

## Corporeidade de adoecidos oncológicos em cuidados paliativos domiciliares: a vivência de familiares cuidadores

Corporeality of oncological patients in palliative home care: the experience of family caregivers

Corporeidad de enfermos de cáncer en cuidados paliativos en el hogar: la experiencia de los cuidadores familiares

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## ABSTRACT

**Objective:** To describe the experience of caregivers in relation to care for diseased body dimensions in palliative care at home. **Method:** Descriptive study with qualitative approach through Bardin's Content Analysis, conducted with caregivers with relatives registered by the Home Care Service of a High Service Center Complexity in Oncology. **Results and Discussion:** The study population consisted of 10 caregivers who received home visits. Based on the analysis of the codes and messages were categorized units of speeches in two axes. Are they: "Corporeality: Experienced cares that meet the Needs Organics" and "Corporeality: experienced cares that meet the psycho-emotional, psycho-spiritual and environmental". **Conclusion:** The care is compartmentalized for caregivers who opposed the loans to the social body and loans to the physical body, first recalling the last.

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**Descriptors:** Nursing, Medical Oncology, Palliative Care, Home Visit, Human Body.

## RESUMO

**Objetivo:** Descrever a vivência de cuidadores no que concerne aos cuidados às dimensões do corpo de adoecidos em cuidados paliativos domiciliares. **Método:** Estudo do tipo descritivo com abordagem qualitativa por intermédio da Análise de Conteúdo de Bardin, realizado com cuidadores domiciliares com familiares cadastrados pelo Serviço de Atendimento Domiciliar de um Centro de Assistência de Alta Complexidade em Oncologia. **Resultados e Discussão:** A população estudada compreendeu 10 cuidadoras que recebiam visitas domiciliares. A partir da análise dos códigos e conteúdos das mensagens, foram categorizadas unidades dos discursos em dois eixos. São eles: “Corporeidade: Cuidados vivenciados que atendem as Necessidades Orgânicas” e “Corporeidade: Cuidados Vivenciados que atendem as necessidades Psicoemocionais, Psicoespirituais e Ambientais”. **Conclusão:** o cuidado está compartimentalizado para os familiares que contrapõem os préstimos ao corpo social e préstimos ao corpo físico, recordando primeiramente do último.

**Descritores:** Enfermagem, Oncologia, Cuidados paliativos, Visita domiciliar, Corpo Humano.

## RESUMEN

**Objetivo:** Describir la experiencia de los cuidadores con relación al cuidado de las dimensiones del cuerpo enfermas en los cuidados paliativos en el hogar. **Método:** Estudio descriptivo con enfoque cualitativo a través del análisis de contenido de Bardin llevado a cabo con los cuidadores familiares con familia registrada por el Servicio de Cuidados en el hogar de un Centro de Servicios de alta Complejidad en Oncología. **Resultados y Discusión:** La población del estudio consistió en 10 cuidadores que recibieron las visitas a domicilio. A partir del análisis de los contenidos de los códigos y mensajes fueron categorizados unidades de discursos en dos ejes. Ellos son: “Corporeidad: experimentado el cuidado que satisfagan las necesidades orgánicas” y “Corporeidad: experimentado el cuidado que satisfagan las necesidades psico-emocionales, psico-espirituales y ambientales”. **Conclusión:** Los cuidados son compartimentados por los miembros de la familia, que oponen la asistencia al cuerpo social y la asistencia para el cuerpo físico, recordando en primer lugar lo último.

**Descritores:** Enfermería, Oncología Médica, Cuidados Paliativos, Visita Domiciliaria, Cuerpo Humano.

## INTRODUCTION

Palliative care facilitates the interaction between the family member and the sick person according to possible care of the patient.<sup>1</sup> The integration of this model with outpatient care is an effective model able to regulate patient's symptoms and help them emotionally.<sup>2</sup> Therefore, it is understood as the duty of the State to offer and technically guide palliative care with outpatient care, providing hospitalization and home care and controlling pain with the supply of opioid drugs.<sup>3</sup>

