



The person-environment relationship in the process of finitude

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Abstract: Objective: To understand the relationship between caregivers and patients who are undergoing the process of finitude with the environment where they are during this process. Method: This is a qualitative, exploratory and descriptive research. According to the saturation criterion, there were 19 participants: 10 patients (5 in palliative care at home and 5 in curative care in Intensive Care Units - ICU) and 9 relatives of the respective patients. They responded to a narrative interview, which is characterized as an instrument that makes it possible to understand how the participant perceives and experiences the environment around her/him. For the analysis of the material, the interview was interpreted through textual analysis using the Iramuteq software. Results: The results indicated great adversities in the process of finitude in both environments: ICU and home; however, the family environment is seen as promoting quality of life and of death with dignity by patients, due to the support network offered by family and friends. Conclusion: the person-environment relationship in the process of finitude is characterized by affections and meanings, and needs to be taken into account as a facilitator of quality of life.

Keywords: Psychology of health; environmental psychology; palliative care; intensive care units; home assistance service.

[es] La relación persona-ambiente en el proceso de finitud

Resumen: Objetivo: comprender la relación de cuidadores y pacientes en el proceso de finitud con el entorno en el que se encuentran durante este proceso. Método: fue un acercamiento exploratorio y descriptivo, cualitativo. Los criterios de saturación incluyeron 19 participantes: 10 pacientes (5 en cuidados paliativos en cuidados domiciliarios y 5 en cuidados curativos en la UCI) y 9 familiares de los pacientes respectivos. Respondieron a un instrumento, la entrevista narrativa, que se caracteriza por ser un instrumento que permite comprender cómo el participante percibe y experimenta el entorno que lo rodea. Para el análisis del material, la entrevista se entendió a través del análisis textual en el software Iramuteq. Resultados: los resultados indicaron grandes adversidades en el proceso de finitud

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en ambos entornos: UCI y hogar; sin embargo, se considera que el entorno familiar promueve la calidad de vida y de la muerte con dignidad de los pacientes, debido a la red de apoyo que ofrecen familiares y amigos. Conclusión: la relación persona-ambiente en el proceso de finitud se caracteriza por afectos y significados, y debe tomarse en cuenta como facilitador de la calidad de vida.

Palabras clave: Psicología de la salud; psicología ambiental; cuidados paliativos; unidades de cuidados intensivos; servicio de asistencia domiciliaria.

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1. Introduction

Health care undergoes constant changes of meaning as history progresses, this is a consequence of changes in the way of seeing the binomial health-disease, its determinants and guidelines of care. For centuries the biomedical model has prevailed, characterized by its focus on the compartmentalized body, biological reductionism and the prioritization of curative care. Today, faced with new conceptions that include the guidelines of the expanded concept in health, we see the relevance of analyzing the individual in a comprehensive, integral way, seeking as an imperative the empowerment of the patient, calling her/him to be an active agent in the process of health and disease. It is an organizational model that restores the configuration of care, emphasizing prevention, health promotion and care for the quality of life, even when there is no cure⁽¹⁻²⁾.

Health care values the acceptance and the relationship, providing innovations according to the needs of each individual, aiming to promote health, well-being, autonomy and active participation of the subject. To do so, it needs different types of actions linked to different profiles of professionals. This starts from the premise that care is always a set of rules and principles that guide the subject-professional relationship and this historical construction reflects directly on the reconfiguration of the social representation of the meaning of falling ill and being cared for in contemporary times^(1, 3).

To talk about the act of caring in health is to engage in activities that contrast in technique and experience. In the Western context, caring for a critically ill patient whose life is threatened is often related to the range of activities performed to enable healing. This factor balances the biotechnological advances in medicine and the exhaustive use of hard and soft technologies, along with the persistent efforts to increase life expectancy. This goal of “saving lives at all costs”, characteristic of the practice of curative care, results, however, in processes that may neglect the success of the activity, mainly because it confronts the limitation of the act of healing⁽⁴⁾.

Factors that foster the practice of curative care often reflect on the service and its dehumanizing practices. The dynamics of the hospital environment and its focus on technologies means that professionals position themselves impersonally in the face of high demands. These professionals are commonly seen to be replacing the relationship with the patient with interaction with the machinery, reinforcing the

fragmentation of care, neglecting the attention to the patients, generating feelings of helplessness and neglect in individuals⁽⁵⁾.

