization of Unified Health System (SUS) patients. The patients admitted to the unit were especially from the emergency service, but also from other hospital units. In France, the hospital was also a large size institute, with 2,133 beds, and a teaching institution as well. In that location there is a Palliative Care Clinic and Coordination of Support Care. This is a service consisting of a Palliative Care Unit and a Mobile Palliative Care Team. The Palliative Care unit had 10 beds.

In the French scenario, medical-social establishments were also part of the study, considering that this is the place where many of the patients go after hospital discharge and where they end their days. As exemplified in the introduction, medical-social establishments are institutions such as, for example, continuous and/or specialized care clinics, long-term institutions, which become the place of life – permanent or temporary – of people with health needs who are or are not in the final stage of life and that for various reasons do not return to their homes. These institutions have the “medical” character, because specialized health care is developed with the people who reside there. They are also characterized as social, because they harbor demands related to the organization of people, families and society to deal with situations of dependence arising mainly from aging.

The study participants were health professionals, people with oncologic disease who were hospitalized in the

PCU's and relatives. Regarding health professionals, we interviewed those who participated in the weekly meetings of the team to define the therapeutic behaviors. After the observations, we identified that certain professionals stand out in the decision-making process of hospital discharge and in the organization for the return to the home, they are: nurses, physicians, social workers and nursing assistants or technicians. As the nursing professionals were more numerous, compared to the other professionals, for this category, after the observations a nurse and a nursing technician were intentionally invited to represent this profession in the totality of the analyzed palliative care team. We emphasize that although health professionals were participants in the research, in this article – which is part of the data – we do not present their perspective. In relation to the people with oncological disease hospitalized in the PCUs, those that met the following inclusion criteria were included: age equal to or greater than 18 years old, prognosis of life expectancy up to six months and prospect of return to the home during hospitalization. Persons who were not residing in Porto Alegre or in the Agglomeration of Grenoble were excluded. In addition, when the person who did not have the physical conditions needed to interact and communicate, family caregivers were included. When the relative was interviewed, in the Brazilian scenario, the one most present at the time of hospitalization or the person in charge of care at home was selected. In the French scenario, the designated person of trust was selected in advance directives of will.

Thus, people at the end of life were selected from previous contact with health professionals and after consulting the medical records. We clarify that the participants of the research represent the cases that we accompany during the field work. Its clinical, economic and social situations are close to many others experienced in the daily life of health services, both in Brazil and in France. We emphasize that we do not privilege the number of informants, but we try to interact as much as possible with them, in order to better exploit the data that emerges, during the expected time for data collection, that is, one year in each scenario.

For the production of the data, the main author of this article accompanied the palliative care teams and patients in the hospital and in the home in medical-social establishments. This latter scenario has been included, since in France such establishments often become the homes of people at the end of life, such as it happened to two accompanied participants. In Brazil, there was no follow-up in a medical-social establishment, seeing that none of the patients were referred to this type of institution. The accompaniments occurred during the day, according to previous

combinations. On average, the researcher stayed three days of the week in the units; the remaining days were reserved for home visits.

The social research techniques used were participant observation, field diary and, to deepen some elements of the observation, semistructured interviews. We emphasize that in Brazil we had the opportunity to interview more relatives than in France. In the French scenario, we had more contact and relationship with people at the end of life. They had better physical and cognitive skills to establish communication and respond to questions. We think that this situation is due to the fact that, in Brazil, people with diseases that do not respond to the treatment that intends to modify them reach the Palliative Care teams when death is near.

In relation to the negotiations to accompany terminal patients and their families, the main researcher arrived in the PCU's rooms introducing herself as a nurse who accompanied the team for a research about "the challenges of being in the hospital and at home". She didn't focus initially on the aspects of end of life. She talked to the patients and their relatives about the hospitalization. Over the conversation, one of the team members made an opening to talk about the end of life situation. Then, after one or two visits, the researcher asked if they would accept to participate in the research. In all cases in which the invitations were made, they were accepted. After this contact and hospital accompaniment, a meeting was scheduled for the home visit.