From an epidemiological point of view, the demographic change through which the country passes translates into population aging, thus altering the mortality profile. Estimates for the years 2016 and 2017 confirm that 600,000

people annually acquire the diagnosis of neoplastic disease in Brazil.<sup>4</sup> Globally, the UK ranks first in the ranking of quality of death in 80 countries. The efforts of the health service and policies, according to the same publication Brazil occupies the 42nd place.<sup>5</sup>

A home follow-up done by a team of palliative professionals contributes to the improvement of the physical contribution, guidelines and technical development, thus reflecting a strengthening of the relationship with family members.<sup>6</sup> It is well known that caring in the process of finitude is a paradoxical phenomenon since Require characteristics based on flexibility, calm and patience, as well as discipline and preservation of the order of the house.<sup>7</sup>

Regarding this, it is considered that home care depends mainly on the family, which assimilates instructions that come predominantly from the hospital staff and in extraordinary cases search the internet and other resources. Teams must provide contextual counseling to facilitate understanding and execution of routines.<sup>8</sup> Three support domains emerge from a qualitative study in this area of focus: development of skills and abilities through information and education, preparation for the end of the terminal illness and contributions to self-confidence as a caregiver.<sup>9</sup>

This history of care in a situation of suffering dates back to the time of the figure of informal caregivers, being provided in places called hospices that housed people in distress.<sup>10</sup> In this context, the notion of body interconnects with the person in its Materiality, resting on biomedical and anatomophysiological pillars in the west, the breakdown of this paradigm begins in the sixteenth and seventeenth centuries. The body becomes separated from the cosmos and finally separated from itself in regard to the breaking of the body with the world to which it belongs, which gives value and meaning to the world.<sup>11</sup>

The study was supported by the sociologist David Le Breton in what relates to the corporeal existence, social and cultural fabric in which the being inserts itself. The author sees the body as the semantic conductor by which the proof of the relationship with the world is developed through perceptive activities and expression of feelings, rites of interaction, gestures and mimics, construction of appearance, body techniques, physical activities, Interaction with pain and suffering.<sup>11</sup> Leonardo Boff, a philosopher and theologian, corroborates that: the living body is subjectivity,<sup>12:143</sup> challenging the concept of corporeality when it says that the characters man-body and man-soul define the total existence. Hence, socially expressed adversity between body and soul, matter and spirit, are usual though not global.

This study aims to describe the experience of caregivers regarding the care of the body dimensions of patients with palliative care at home.

## METHODS

This is a descriptive research with a qualitative approach, through the Bardin Content Analysis. Content Analysis is based on an association of practices that allow the analysis of communications, using systematic mechanisms and codes to describe the content of messages by stipulating rules of completeness and representativeness.<sup>13</sup>

The research institution was a Center of High Complexity in Oncology (CACON) in the metropolitan region of Belém, which has 17 other medical specialties. In it, the Home Care Service (SAD) was implemented in 2001, making CACON the first in the region to offer palliative care services outside the hospital.

Caregivers' home visits were first held on Mondays through Thursdays with SAD to establish basic contacts, meet them and explain to them the reasons for the insertion of the researchers, in order to identify family relationships. The inclusion criteria obeyed: relatives of cancer patients enrolled in the home palliative care service in the city of Belém and districts of Icoaraci and Outeiro; older than 18 years; Who elected themselves as family caregivers. Family

members suffering from home palliative care from pediatric oncology were excluded.

Subsequently, visits were made by researchers without the company of SAD, on all days of the week and in shifts duly scheduled. Data collection points were elucidated, as well as interviews made through a semi-structured interview script, being recorded after authorization of the participants with the aid of an MP4 (Media Player 4). The Free and Informed Consent Form was preliminarily signed. Given the above, the interviewees' speech was transcribed, identifying them by alphabet letters and Arabic numerals (A1, A2, A3, A4...).

Resolution 466/2012 followed, taking into account the maximum safety and well-being of those involved, for which purpose this project was submitted to the analysis of a Research Ethics Committee. After its appreciation and approval by the Ethics Committee of the Health Sciences Institute of the Federal University of Pará under protocol number 23492314.0.0000.0018 the researchers went to the field.

## RESULTS AND DISCUSSION

The study population comprised 10 caregivers who experienced homeopathic palliative care and received visits from SAD, as shown in Table 1.