In this scenario, therapeutic obstinacy becomes routine in the hospital environment, through the excessive use of technological devices, in order to prolong life, leading the patient to continue in suffering. A consequence of this obstinacy, dysthanasia prevails in Intensive Care Units (ICUs). There is a slow and painful death, resulting from invasive and futile procedures, in view of the irreversibility of a disease, in order to keep the patient alive. It is reinforced by a culture that denies and rejects human mortality and reveals the biological dimension as the only one worthy of care. In this context, the damage experienced in the ICU environment for patients in the process of finitude is immense, as they are isolated from their family, lose their autonomy and dignity, and experience their death with stress, sadness, anxiety, suffering and pain^(4,6).

In opposition to this practice emerges orthothanasia, which respects the natural process of death without disproportionate prolongation. As a way of operationalization, palliative care is presented as an approach of modern care, which adds or replaces, at a certain moment of disease progression, the perspective of curative care. Its basic focus is to expand humanized and integral care, acting in the prevention and management of symptoms and offering quality of life and death for patients with serious life threatening diseases. Its actions may occur in four phases: (1) early palliative care, when the patient has a good functional status, with a prognosis estimated in months to years; (2) complementary, when the patient presents intermediate functional status, with the prognosis estimated in weeks to months; (3) predominant, when the patient presents low functional status, with characteristics of irreversibility of the underlying disease, and the prognosis is estimated in days to a few weeks; and (4) exclusive, aimed at patients with low functional status and rapid and irreversible decline in general status, i.e., end-of-life care⁽⁷⁾.

One of the guiding principles of palliative care is the confirmation of life and the acceptance of death as a natural course. There is no pretense to advance or prolong finitude. For this, it aims at the early identification of physical, psychosocial and spiritual problems and respect for the dignity of the patient, the integration of her/him and her/his family, as active and caring agents, as they are subjects who have accompanied the illness and need this attention⁽⁷⁻⁸⁾.

For the performance of these activities, an interprofessional health team is necessary that prioritizes biopsychosocial aspects of the individual in the correct way. Thus, accepting the prognosis of the individual's disease and its finitude is to know and have the opportunity to work on their expectations and fears, facilitating the rediscovery of ways to increase their well-being and for those involved, leading them in the process of dying. All this requires the construction of effective communication between the triad - professional, family and patient. Aligning this dialogue results in the reliability of relationships, but also provides security, bonding with the team, respect, autonomy, active participation of those involved and an effective improvement of quality of life at this time⁽⁷⁻¹¹⁾.

The practice of palliative care can occur in several centers of care. It may be present in inpatient wards, outpatient clinics, emergency rooms, ICUs and even in hospice or home care, the latter being the idealized place for the practice of exclusive palliative care dedicated to patients in the process of finitude⁽¹²⁻¹³⁾.

The caring at home service, known as home care, is considered promising in palliative care. By mediating the proposal of humanization in care, it seeks to

promote deinstitutionalization and provide social and family relations; factors that add safety and comfort in the process of finitude. However, it still represents a challenge for health care in Brazil, reflecting directly on health management, given the high rates of hospital treatment and high expenses for long periods of hospitalization⁽¹⁴⁻¹⁶⁾.

It is noteworthy that both modes of care, whether curative or palliative, in the ICU or home care, show some limitations for the persons involved during the process, especially family caregivers. These are fundamental subjects in the care process, favoring the maintenance of affective relationships with patients, helping them to feel cared for, increasing their quality of life and supporting them to cope with the disease process⁽¹⁴⁾.

Moreover, the family often participates in this caring in an environment of sickness and apprehension along with the patient, from the initial diagnosis, which is characterized as a phase of intense suffering, until the prognosis, especially if it is identified as guarded, when there is usually denial and paralysis of those involved⁽¹⁷⁻¹⁹⁾. Therefore, considering the macro perspective of palliative care, it is necessary to monitor how the family deals with the disease, observing what stage of life they are in, how they are organized and the position the patient occupies in the family network, extending this care to all involved⁽¹⁴⁻¹⁸⁾.

In this singular context, it is understood that there are particularities that strongly influence the process of dying. One is the environment where the patient receives care, whether curative or palliative⁽¹⁸⁻²⁰⁾. In ICUs, suffering causes an imbalance in family and social dynamics, given that the patient is isolated, and the family is frustrated at not being nearby. On the other hand, it offers a certain security to family members, who are not committing themselves to the care, not responsible for the risks of complications related to the clinical condition, or for not suffering from the belief of helplessness and carelessness^(16,18).