The field diary was designed from notes registered manually on a notebook during the field trips. A total of 354 pages, recorded in a text file in *LibreOffice Writer version 4.4*, written in *Times New Roman*, size 12, space between lines 1.15. The home observation guide focused on the following aspects: relationship between the main caregiver and the patient; relationship between other relatives and the main caregiver and patient; organization of the family to receive the patient at home; and organization of house to receive the patient.

The interviews lasted approximately 35 minutes, were recorded in audio with a digital recorder and then fully transcribed to the text program *LibreOffice Writer version 4.4*, written in *Times New Roman*, size 12, space between lines 1.15; with a total of 119 pages. The whole transcription and translation process of the interviews was made in French by the main researcher. According to the discursive approach which belonged to the participants speeches, the empirical material was organized in charts which formed the *corpus* of this research. This *corpus* was submitted to cultural analysis and, in this article, we acted according to medicalization and governmentality notions<sup>(14-15)</sup>.

Regarding the ethical aspects, it is shown that in Brazil, in every stage of the study we followed the rules of Resolution No. 466/2012. The research proposal was submitted to the Research Ethics Committee (REC) with an Ethics Committee Certificate of Approval No. 43747015.5.0000.5327. It was approved under Opinion No. 1.072.851. In France, we had the written authorization of the hospital and PCU officers to carry out the study. There, according to the Public Health Code (PHC) in place, it is not necessary that nonintervention study participants, in the case of an ethnographic study, sign a free and clarified consent form, since there is no risk for their health. In these cases, it is directed to researchers who request only verbal consent of the participants. Therefore, we asked for oral consent from all participants.

To assure participants' anonymity, we used fictitious names. In the case of PCU patients, we chose fictional characters from Brazil and France history. The family caregivers were identified as: "caregiver + fictitious name of the person in palliative care".

## ■ RESULTS

Participants in the study were six people at the end of life and four family caregivers. Regarding the patients, in Brazil we accompanied two women, Tereza Cristina and Isabel, 60 and 64 years old; and a man, Pedro, 61 years old. The period between the beginning of the accompaniment and death ranged from 15 to 45 days. In France, we also accompanied two women, Marie and Jeanne, 83 and 71 years old, and a man, Louis, 73 years old. Accompaniment time ranged from 11 to 40 days. Regarding the relatives, three Brazilian women and one French woman were interviewed, two daughters and two wives.

Of the six patients, five returned home, and one, French, was referred to a social-medical establishment that houses elderly people with dependency, a place that became their home until the moment of death. Two patients, one Brazilian and one French, returned after a second hospitalization to their daughter's and daughter-in-law's home, respectively, due to an increase in dependence on basic life activities.

From the analysis, the following categories emerged: "They do not know where I live": the home as a space for the end of life; and "They are good here, but in another way": care actions in medical-social institutions.

### **"They do not know where I live": the home as a space for the end of life**

In relation to the Brazilian homes, we find two different situations. In the first follow-up, with Pedro, the family lived

in a two bedroom apartment, which had a living room, a bathroom, a service area and a space that looked like a mezzanine, a game environment and an area for some of the house's plants. In the second one, with Isabel, the home was located in a neighborhood with few sanitation conditions. The streets near the house were not paved and access to the residence was difficult, as described in the field diary:

*I meet Pedro on a bed, it was similar to a hospital bed [...]. Pedro's wife gives me a report on her husband's condition, shows me the transparent film-type bandages that the daughter got from an acquaintance to put on the father's heel and trochanter area [...]. In the room, three cherry-colored wardrobes surround the room. In one of them, which stood at the headboard of Pedro's bed, there were medications and healing materials. Peter's wife comments on changes in eating habits. She says she has made stew, rice, and pea cream. Everything with less salt [...]. I go for the end of the visit, Pedro's wife asks me to see if his back is well cared for, because she and her daughter were finding it very red and they thought it was due to the pyramidal mattress they got. (Field diary, June 26, 2015)*