**Table 1** - Research subjects, by sex, age, schooling, profession and family income. Belém (PA), Brazil, 2016

| Caregivers | Sex    | Age | Education              | Profession            | Family income    |
|------------|--------|-----|------------------------|-----------------------|------------------|
| <b>A1</b>  | Female | 53  | Elementary incomplete  | Housewife             | 1,5 minimum wage |
| <b>A2</b>  | Female | 18  | High School incomplete | Student               | 1 minimum wage   |
| <b>A3</b>  | Female | 43  | Highschool             | Operational Assistant | 1 minimum wage   |
| <b>A4</b>  | Female | 42  | Higher education       | Professor             | 2 minimum wage   |
| <b>A5</b>  | Female | 33  | Highschool             | Housewife             | 1,5 minimum wage |
| <b>A6</b>  | Female | 26  | Higher education       | Autonomous            | 2 minimum wage   |
| <b>A7</b>  | Female | 36  | Higher education       | Nurse                 | 9 minimum wage   |
| <b>A8</b>  | Female | 61  | Highschool             | Professor/Retired     | 5 minimum wage   |
| <b>A9</b>  | Female | 42  | Higher education       | Social Assistant      | 9 minimum wage   |
| <b>A10</b> | Female | 56  | Highschool             | Autonomous            | 4 minimum wage   |

Source: data collection, 2016.

The age range ranged from 18 to 61 years, between daughters and wives, with varying levels of schooling: one incomplete elementary school, one incomplete secondary school, and four in high school and four in tertiary education. The majority (6 caregivers) had a monthly income of less than 2 minimum wages.

The meanings involved were achieved by recognizing or not the existence of first-order care with the questioning: Of all the daily cares of your family member, do you believe there is one that is the most important? Subsequently, when faced with the focus on physical-organic nuance: Do you believe that there are needs and cares other than just your family member's physical that are important?

After the discursive theoretical deepening about corporeality and the feasibility in identifying and describing its constituents, two categories synthesized the synthesis perpetrated. It was judged that starting from a comprehensive, non-specific background on the studied dimensions of corporeality, one would perceive the caregiver's experience of the family member's body during the oncological finitude.

### **Corporeity: lived care that meets the organic needs**

Aspects related to the "physical body" have emerged, in which the degree of importance of the caregiver relative to basic human needs is perceptible. Observed in the speech hygiene care:

*Now, at this moment as it is, the most important is the bath. He's fine, he's not injured. (A1)*

*For me, the most important thing is that when you have to do this, cleanly clean your clothes [...] (A4)*

*Look, what I think is more important is the hygiene of her parts. [...] Why not to get pee, with bad smell "right". For example, my sister took care of a lady, but when she went out to work, she would be full of poop, pee, it would smell bad. But I'm damn careful about these things. (A8)*

*It is the bath, because it is a tumor that is secreting [...] We put the water that falls on top and there is the sorinho that I play, I play serum and clean with the gauze. (A10)*

Within this scope, one interlocutor expressed the need to ensure and offer the sick person adequate food.

*Feed her. It is very important, she eats little, and if she fails to feed her, then you know! (A8)*

For caregivers to safeguard vital organic functions of certain parts of the body or to prevent the observation of the

tumor are behaviors that signal a practice of protection of the place in the body and with a possible unfavorable emotional reaction of the subject.

*Her body? It's the lungs, her lungs, very important, so the throat, her respiratory part at the moment is what I'm most careful about. (A10)*

*The preservation of the place where the tumor is, because she likes very much to see, and for her it would not be interesting the visualization, so I do everything for her not to see. I have a more special care of not visualizing her, but even so she still wants to see. Ask to take a picture. (A7)*

*It has given me a job to visit this business because she does not want to. Aside from the fact that everyone who knows her who comes in here and sees the state she is in now, she is devastated because she has lost her features. (A8)*

Abstaining the individual from visualizing the tumor, implies not to aggravate the state of related body dissatisfaction to early neoplasias. Social isolation comes from deforming and/or incapacitating pathologies such as cancer, which reduces the quality of life and self-esteem of those affected.<sup>14</sup>

The care for the sick person also runs through the necessity of not causing the aggravation of the physical state already debilitated by the terminal illness. Therefore, change of position and prevention of falls, are indispensable factors in the safety of the individual in home care.