Home care as palliative care also produces family illness, as managing the daily care for an end-of-life subject is an extremely tedious activity and demands an emotional, physical and even financial burden, compromising the quality of life of those who perform it. Caregivers can be socially isolated, experiencing losses, including work activities, and are prone to acquire physical and psychological exhaustion, which can lead to a feeling of imprisonment, when the caregiver's life is exclusively focused on meeting the patient's demands. On the other hand, the patient lives their last days of life close to those who are important to them, without unnecessary invasive procedures, while under the care of the team of home visiting professionals^(16,18,20-23).

Whether in the ICU or at home, the family caregiver will deal with the moment of death of the patient in the process of finitude. This event can generate many negative memories for the caregiver, especially in home care, due to the continuity of living in the place of the occurrence. This factor, added to the fear or difficulty of taking care, results in the frequent choice of the hospital as being the most suitable environment to die in^(22, 24).

Faced with the numerous challenges of caring for a family member in the process of finitude, for those who are afraid of the complications, responsibility and negative memories associated with this moment, spirituality emerges as one of the main defense mechanisms, enabling the development of a new way of looking at the path of the disease. The spiritual view emerges as significant through the process

of becoming ill, giving meaning to the lived experience and collaborating with the development of the subject in the face of death and dying⁽²⁵⁾, and promoting well-being, maturity and personal evolution⁽²⁶⁾.

This discussion opens up prerogatives to analyze the person-environment relationship in the process of finitude. It is from this scenario that one perceives the behavior of the individual in the space where she/he is inserted and how she/he appropriates this place, producing subjectivity and building her/his identity. To this end, Environmental Psychology has been concerned with the process of human action on the environment and the way it reflects on the individual, that is, how it affects her/him and how it is affected by her/him. Symbols and values, whether conscious or unconscious, are embodied in a relationship of mutual exchange. Thus, all the incorporation of the environment occurs in the interaction with the individual and the environment, thus constituting itself as part of the self, where conscious and unconscious representations are constructed⁽²⁷⁾.

Under this assumption, it is intended to address this person-environment relationship in the context of hospital and home, specifically in the ICU and home care, and how the proper aspects of this relationship contribute to the promotion of health and well-being of affected patients with cancer and other life-threatening diseases. Therefore, it must be considered that there is reciprocity in the relationship between behavior and place, and this reciprocity happens in a bidirectional and interdependent sense. From this, it is understood that the environment is constituted of the physical environment where the subject is inserted, be it natural or constructed, and that is inseparable from the social, political, cultural and psychological. This environment is everything that is contained within it, be it objects, people, and any changes that occur in its configuration⁽²⁸⁾.

Regarding this aspect in the context of finitude, the literature indicates that the person-environment relationship demonstrates an indicative of factors that result in stress. The physical space of the hospital impacts the therapeutic treatment of the hospitalized patient, especially when it is depleted of identifiable figures and marked by depersonalization. Along with this, the disease is the propellant of several losses, in regards to the environmental relationship, the individual will need to learn the customs and rules of the environment in which they are inserted. The effects of this dynamic, together with the fragility imposed by the disease, are integral parts of the health-disease relationship, which in this case triggers high levels of stress and suffering⁽²⁹⁻³¹⁾.

On the other hand, there is a lack of studies on the person-environment relationship in the process of finitude and home palliative care. It is only known that if, on the one hand, this place represents safety and belonging to the patient, it is also a place of sickness for the family and / or caregiver⁽³¹⁾.

In this manner, Environmental Psychology points to the concept of restorative environments, which are understood as those that provide the renewal of directed attention, and the consequence of this is the reduction of mental fatigue. It concerns an environment that produces aspects beneficial to health. Thus, the concept of restorative environments incorporates the quality of life of people in their respective spaces, minimizing the characteristics of confinement, social isolation, and the decrease or even loss of autonomy. Therefore, it is often seen that the family environment plays a restorative role in the process of the subject's illness. Hence there is a need to reflect on the family environment as one that can

provide the subject with a better experience at this time in their life, emphasizing their connection to spaces and places, where, during this journey, the home is recognized as an emotional territory⁽³²⁻³⁴⁾.

Given the above, this research aims to create a dialogue and intersection between Health Psychology and Environmental Psychology, understanding aspects that can improve the conditions of assistance and care of patients in the process of finitude, focusing on the relationship of patients and families with the environment. It is observed that in both contexts of care, ICU curative care and home palliative care, there are several issues to be observed and evaluated. Is the ICU or home care service more or less beneficial for experiencing the quality of death? Are these environments restorative or stressful? How are these aspects experienced and elaborated by patients and family caregivers within their own individual course in these relationships and in the person and place process? Given these questions, this research aims to understand the person-environment relationship of patients in the process of finitude in curative and palliative care and their family-caregivers.