*In the bedroom, I find Isabel lying [...]. We talked about the wheelchair Isabel has next to her bed. They tell me it is very good, although it is too large. Isabel is short and does not fit properly in it, besides, the wheelchair does not pass through the bedroom door [...]. She drinks water in a soft drink bottle improvised with a hole in the lid and, in this hole, a short straw. [...] The TV was taken into the bedroom. Two chairs for the visitors. On the dresser, a basket with the medicines Isabel has been taking and sunflower oil to moisturize the skin [...]. She [the daughter] tells me it is time to turn and change her mother. While the daughter changed her, I observed they had a "furniture" in the bed. (Field diary, Friday, July 17, 2015)*

In French houses, sick people are also transferred into bedrooms and the arrangement of the house is modified. What we identified as a difference is the strong presence of hospital techniques and practices in these environments.

*I introduce myself and she (daughter in law) asks me to come in, but first she shows me two burnt bed sheets. She tells me Marie caused, unintentionally, a small fire. She says her mother in law has been having hallucinations. She takes me into the bedroom where Marie is [...]. Marie was lying in her bed, she was using the delayed indwelling bladder catheter and also had installed the controlled release morphine pump, controlled by the person. Around*

*her there were pictures [...]. "Her" bedroom was small. Actually, the bedroom was improvised in order to receive her, because she used to live in an apartment, but had no access conditions, nor conditions to be there alone, this way, she was taken provisionally to her daughter in law's house. In Marie's bedroom we found her hospital bed, a table with materials and medicines in use. There were also spreadsheets where the cares provided by the nursing assistants and the nurses were noted. (Field diary, March 3, 2016)*

Among the visited people, Jeanne was the only one who did not receive the researcher lying in the bedroom. Even in her last days, Jeanne showed some independence, either in terms of medication control, or related to organizing life before death.

*I am afraid of what is coming related to the disease degradation, for sure. I am afraid of the pain and afraid of suffering. I am afraid of dying in bad conditions, because I know I am dying. I became aware two or three months ago that everything was lost and that they would stop with the "chemo". They stopped everything and told me: "that's it". Then, I had time to reflect and ask myself: what are you going to do? And there isn't anything to do. But don't you think I am like this because I am not afraid. Because I have my daughters to take care of, my granddaughters. I need to organize all this... (silence). It's sad what is happening to me. (Jeanne)*

Being independent to do one's daily activities is one of the factors that cause people in their final moments suffer, they become dependent on their families and friends for housekeeping or for bodily care. As far as Brazil is concerned, people in their final moments were more care-dependent in the final stage of their conditions, compared to patients in France, as exemplified in the following excerpt.

*Only now am I feeling it was what I thought. [- Researcher: ¿what is it that you thought Madam?] That I might not be able to walk. I see I cannot go out walking. It anguishes me. Not even at home, if I could only do it, just move. Because, I think, I am always going to find someone in the street that can do me a favor. In home, I am alone, that's it. I went here and there and did something. (Isabel)*

Despite having identified the desire to stay at home, difficulty in handling the symptoms, especially pain (as demonstrated by the following participant's testimonies), made it impossible that death occurred in this environment. None of the patients who were accompanied died at home.

*Things weren't that bad at home. I tried to follow, strictly, what was agreed in the hospital. So, everything went fine the first week [...]. My major problem is pain. I've been having deep crises of pain for a few days, and it gives me the creeps. Because pain is so deep. (Jeanne)*

*She had quite a headache and had to go twice to the emergency room of [name of the hospital] for them to inject her the medication, because she was in such pain. She cried a lot and her state worsened very quickly. (Teresa Cristina's daughter)*

### **“They are good here, but in another way”: care actions in medical-social institutions**

The “Life and Welcoming Shelters” (Lieu de vie et d'accueil, L.V.A), like the Clinics for continuous care and re-adaptation (*Clinique de Soins de Suite et de Réadaptation, SSR*) and the long-permanence institutions for the most dependent elderly (*Établissement d'hébergement pour personnes âgées dépendantes, EHPAD*) have become the home to individuals in their final moments of life living alone, or in cases when their families cannot take them in after hospital discharge. Life Shelters are spaces where people share the same environment. Generally, each person has their own room, but certain activities like reflections and free times are shared in common areas.