*It would be a change of position to prevent formation of ulcer, which is now a patient that requires more special care in this part. It would also be to avoid fracture because she already lifts, as her balance is already shaken she tries to lift a lot, she already even fell, did not hurt even because the position, I believe, that she fell, was not conducive to fracture. So those care related to falling, ulcer related I believe are very important. (A7)*

It is important that caregivers are kept informed about pressure injuries, basic information about physiology, possible findings and ways of prevention, being the responsibility of SAD through health education. However, the way care is given or even the non-application of care can reflect the risks of appearance. Even with more attentive caregivers, if the pathophysiological conditions of the patient develop negatively, there is still the possibility of the appearance of pressure injuries.<sup>15</sup>

It was then noted, in light of what had been expressed up to then, a care for the reflexive and non-systematized body, exercised by one of the interlocutors who signaled

that everything depends on the day they are and the breadth of demands. This way of understanding and processing care demonstrates that there is nothing important in any situation, highlighting the importance of evaluating the organic demands of the patient and developing them from the daily analysis and evolution of the subject.

*[...] if it is a day that she is not well in the stomach for me the remedy is not more important. It's her comfort, she spent these days throwing up [...]* (A9)

Only the family caregiver can infer the worsening of the condition due to the daily closeness, observing the extent of the adverse effects and changing the priorities. In the mentioned speech, the interlocutor emphasizes that in the days that the mother wakes up well she chooses to prioritize the hygiene of the sick person.

*[...] then it depends on how she wakes up, if she wakes up well for me, the most important thing is hygiene. I worry a lot. I say that to her. I even talk to her. "Mom thought. Stinking" (laughs) ... the most important thing is how it dawns, I do not impose anything on it, I see how it wakes up there I develop, listing what I think is the main thing.* (A9)

In a similar way to that experienced by the caregiver, to conceive a multidisciplinary holistic and subjective care that is attuned to the differential of beliefs and customs - multicultural health, of sick people and caregivers; Should be promoted by professionals and students involved in cancer oncology. Needing encouragement about the notion of spirituality, well-being, anguish, and cultural receptivity, critical action plans must be developed after identifying the inadequacies of each reality.<sup>16</sup>

The organic-physical and anatomical experience of the terminal cancer of their bodies is still the most exhaled by the informants, since they were the first significations reached. This care is taken as urgent, the family member is daily caught up in the range of needs of a (usually) bedridden body, which has a high risk of tegumentary involvement, with a deficit of self-care and requires constant vigilance regarding symptoms and complications of Neoplasia.

### **Corporeity: lived care that meets psycho-emotional, psycho-spiritual and environmental needs**

Although it refers care to a part of the body - the head, the familiar knows that the psycho-emotional dimensions of the patient are affected, and often can only support the listening and through words that value the expectation of improvement in the picture, omitting the real state.

*Yes, they are important, take care of his head ... For him to feel, have to pass to him that he is well, that he will be fine. We even see that he is no better, but you have to give him strength, do you understand? Sometimes he cries, he talks to me starts to cry, then he goes into depression ... You have to give a force, a word.* (A1)

In a study that recorded depressive disorders and hope in a cohort of elderly people diagnosed with cancer and their marital caregivers, living at home, findings corroborated to high levels of distress and depression of the patients in comparison to their relatives. Other sources of social support (such as friends) were small compared to the support of spouses and family members, however, levels of psychological distress of the patients were positively correlated with senility and negatively correlated with improved levels of hope.<sup>17</sup> The experience Of the caregiver about the psycho-emotional support that makes up the corporeality, encompasses, therefore, the stimulus to the confidence that better days are to come, and the fearlessness about the future.

From this perspective, the preservation of consciousness concerns the preservation of spatial orientation, and seeks to maintain intact the state of consciousness correlated with the dignity of the human being.

*Although she is not very conscious, but we talk and she always says "Look, it's morning, the time, today is such a day, we are already in such a month". Since she can not see right. Sometimes she asks what time she has, sometimes she herself asks for medicine if she has no medicine to take.* (A2)

Meanings experienced in psycho-emotional care may be linked to love and care for family caregivers. Impatience and stress are alluded to as elements that may be part of daily life, however they are expressed as inadequate and harmful to home care.