2. Method

Type of study

A qualitative, exploratory and descriptive research was conducted. The choice for the qualitative perspective was made so as to enable the researcher to understand the human experiences, the difficulties and behaviors of the individuals involved, and unveil and interpret the speech of the participants. In this way, exploratory research aims to involve researchers with the object and give a broader and deeper view of it, while descriptive research seeks to understand the phenomenon in its entirety and complexity, and describe it⁽³⁵⁾.

Participants

According to saturation criteria, 19 participants were included: 10 patients (5 in palliative care in home care and 5 in curative care in an Intensive Care Unit - ICU) and 9 family caregivers of the respective patients. Inclusion criteria were: being a patient with a poor prognosis, cancer or another serious disease, and being in palliative care in home care or curative care in the ICU; or being a relative of these patients (see description of participants in Table 1).

Instruments

A Narrative Interview was used, characterized as an unstructured technique that serves to deepen perceptions and attitudes, from the reflection of narrated history with the elaboration of socio-historical contexts lived by individual experiences⁽³⁶⁾. From this, the objective was to gain access to the participant's experience through a trigger question: "How is it for you to be at the hospital / at home at this time in your life?" (directed at the Patient) or "How is it for you to take care of your family member at the hospital / at home at this time in his or her life?" (directed at the family member).

Table 1. Survey Participants

Nº	Category	Locus	Approach to Care	Sex	Age	Patient's Illness
1	Patient	Home	Palliative	F	69	Polyneuritis
2	Patient	Home Care	Palliative	M	73	Cancer
3	Patient	Home Care	Palliative	F	83	Stroke
4	Patient	Home Care	Palliative	F	42	Charcot/Ataxia
5	Patient	Home Care	Palliative	F	97	COPD
6	Patient	ICU	Curative	M	79	COPD
7	Patient	ICU	Curative	M	61	Cancer
8	Patient	ICU	Curative	F	29	Broncopneumonia
9	Patient	ICU	Curative	F	86	Renal Failure
10	Patient	ICU	Curative	M	82	Cirrhosis
11	Family	Home	Palliative	M	36	Stroke
12	Family	Home	Palliative	F	68	Cancer
13	Family	Home	Palliative	F	46	Cancer
14	Family	Home	Palliative	F	42	Polyneuritis
15	Family	Home	Palliative	F	64	COPD
16	Family	ICU	Curative	F	54	COPD
17	Family	ICU	Curative	F	62	Cancer
18	Family	ICU	Curative	M	63	Renal Failure
19	Family	ICU	Curative	F	43	Cirrhosis

Ethical Procedures and Data Collection

This research was approved by the Research Ethics Committee, through decision No. 3.215.621, and was developed in accordance with the ethical standards, in compliance with Resolution No. 466 of December 12, 2012 of the National Health and Safety Council, after obtaining the free and informed consent, including the signing of the Informed Consent Form (ICF) by the participants. Prior to the start of data collection, the researchers selected the patients who met the inclusion criteria, visited the patients, and made the invitations, explaining the research procedures. The interviews were conducted individually and with the help of a recording device, at a time and place determined by the participant. It is emphasized that, in view of the patient's death process, these meetings were offered as moments of listening to the patients, and data collection was the secondary objective, consequent to this listening.

Data analysis

Data were evaluated in two steps. The Narrative Interviews were interpreted through textual analysis of the Iramuteq software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*), through the Descending Hierarchical Classification (DHC) for the creation of the dendrogram with the

emerging classes, where the higher the χ^2 , the more associated the word is with the class, and disregarding the words with $\chi^2 < 3.80$ ($p < 0.05$). In the end, a word cloud was presented, from which it is possible to visualize the most relevant words of the speeches, the largest ones having the most frequency.

3. Results

Analysis of Narrative Interview

This topic discusses the analyzes that aim to understand the person-environment relationship in the finitude process, from the perspective of the patient and the caregiver in curative and palliative care. The general corpus consisted of nineteen texts, separated into 508 text segments (TS), with 398 TSs (78.35%). There was an emergence of 17,692 occurrences (words, forms or vocabulary), being 2,351 distinct words and 1,227 with a single occurrence.

The analyzed content was categorized into four classes. Class 1, “*Pathway of illness: adaptation to diagnosis and guarded prognosis*”, with 92 TS (23.1%), refers to the moment of adaptation to diagnosis and guarded prognosis, presenting negative feelings about reality. Class 2, “*Interfaces of care: the caregiver’s routine and the importance of the support network*”, with 108 TS (27.1%), highlights the family / caregiver’s routine as the front line of this care and its difficulties, and the support of friends in the moments of hospitalization.