*I got to the Clinic [SSR] around 2 pm. There was a beautiful garden outside. I ask Louis if he felt homesick and he answers: “Of course! I don't feel at home here, but I know I'll never get back home” [...]. There was a little table to his side, similar to the ones you find in hospitals, with a box of biscuits, one or two books he had in the hospital and some magazines. His bed, in the institution, was also like the ones you find in hospitals. Besides, there was a TV in the room. (Field diary, Thursday, February 4, 2016)*

*[...] On the site [an EHPAD], there's a counter/sink to prepare medications, two computers for the professionals to do the registrations. We headed to the patient's room. On the way to his room we go through the common area or dining room, where several elderly people were around some tables. Some of them were talking to each other, and another just “staring into space”. On the room, we found a customized environment. The walls had two murals with the woman's and her family's pictures [...]. In the room, there was an individual bathroom. (Field diary, November 24, 2015)*

In these establishments, the number of nursing professionals is often limited and not proportional to the number

of internees. At the time of the visits, going through the corridors, we watched the nursing professionals almost always in movement with their materials through the institutions' long corridors, distributed in a similar way to the floors of hospitals. Despite care actions been taken, families feel that it is an accompaniment less singularized than the one offered in the PCUs.

*In my opinion, in the Palliative Care (unit) workers are much more attentive to the patient. They are much closer to the patient. They take care and calm the patient, make them serene. Here, there's also care, but given the number of sick people in relation to the number of people that care for them, they have no time to do what they could do in Palliative Care. But they are very good here, they are also good. But if there is no time to be interested... like we say... to be closer to the patient. They are good here... but in another way. (Louis' wife)*

## ■ DISCUSSION

The homes, though distinct in their constitutions and localizations, show similarities in how they are (re)configured after hospital discharge. The rooms are transformed. The bed is disassembled or repositioned, almost always moved from the corner to the center. Such changes facilitate that two people, for example, clean the patient's body or change their diaper. There are chairs around the bed. They are for the visitors, who come less frequently as death approaches.

People move away from the dying to avoid contact with what is fearful to man: the idea that the death will come for everyone. In the contemporary time, a period also known as the “biological century”, accompanying someone in the end of life enables us to perceive our fragility, while checkmating the discourse of beauty, longevity and immortality arising from molecular technologies. Such technologies culminated in the invention of the “biological citizen”, understood as that who has the right to access the health resources and treatment offered by biotechnology, which promise to improve body performance and extend life, modulating identities<sup>(16)</sup>.

In Brazilian homes, the TV fills up an empty space left out by the voids. It is one of the last forms of entertainment and contact with the outside world for those who cannot go out of their rooms any longer. Sometimes, the radio also fills that space, especially in France. Those media are part of the subject's constitution, and work as a pedagogical device that teaches, attributes significance, positions and educates people. They will fulfill that role even in the final stages of life<sup>(17)</sup>.

The room space is modified so it looks like a hospital bed. Besides the death bed, photographs are used as a way to recall the sick person's life experiences, a gesture close to the one done in the PCUs. Almost always, there is a table with the materials and medications needed to care for the patient at the headboard of the bed. They are improvised materials and products to reproduce the effects of the hospital. Such rituals customize the death bed, soon to be the home of the last revelations and affections<sup>(18)</sup>. On the other hand, in our opinion, this space becomes medicalized as well.

Organizing it similarly to what you find in hospital nursing wards, families try to care for the sick person, besides comforting themselves. Dying becomes an experience cross-permeated by the discursive practices in the health care, technological and economic areas. Technological devices, like medications, technical procedures and materials long ago incorporated into the hospital space as modulators of health care practices<sup>(14)</sup>, extend to the home, bringing continuity to the medicalization of life.