*One thing I think is very important is love, right? Sometimes we get stressed, but then we go there and we give her a lot of love ... I think it gives her a lot of strength so that she can live to want to continue this fight.* (A2)

*For me, the most important thing is that when you have to do this care as a cleanliness, change the clothes, the greatest care that has to be done like this, is the attention, affection, do nothing annoying. Institution) have always told me this.* (A4)

*Well, besides, I give her a lot of affection, I watch a little television with her because that's the only thing I still see.* (A8)

One of the interviewees contrasted purely physical, pharmacological and psychological therapies with love.

*I think affection and affection are much more important than you are here cleaning - excuse the expression; The butt of someone who can not move their hands. I'm sorry, but it's the truth, the self-esteem of the person lifts up and you feel loved, you feel wanted, you feel that "people do not want me to go, people want me to stay, people love me". This is much better than any kind of medicine, any kind of therapy, any kind of psychologist, I think love is very important. (A5)*

According to a qualitative study carried out in rural areas of Norway, about the meanings of receiving home care in advanced cancer, it was stated that rarely does the nursing professional approach a conversation after their assignments. The state of insignificance that recurred sickness report, happened on the occasion of technicality allied to the understanding that it is just another number/individual being receptacle of dedication, which hurts its particularity.<sup>18</sup>

Psycho-spiritual care and human corporeality were verified, mainly linked to religion. With the speech of relatives, it was realized that the maintenance of religion feeds the spiritual body of the entity with cancer.

*So today we work more in this part, in the part of the spiritual that is what comforts her a lot in the psychological part. (A7)*

*We are spiritists, so when she lived only every day in the morning she made gospel in her house, there she read the gospel according to spiritualism, prayed and prayed for support for everyone, so I tried to bring it here. Sometimes she is not in the mood to talk, I realize agony ... Then "Momma let's do a prayer, can we pray?" So we always have this spiritual care, so, among all her suffering, this part not only of the body, only material, not just food, has to be more spiritual. (A9)*

According to the above, religion or spirituality is a foundation that begins the patience to deal with the conditions imposed by the neoplasia, appearing as an increase to hope and confrontation.<sup>19</sup>

It was considered when asked about "non-physical care", those directed to the environment. In the past, if the psychosocial, emotional, spiritual demands make up the corporality in the terminal, it is also substantial to look after the environment, guaranteeing serenity and privacy, converging to the ideal of a good environment and a smooth passage. However, sustaining an orderly, noise-free home can become an attribute that distances them from the other important faculties of being cultivated in the body of the sick.

*Because so at home we spend so much time in this situation so solve the material things to take care of him, buy his little things and leave everything right, that really the psychological part, the spiritual part is left with a very large, very large gap. (A6)*

*I think so, noise business, she does not like television ... So this noise business I avoid. Visit too, she does not like it very much. (A8)*

Finally, a caregiver related about "non-physical care", which through the care and differentiation of the dishes, personal products, cleaning utensils and hygiene was surrounding it with safety and a pleasant environment.

*Yes, yes, for example, the dishes. The dishes we use to make his food are separated, when we wash it is with a different sponge, a sponge of his own. We have a container that holds all his dishes, keeps all the equipment for nutrition, is the bath soap, the liquid soap only him, we use the normal soap, shampoo is also his alone, the clothes, bedding Mom washes and tries to keep everything clean. All of it is very clean. (A6)*

The discourse of the interviewee shows the consonance with much of the stamped by the environmentalist theory of Florence Nightingale, resignifying the common sense in the form of caring for the corporal existence. The main point of the contribution of theory is in the organization and care for the environment, designating that everything that surrounds the subject interferes and defines health issues and their recovery. Therefore, the environment that involves being ill is directly related to their treatment and can promote healing or harm in the process.<sup>20</sup>

More than that, when they take care of the body they watch over the life that surrounds them and the relationships make the sick person feel welcomed, passing through the food, the air that is breathed and the organization of the ecological space. It is precisely these components that form the unity of our identities, this requires from the part of the family the apprehension that all that is normal to human life, including encounters and existential mismatches, health, illness and death.<sup>12</sup>