Class 3, “*Daily Losses of Patient and Caregiver*”, with 122 TS (30.6%), depicts personal losses and resignations, whether of patient autonomy or caregiver’s ability to resume their life, and how these experiences result in a new way of seeing suffering, with spirituality as a coping mechanism. Class 4, “*Hospital environment (curative care) vs home environment (palliative care)*”, with 76 TS (19.1%), presents the helplessness of curative treatment in the discovery of the disease, the deficit in medical care and the family environment as a quality of life strategy, providing space for the family and the patient to be protagonists of their health-disease process.

Class 1 - Path of illness: adaptation to diagnosis and guarded prognosis

This class consists of 23.1% ($f = 92$ TS) of the total corpus analyzed. It includes words such as “Know” ($\chi^2 = 23.70$), “Discover” ($\chi^2 = 16.84$), “Time” ($\chi^2 = 13.86$), “Surprise” ($\chi^2 = 13.44$) and “Phase” ($\chi^2 = 10.05$). It refers to the period of adaptation to the diagnosis and guarded prognosis as a moment full of negative feelings that are revealed during the course of illness.

From July until now, when we found out, I haven’t sleep well, I have my cell phone all the time, waiting for news, and being scared of news. Because it happened twice since he went to the ICU with severe gastrointestinal bleeding and I accompanied him and seeing my father like that... But being scared that something bad will happen, which is what we unfortunately expect from this disease, that’s it. [...] When we found out, it took us by surprise that the doctor also gave us [...] he told us that he only had 3 months, right? He gave him exactly three months of life. (Participant 13)

But I get up to get my little things, not waiting for the others, you know? I wish I had a full life. I don't have [...] twenty four hours lying here, I turn this way, I turn the other way, that's how it is. I am not in the mood for anything. (Participant 05)

The reports show that since the discovery of a diagnosis of a serious illness, such as cancer, or in the face of a poor prognosis, patients and their families have seen their lives change, either to dedicate themselves to treatment or to be sure at the end of life. These are times that are difficult for everyone involved, needing adaptation and support.

Class 2 - Interfaces of care: the caregiver's routine and the importance of the support network

This class presents 27.14% ($f = 108$ TS) of the total corpus analyzed. It includes words such as "Difficult" ($x^2 = 21.87$), "Home" ($x^2 = 12.27$), "Complain" ($x^2 = 8.12$) and "Tired" ($x^2 = 2.39$). It discusses the routine of the family caregiver as the front line of care and their difficulties in daily life. The caregiver participants also point out the distance from other family members and report on the support of friends during hospitalization periods.

There are days when I come here at midnight. They'll pick me up because she's decided not to sleep, not to close the door, you know? Then when I arrive, she says: 'What are you doing here at this time?' But, woman, it is getting very tiring to come and go and come [...] There are days when I come here at Midnight, woman. I have just arrived, five o'clock, midnight, I have to go back [...] But they don't think so. Which is why I follow her wishes. Woman, no one wants to take care of the elderly no, no one, no, it's just here. (Participant 12)

Faced with this impasse, the family member experiences an unpleasant and lonely emotional experience, which impairs their quality of life, autonomy, and generates negative consequences that are physical, psychic and social. This situation is even worse when this task is exclusive or predominant for a single responsible individual, distancing the person from other family members, causing the caregiver to suffer feelings of helplessness, which can be alleviated by the help from other support networks.

A friend comes now to stay with me at noon and she stays until three, there are another couple of friends who stay with me until about five o'clock. I only have friends, because my family is living abroad, they don't live here. Actually they are from here, I came here and there were many friends coming to visit me and they are all like that, gosh. (Participant 08)

But interestingly, the most interesting thing [...] "M", that day started walking, you see, but this was all in here, around the whole house, that is gratifying. I would really like to have a great-grandson, a great-great-grandchild, everything I like. Family, family is good. In the hospital you have to stay there in that regime, right. And we have days that I can't stand it even at home, even more in hospitals, it's kind of difficult, I don't like hospitals, no. (Participant 11)