We also evidenced in France a medicalization process of the last stages of life in the home space. A process strengthened and subsidized by the State, which funds material and human resources for (re)organizing the home in terms of turning it into the space for the end of life. An investment that, even if costly, is still more economical and strategic than the hospital, because it creates strategies for governing the population<sup>(19)</sup>. Sometimes, this situation seems to generate inconveniences in families, due to the presence and flow of different people in the house space. Especially, people with a higher level of schooling tend to refuse home visit to the State's agents<sup>(20)</sup>.

In this sense, the technological apparatus implemented for the care of the sick persons with a disease which no longer responds to the treatment aimed at modifying it extends the end of life and keeps the sick person longer in bed, provoking other alterations in their body and in their relationships. "Death at the end of the tunnel becomes less certain and more distant, as a result of a condition that lasts and that the system tries to extend"<sup>(18:250)</sup>. With the investment on medications, probes and other devices used by the health care area, even in Palliative Care, diseases tend to take longer to "conclude their works" and, in this way, extend the waiting days of the sick persons, lying in their beds.

The symptom that is most present at the end of life is pain. It disturbs and causes fear, because it deprives the sick persons of enjoying the little pleasures, possibly the last ones. Pain intensification is also an alert for the fact that the disease is advancing and that death might be approaching. In the house space, people in their last stages of life

and their families control drug administration and change the environment. Despite this, as days go by, pain intensifies and, due to culminating crises, many people do not remain at home until death. Both in Brazil and in France, when pain exacerbated, people went to the hospital. They finally died there.

In France, despite the full available apparatus implemented by the State to keep people at home, the majority of the population does not die in this environment. According to a report from that country's National Observatory of the End of Life, 91% of the French already faced a death situation, but only 36% already accompanied a person at the end of life<sup>(21)</sup>. It is common in this country that the elderly lead lonely lives. So the French government designed devices which seem to be alternatives to the home for the care of that population in situations of fragility, disease and, also, at the end of life.

Medical-Social institutions are structures funded by the French government which welcome people with social difficulties and health problems. These institutions offer professional care, customized and adapted, to the needs of children, adolescents, adults, and seniors. In this sense, as population ages, the State devises strategies intended to attend to the transformations in relationships and in family configurations. If until the 1980s, the government was focused on politics and interventions about children and the youth for the working world, now a second demand emerges: elderly people who live alone and that, due to life prolonging, need accompaniment. In this way, when we analyze governmental tactics on the subject of non-contemporary end of life, we identify that the State does not effectively address the control of a territory or a political structure, but proposes strategies to lead people and things into the small spaces<sup>(15)</sup>, be them homes or institutions.

Institutions make use of equipment, medications and structures that are part of a market produced to attend to the inherent demands of dependency, demands that include those experienced in the process of dying. In this sense, we signal medical-social institutions as a combination of hospital elements with the customization of the home. It is a costly strategy for the national treasury and one which does not always attend to the expectations and requests of the sick persons and families, at least of those accompanied included in this studio, who believed it is hospitals, specially the Palliative Care services, that must provide dignity at the end of life.

Even with the technological apparatus and with the material resources available in those institutions, both teams and families do not seem to know how to cope with the

precedent moments of death, since that when they enter the agonic phase, also known as death's active phase (last hours/days of life), institutions tend to refer people to the hospital, location that continues to be the home to death<sup>(22)</sup>.

## ■ FINAL CONSIDERATIONS

In this study where we describe, analyze and discuss how homes and medical-social institutions are set up as spaces for the end of life, we identify that the hospital changes the way home care is carried out, and vice-versa. We understand that selecting the place where a person wants to end their days is a predominantly political decision, not an emotional one. People at the end of life die where it is permitted for them to do so, not where they want to. Normally, they prefer their homes but, when they are no longer capable of taking care of themselves, they delegate the decision on how they will end their days to their families. Families think about their relative's comfort and about what will be most practical and feasible considering their capacities to take on the responsibility for a person that will present more and more dependency for the basic activities of life.