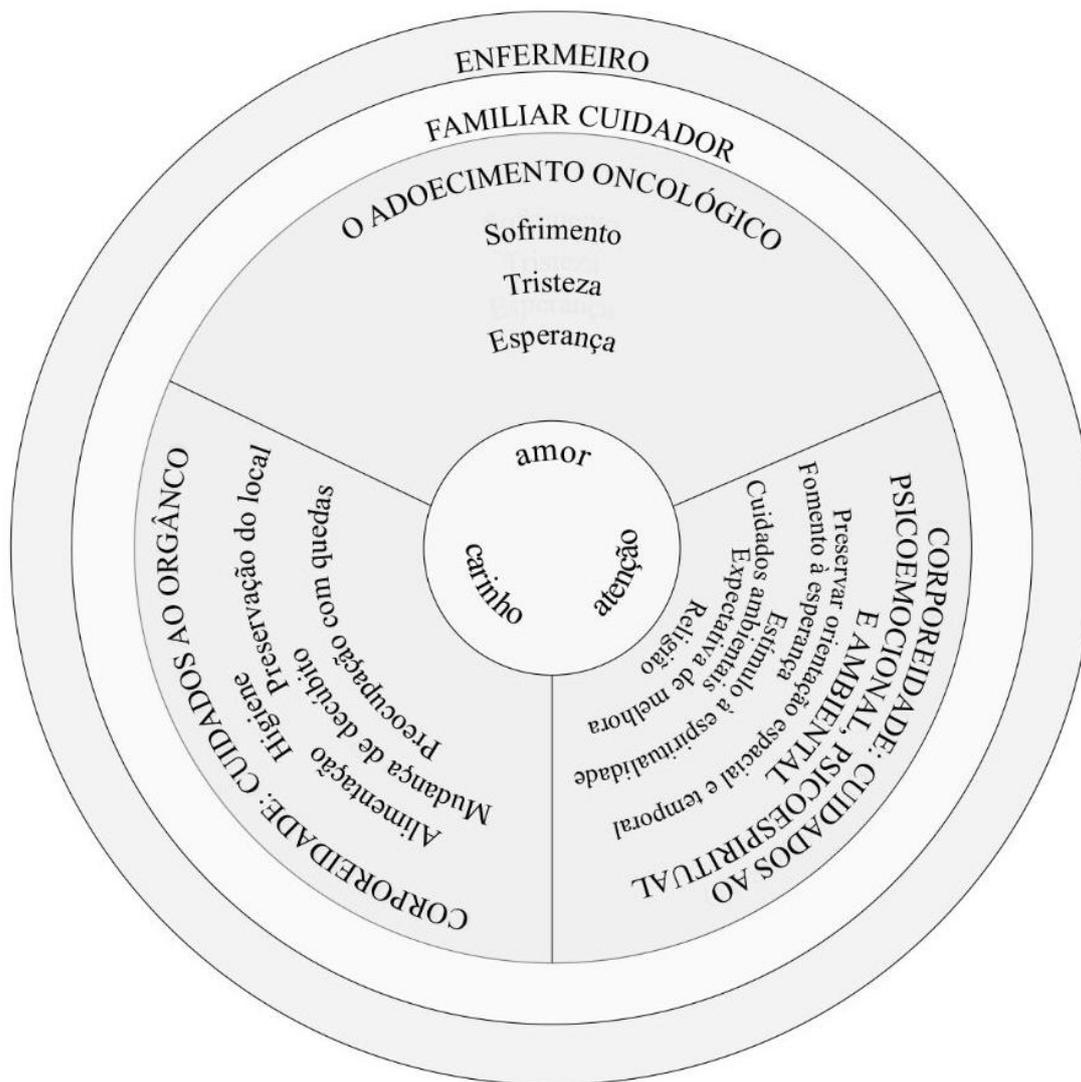
Usually, signs of non-assimilation of goodbye, suffering, sadness and anguish were unveiled in speeches, intrinsically linked to depression and sadness of the terminally ill by cancer. This corroborates with the findings that consider the presence of depression are crucial aspects to be evaluated in cancer. Of course, to break this condition, the caregiver is a key factor, since after the team's departure it tends to disarm the body's psychological and emotional pains, but this refrains from fighting its own.<sup>21</sup>