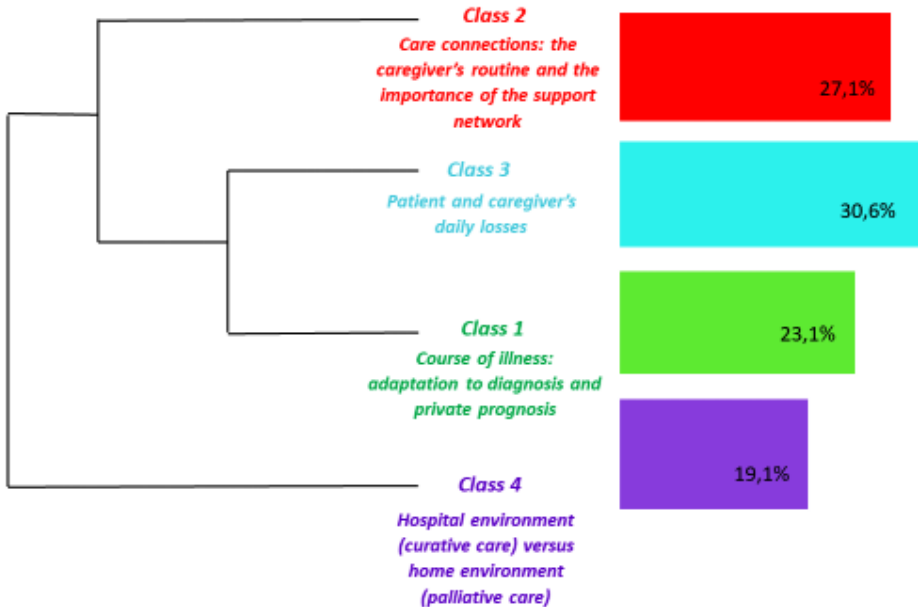


Figure 1. Dendrogram of Descending Hierarchical Classification

In this context, it is important to highlight that the family caregiver needs a support network, whether from friends, other family members or the professional team. It is reinforced, therefore, that the dignity of the death process must be offered to both the patient and the family.

Class 3 - Daily Losses of the Patient and Caregiver

This class consists of 30.6% ($f = 122$ ST) of the total corpus analyzed. It includes words such as “Sick” ($x^2 = 25.34$), “Understanding” ($x^2 = 18.00$), “Caring” ($x^2 = 27.86$), “Check into” ($x^2 = 17.00$), “Experience” ($x^2 = 11.46$) and “Cry” ($x^2 = 5.80$). Participants discuss their personal loss and resignation during illness. Factors such as “paralysis” of the caregiver’s life and patient autonomy emerge. On the other hand, they report that suffering has enabled a new way of seeing life, with spirituality considered as a coping mechanism.

Taking care of her, is how can I say this, is fortifying and at the same time, and at the same time, it is devastating, because you see, I can’t even talk, you see [...] her sick, and you want to do something, and you can’t do it [...] Never being able to have children, that would be my biggest fear and so, after she got sick, I had to give it up, you know? I had to give up having a child, I had to give up the life I had always dreamed of, that I always imagined. (Participant 14)

At the right time and [...] then, before she got sick, this time. Even though she wasn’t so lucid when she saw me crying, she always had the right words to say and now she hasn’t, there’s no more. That’s what hurts the most. (Participant 14)

I read Psalm 91 and Psalm 23, and when I read the psalm to her, she started to cry, you know? And so, we see hope when we see this, right? (Participant 14)

But I've always learned one thing, I'm a Christian, I'm God-fearing... and I've learned something from Jesus that we must understand that all things work together for good to those who love God. (Participant 07)

The path of illness is marked by several stages. The spiritual dimension always emerges as a defense mechanism to the reality of the disease, and thus enables the development of a new way of seeing the process, giving meaning to the disease and meaning to life. These factors provide a maturity to the disease and provide personal evolution. Therefore, spirituality transports the patient and family to a plane that assigns meanings to the disease, making this path more lenient so that they can see the end of life with dignity.

Class 4 - Hospital environment (curative care) vs Home environment (palliative care)

This class refers to 19.1% (f = 76 ST) of the total corpus analyzed. It includes words like "Treatment" ($x^2 = 69.28$), "Doctor" ($x^2 = 63.80$), "Disease" ($x^2 = 25.07$), "Involvement" ($x^2 = 21.45$), "Cancer" ($x^2 = 20.47$), "Pain" ($x^2 = 16.88$), "Relative" ($x^2 = 8.17$) and "Environment" ($x^2 = 5.48$). The participants report on the helplessness experienced in the discovery of the disease and the course of curative treatment. There is emphasis placed on the shortage of medical assistance in hospital curative care, which is independent of social status, in contrast, the family environment emerges as a place that offers a better quality of life, providing a space for the family and the patient to act as protagonists of the health-disease process.