The fact that, in some cases, we have interviewed the relative caregiver and not the patient, and the scarce accompaniment time with some patients can be considered as limiting factors for this study. Despite that, we believe that doing the research with people who are about to die (mainly in their homes) requires adaptation, sensitivity and flexibility on the part of the researcher in view of the fragile conditions the majority of people in that phase of the disease is.

In Brazil, even when socioeconomic conditions are not favorable, affection, complicity and solidarity among family members allow for home care. As long as there is no single material or equipment that could improve home care, families turn to creativity and adapt utensils that could diminish suffering in the process of dying. In France, access is possible to countless devices, which favors home stay. Meanwhile, younger and younger families do not seem to have the culture of taking in someone in the final stage of life in the house.

Finally, we perceive that the French government faces a situation from which it is necessary to devise new strategies to conduct the population. It is not only about governing the lives of children and adolescents to turn them into working adults. It is about acting in front of an aged population. People live longer and that time was also added to the last days of life.

In both scenarios, when death approaches, sick persons and families do not want to stay at home. Death causes

fear. Unpredictability too. In these cases, the road to take is that of the hospital, where suffering will be alleviated and pain lessened. Medical-Social institutions as a space for the end of life have been an alternative which is incorporated gradually by the State. It is yet to be known, in the course of the following years, how access will be organized and what assistance these institutions will give to individuals at the end of their lives.

## ■ REFERENCES

1. Abbagnano N. Dicionário de filosofia. 6. ed. São Paulo: Editora WMF Martins Fontes; 2012.
2. Pivodic L, Pardon K, Morin L, Hall JA, Miccinesi J, Cardenas-Turanzas M, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health*. 2016 [cited 2019 Jan 14];70(1):17-24. Available from: <https://jech.bmj.com/content/70/1/17>
3. Champion N, Medigovich K, Morrison P. Exploring why some terminally ill people die in hospital when home was their preferred choice. *Aust J Adv Nurs*. 2016 [cited 2019 Jan 15];33(2):6-12. Available from: <http://www.ajan.com.au/Vol33/Issue2/33-2.pdf>
4. Hui D, Nooruddin Z, Didwaniya N, Dev R, De La Cruz M, Kim SH, et al. Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": a systematic review. *J Pain Symptom Manage*. 2014;47(1):77-89. doi: <https://doi.org/10.1016/j.jpainsymman.2013.02.021>
5. Ministério da Saúde (BR). Comissão Intergestores Tripartite. Resolução nº 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema Único de Saúde (SUS). *Diário Oficial da União*. 2018 nov 23 [citado 2019 jan 14];155(225 Seção 1):276. Available in: <http://www.in.gov.br/web/dou/-/resolucao-n-41-de-31-de-outubro-de-2018-51520710>
6. Ministère des Affaires Sociales, de la Santé et des Droits des Femmes (FR). Plan national pour le développement des soins palliatifs et l'accompagnement en fin de vie - 2015/2018. Paris: Ministère des Affaires Sociales, de la Santé et des Droits des Femmes; 2015 [cité 2019 jan 14]. Disponible depuis: [https://solidarites-sante.gouv.fr/IMG/pdf/031215\\_-\\_plabe56.pdf](https://solidarites-sante.gouv.fr/IMG/pdf/031215_-_plabe56.pdf)
7. Assareh H, Stubbs JM, Trinh LTT. Variation in hospital use at the end of life among New South Wales residents who died in hospital or soon after discharge. *J Aging Health*. 2019;26:898264319848582. doi: <https://doi.org/10.1177/0898264319848582>. [Epub ahead of print]
8. Wilson R, Gougham F, Whitburn T, Higginson IJ, Gao W. Place of death and other factors associated with unnatural mortality in patients with serious mental disorders: population-based retrospective cohort study. *BJPsych Open*. 2019;5(2):e23. doi: <https://doi.org/10.1192/bjo.2019.5>
9. Dong T, Zhu Z, Guo M, Du P, Wu B. Association between dying experience and place of death: urban-rural differences among older Chinese adults. *J Palliat Med*. 2019 May 23. doi: <https://doi.org/10.1089/jpm.2018.0583>. [Epub ahead of print]
10. Oliveira ST, Kruse MHL, Cicoletta DA, Velleda KL. Visita domiciliaria en el Sistema Único de Salud: estratégia de biopolítica. *Rev Uruguaya Enferm*. 2018;13(1):9-21. doi: <https://doi.org/10.33517/rue2018v13n1a2>
11. Cordeiro FR, Carlin N, Kruse MHL. La sortie d'unités de soins palliatifs au Brésil et en France: expériences de patients atteints d'un cancer avancé et de