It must be admitted that human transience is demonstrated by bodily life, and dying only happens after

the end of the equilibria and energies inherent in men, death is factual in earthly life. It is noticeable in this clipping that man-body-soul do not oppose, that the physical (often confused with the body itself) is only part of the human being, and not its completeness, therefore the term corporeity is currently elected to deal with these Issues.<sup>12</sup>

David Le Breton considers existence as corporeal. The social actor is delineated by the body, marking the individual and establishing a border in relation to the existence of another, while the social bonds of the subject expand through the corporal affirmation, giving it more notoriety. When there is crisis in the identity or legitimacy of bodily actions, the correspondence of this with the world is shaken, affected by these oscillations the subject hesitates to conform to the physical incarceration of which it is object. The body should not be a place of detachment, but of inclusion that surpasses individual existence, yet simultaneously connects the subject to others.<sup>11</sup>

Figure 1 - Experiencing the body of the sick person according to the family caregiver. Belém (PA), Brazil, 2016.



Source: data collection. Belém - 2016.

It is worth emphasizing in the first instance through the inquiries, aspects related to corporeality in their physical and organic bias as in Figure 1: food, medication, evacuations, dressings and care with ulcers. Only after this did other faculties reflected in corporeality arise, such as love, affection, active listening, maintenance of consciousness, hope, and encouragement of religiosity/spirituality.

The body is not restricted to a repertoire of organs that follow anatomical laws, it is a catalyst for multiple symbols and cultural variables,<sup>11</sup> he encompassing brought about by the concept of corporeality inaugurates a more globalizing vision of the human being, the spirit integrating matter and caring. Of matter is to determine what animates it.<sup>12</sup> It has been found that family caregivers consider the dimensions of corporeality in their experiences, even though the organic vision prevails as a paradigm.

All of the aforementioned is in line with the contextualizations culturally reproduced by the body, which incessantly pursues sound characteristics established by the postmodern reality and, therefore, does not only get biologically ill. It is the social determinations and the shock with the disease that shake the idealization about healthy existence.<sup>22</sup>

Thus, the legitimacy of actions that transcend only satisfactory physical experience as a component of the corporality of the terminally ill are unveiled. Simultaneously, there is recognition by caregivers of the expectation that something unusual and good will expand the patient's psychoemotional (bodily) experience, mitigated by the cancer's termination. Among the sick in palliative care, I look forward to something surprisingly pleasant and exceptional to lead them out of the routine organized daily around technical care.<sup>18</sup>

We incorporate during the physical experience the attributions that are assigned to us by the world, and in this way we construct our existence. After the advent of the disease, it is in the corporal domain where the diseases will be expressed, and through the senses the sick people enjoy the experience of pathologies that affect them integrally. The damage inflicted by organic losses and senses leads to failures in body fullness.<sup>23</sup> Notoriously, the being in disequilibrium seeks solutions to restore its dynamic balance, in the same way that it proclaims the theory of Basic Human Needs defended by Wanda Horta.<sup>24</sup>

Unfortunately, the terminality of cancer is irremediable, and the family is situated between the reality that is established by daily observation of distressing signs and symptoms and the need to provide support. Just as, through the confrontations experienced by the caregivers, it is inferred that the proximity of death generates deleterious effects on the corporality of the terminally ill patients by cancer and a decrease in the viability of self-experimentation.

Building up the ideal of caregiver integration, a recent qualitative approach, concluded that often psychoeducational interventions in home palliative care were successful because

they were rewarding for those involved.<sup>25</sup> The smoothing of unexpected transitions and the glimpse of progress in quality of care Life, on nursing coordination, were also described in a service that offered a palliative approach to chronic diseases through innovative solutions, sources of support, training and lifelong education. The palliative approach should be taught to caregivers for sustainability of home care in people with chronic diseases.<sup>26</sup>

Thus, the nursing care plan should integrate the family, although with a differentiated focus of the sick person. Although its participation in the team's services is controversial, this framework should not be a tool of unrealistic optimism about healing, but a coping strategy. Not only the family's commitment depends on the improvement of the patient's quality of life, the caregiver and sick person's dyad must take advantage of professional knowledge.<sup>17</sup>

## CONCLUSION

The aim of this investigation was to describe the care dimensions of the body of patients in palliative care domicile, from the perspective of family caregivers. Their experiences manifest the knowledge that healing will not be achieved and that the aggravated physical state can only be circumvented, however, they often manifest as a (im)perceptible desire for the aspiration of a probable physical reestablishment.