With the best private doctors and everything, and I... and I felt lost, because I was going to a doctor one day, asking for some tests; I would return, take it there, and he'd prescribe some medicine. Oh, M did not improve, M was very weak, then I returned to the doctor, then the doctor said 'oh, because you need to look for such a doctor', then I went to another doctor, then went to another doctor [...] Then I thought it was very serious, because I had never experienced this... the doctors did not get involved with the situation. You come, they look at you, prescribe a medicine... if it worked, it worked; if it didn't, go to another, understand? You don't feel that the doctor is your ally against the disease. You feel lonely and no doctor is committed. You call, you can call, when you call their cell phone, they don't answer, they give you other news, no one gets involved. (Participant 15)

So I think I'm not missing much. So let's suppose I say that [...] what's missing in my home treatment? Maybe a doctor is missing in the house do you understand? [...] Because at home you do not separate from your family, you do not separate from your grandchildren, you do not separate from your wife, and you have a treatment that's a thousand times better. Because nothing is missing, you know? (Participant 01)

Because it really is wonderful, being able to be treated for any illness in your home environment, it's the business. (Participant 01).

4. Discussion

The survey results show that the discovery of the diagnosis of cancer or other serious diseases, and their guarded prognoses, interrupts the life course of patients and their families. They see their present and future life plans threatened by the possibility of death⁽⁴⁾. At this moment the fear is confirmed, amid denial, revolt, sense of failure, fear or paralysis of all those involved⁽⁶⁾. Therefore, the support of the team with a receptive attitude to the caregiver, offering emotional support to the patient, is essential for them to elaborate the difficult news, the irreversibility of the disease and the guarded prognostic course⁽¹⁷⁾. On the other hand, caring for a family member in the process of finitude is an activity that can cause many conflicts and disorders in the parental structure, but especially in the caregiver's family life. They are burdened with an activity that causes daily losses in several areas, there is a reduction in their quality of life, since they need availability, time and full commitment to the effectiveness of this care. By defining this responsibility, one loses the freedom to enjoy one's own basic needs in order to be available to the entity who has the priority of attention. This factor results in emotional overload, physical, mental illness and suffering for the family member, due to the difficulty in elaborating the lived reality^(7-8, 27).

In addition, caring for a family member undergoing a process of finitude in the home environment means dealing daily with the possibility of a traumatic episode, that is, death itself, an episode that terrifies most family caregivers^(1-3, 24). Due to this scenario of suffering, the act of caring is full of contradictory feelings. The family caregiver invests energy and takes pleasure in contributing to the minimization of the patient's physical and emotional suffering. On the other hand, over time, this exclusive attention becomes sickening in itself and sometimes creates a suffocating and imprisoning relationship, as it is focused on meeting the specific demands of the entity, which results in a sense of dependence and uselessness^(13, 23).

As a consequence of this sometimes excessive care, the loss of autonomy of patients is observed at many times in the course of illness. To speak of autonomy is to draw a counterpoint to the sense of freedom, although not all freedom is synonymous with autonomy, given that it is necessary to be aware of reality to appropriate it. Loss of autonomy is a damage that is most strongly evident at the end of life. Significant factors, such as level of consciousness, impaired communication or depression, may influence the reduction in the individual's autonomy, resulting from the disabling process of their health^(21, 24).

In this context of suffering, loss of autonomy and freedom for all involved, we highlight the importance of the support of family and friends, for the patient and family caregiver, considering the need that every subject has for affective relationships, making them vital in the illness process. From this angle, the help offered by this support network results in a significant experience for both caregiver and the one being taken care of, making these relationships powerful tools for coping and improving quality of life^(17, 22).

Spirituality and / or beliefs also contribute to the process of coping with life-threatening diseases. They are presented as reducers of suffering, influencing the way these patients experience the health / disease process, promoting well-being and other attitudes towards death and dying⁽²⁵⁾.

Finally, the results reveal that one of the most difficult decisions for patients and families is materialized in choosing the care approach and where the dying process will

be experienced. Given the diagnosis of a serious disease and its poor prognosis, the choice for curative or palliative care and for a particular environment, *ICU or home-care*, is prescribed, among many other factors, for the understanding and acceptance of death by all involved, as well as the family, psychic, financial and social structure.

There is a strong discussion about humanizing and quality care in the hospital environment. It is known that providing this type of care requires attention to various elements, from the physical and technological structure, to a professional education that emphasizes the value and respect to the patient, ensuring a quality care. Remember that in some cases, needing a medical or hospital service is a scenario that can be permeated with anxiety, anguish, and fear of life and death. Often, the dynamics of this environment forces the professionals to position themselves impersonally, with difficulty in humanization and in the face of high demand the fragmentation of care is reinforced, causing patients to feel helpless and that there is a lack of care^(5,7,9,11).