- leurs familles. *Médecine Palliative*. 2018;17(3):139-147. doi: <https://doi.org/10.1016/j.medpal.2018.03.002>
12. Cordeiro FR. O retorno ao domicílio em cuidados paliativos: interface dos cenários brasileiro e francês [tese]. Porto Alegre (RS): Escola de Enfermagem, Universidade Federal do Rio Grande do Sul; 2017 [cited 2019 Jan 10]. Available from: <https://www.lume.ufrgs.br/handle/10183/152722>
  13. Miranda HC. Michel Foucault e a antropologia. Curitiba: Editora Prismas; 2016.
  14. Illich I. A expropriação da saúde: nêmesis da medicina. 3. ed. Rio de Janeiro: Nova Fronteira; 1975.
  15. Foucault M. Segurança, território e população: curso no Collège de France (1977-1978). São Paulo: Martins Fontes; 2008.
  16. Gaudenzi P. Mutações biopolíticas e discursos sobre o normal: atualizações foucaultianas na era biotecnológica. *Interface (Botucatu)*. 2017;21(61):99-110. doi: <https://doi.org/10.1590/1807-57622015.0870>
  17. Cordeiro FR, Kruse MHL. Production of an end-of-life curriculum vitae through the pedagogical apparatus of the media. *Interface (Botucatu)*. 2015;19(55):1193-205. doi: <https://doi.org/10.1590/1807-57622014.0199>
  18. Perrot M. História dos quartos. São Paulo: Paz e Terra; 2011.
  19. Dantony C, Vassal P, Blanc P, Charles R. Développement des soins palliatifs de proximité à domicile: expérience de trois équipes mobiles. *Médecine Palliative*. 2018;17(6):323-30. doi: <https://doi.org/10.1016/j.medpal.2018.05.002>
  20. Observatoire National de la Fin de Vie (FR). La fin de vie des patients hospitalisés à domicile: HAD, fin de vie et précarités. Paris: Observatoire National de la Fin de Vie; 2015 [cité 2019 mar 09]. Disponible depuis: [https://www.fnehad.fr/wp-content/uploads/2015/03/HAD\\_Rapport\\_VF.pdf](https://www.fnehad.fr/wp-content/uploads/2015/03/HAD_Rapport_VF.pdf)
  21. Observatoire National de la Fin de Vie (FR). Fin de vie, un premier état des lieux: rapport 2011. Paris: Observatoire National de la Fin de Vie; 2011 [cité 2019 jan 23]. Disponible depuis: <https://bit.ly/2XBxoiC>
  22. Leblanc-Briot MT. Fin de vie des personnes âgées. Jusqu'à la Mort Accompagner la Vie. 2014 [cité 2019 jan 23];119:97-108. Disponible depuis: <https://www.cairn.info/revue-jusqu-a-la-mort-accompagner-la-vie-2014-4-page-97.htm>

#### Acknowledgments

To Comissão de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) and Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq) for funding this research, and to Dr. Noelle Carlin, from the French Society for Accompaniment and Palliative Care (Société Française d'Accompagnement et de Soins Palliatifs, SFAP), for their coguidance during the abroad stage of the doctorate in the French institution where the study was carried out.

#### ■ Corresponding author:

Franciele Roberta Cordeiro

E- mail: [franciele.cordeiro@ufpel.edu.br](mailto:franciele.cordeiro@ufpel.edu.br)

Received: 03.09.2019

Approved: 06.27.2019