Home care is a process that results in several factors of an emotional and affective nature. The process of death at home, despite creating a physical and emotional burden for the caregiver, is supported by the presence of family and friends, providing strength to cope through the course of the disease. Experiencing this moment makes everyone feel empowered, because, in general, the family is a source of support to its members and is configured as a key part of care. Thus, the family environment generates well-being and humanization for everyone involved in the context^(12, 18, 29).

The family environment plays a restorative role in the subject's process of illness. Understanding the relationship that the subject has with this place, refers to the attachment / bond that was acquired throughout life. Home is the first place where the subject establishes an identification, becoming over time an extension of her/himself and structuring part of her/his individual and social identity. It is in the home environment that the individual develops life and over the years there is a symbiotic relationship with the home. The term environmental docility refers to the positive affect that is the result of the person-environment relationship, this balance enhances the personal and psychosocial performance of the subject throughout the course of the disease, and this environment enhances well-being for the patient^(27-28,39-40).

From this conception, to reflect on the family environment is to reinforce that it is more likely to provide the subject with a better experience of the process of illness and finitude, emphasizing the bond with spaces and places, since the home is recognized as an emotional territory, which is responsible for the construction of meanings and subjectivity of individuals. Given this construct, the literature points out that every physical environment causes emotions, and there is the propensity of individuals to feel more uncomfortable in the hospital environment, thus, the affective as well as the natural environment has a restorative effect by expanding components of well being for physical and mental health^(32-33,41).

5. Conclusion

Throughout the research we sought to understand the relationship between people and environment in the process of finitude, in the contexts of the Intensive Care Unit (ICU) and the home (Home Care), from the perspectives of patients and family caregivers. During the course of illness, both caregivers and patients are exposed

to intense physical, emotional and financial burdens and a routine of uncertainties about the prognosis of the disease and plans for life.

Caring for a patient in palliative care is an activity that requires a routine from the caregiver of intense responsibility and surrender, and this function is generally lonely, as in most situations only one family member is appointed to this position. As a consequence, there is a need to readjust the family dynamics and home environment to meet the patient's needs, allowing for the emergence of contradictory feelings such as attachment to the exercise of care, followed by tiredness and frustration with the demands. Difficulties are present in both environments, but can be experienced more intensely in the context of home care.

On the other hand, when looking at the institutionalized death process, it was found that patients in curative care in the hospital environment experience a feeling of space "*expropriation*", as they are deprived of their homes, experiencing a new routine of times and norms and distancing from their family members, which also generates stress and illness. This is because space / environment transcends the physical place, because it is made up of people, affections, memories, and meanings. Thus, the patient will need to make an action of appropriation of this new space, giving meaning to this experience, enabling the emergence of new meanings and constructions, which may be negative or positive in this regard.

Regardless of the approach to care chosen or the environment where the process of finitude will be lived, the importance of the family and friends support network is emphasized, since affective relationships play a fundamental role in the individual's life, and they are quality generators of life. As the patient is supported and cared for, she/he feels more empowered to face the path of illness and acceptance of the death process. Another factor to be considered is the loss of patient autonomy, which emerges as one of the determinants of the quality of the disease process in both care modalities.

In the end, it is clear that home care is indicated by patients as the best place to experience the process of finitude, since the family environment is a coping resource and a tool that minimizes the fragility imposed by the disease, which often favors purely organic care over technical knowledge. The home environment can be restorative and a producer of quality of life and death.

It must be considered, however, that this choice is specific, determined by multifactorial reasons. Both forms and places of care present affective, economic and social costs to the patient-family dyad. In this process of choice, the physical structure of the house, economic factors, support network, psychological conditions and family availability should be considered, while in search of the best environment to offer dignity of life and death to the patient, but also to the family, who take care and need to be taken care of. Therefore, it is necessary to explore health technologies that target the patient in their various moments and particularities, since the denial of the death process is a factor that causes them numerous damages, and since an individual / person needs specific care, this helps provide them with a better quality of life as long as it persists.

One of the limitations of the research concerns the difficulty of access to participants with the profiles established in this study. We suggest conducting studies of large-scale surveys on the subject. This is expected to foster debate on the care of patients in the process of finitude, encouraging the creation of proposals that consider the person-environment relationship as a facilitator of new meanings and affects during the course of illness.

6. References

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