The dichotomous view between the physical body and the social body (psycho-emotional, psycho-spiritual and environmental care), compartmentalizes care visibly influencing speech, remembering as first-order sleeplessness those specified to organicity. However, the subjective-immaterial and objective-material dimensions are linked to the human body and not opposed. Through the bridge that the corporeality consolidates, it was verified just as the relatives seek to supply the needs of the subjects in finitude.

Everyday, suffering and smiling, the relative not only cares how he was instituted as the first hypothesis, he experiences as a spectator to a greater or lesser degree the corporal mitigation of the one with whom he has ties. It is plausible to confront the irremediable death by cancer with the slowing down of bodily functions and faculties. Through the immersion in the interviews it is clear that to watch over the corporal dimensions during finitude is to feel that the existence of the other completes to him, because as long as there is life is the minimum to do: to fulfill its role of familiar.

Nursing behaviors need to provide means that begin effective coping with the disease, encouraging them not to neglect aspects inherent in the subjective faculties of being ill. In the visits the team must invest in the biopsychosocial and emotional support uniformly, preparing all the implicated for the denouement.

In short, the foundation of corporeality as a relational, philosophical, educational, psychological or spiritual presupposition must be diffused in health as the experiences and existential meanings in the process of health and illness

that reaches the human body are inquired. The clarifications contained here confirm the nobility found in a human existence trying to supply others, testifying that the body does not support existing alone.

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## REFERENCES

1. Nunes MGS, Rodrigues BMRD. Tratamento Paliativo: Perspectiva da Família. *Rev enferm UERJ*. 2012;20(3):338-43.
2. Back AL, Park ER, Greer JA, Jackson VA, Jacobsen JC, Gallagher ER et al. Clinician Roles in Early Integrated Palliative Care for Patients with Advanced Cancer. *J Palliat Med*. 2014;17(11):1244-8.
3. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Departamento de Atenção Básica. Caderno de Atenção Domiciliar, volume 2. Brasília (DF): Secretaria de Atenção à Saúde; Ministério da Saúde; 2013. 207 p. [Internet]. [Acesso em: 16 set 2016]. Disponível em: [http://bvsms.saude.gov.br/bvs/publicacoes/caderno\\_atencao\\_domiciliar\\_melhor\\_casa.pdf](http://bvsms.saude.gov.br/bvs/publicacoes/caderno_atencao_domiciliar_melhor_casa.pdf).
4. Instituto Nacional de Câncer José Alencar Gomes da Silva (BR). Coordenação de Prevenção e Vigilância. Estimativa 2016: incidência de câncer no Brasil. Rio de Janeiro (BR): Instituto Nacional de Câncer José Alencar Gomes da Silva; Ministério da Saúde; 2015. 126 p. [Internet]. [Acesso em: 16 set 2016]. Disponível em: <http://www.inca.gov.br/estimativa/2016/estimativa-2016-v11.pdf>.
5. The Economist Intelligence Unit (EIU). The Quality of Death Index: Ranking palliative care across the world. EIU; 2015. 72 p. [Internet]. [Acesso em: 12 abr 2016]. Disponível em: <http://www.apcp.com.pt/uploads/2015-EIU-Quality-of-Death-Index-Oct-6-FINAL.pdf>.
6. Ribeiro AL, Almeida CSL, Reticena KO, Maia MRG, Sales CA. A enfermagem no cuidado paliativo domiciliar: o olhar do familiar do doente com câncer. *Rev Rene*. 2014;15(3):499-507.
7. Queiroz AHAB, Pontes RJS, Souza AMA, Rodrigues TB. Percepção de familiares e profissionais de saúde sobre os cuidados no final da vida no âmbito da atenção primária à saúde. *Ciênc Saúde Coletiva [internet]*. 2013;18(9):2615-23.
8. Bhatnagar T. Palliative Home Care: A Designer's Perspective. *Indian J Palliat Care*. 2015;21(2):250-52.
9. Harrop E, Byrne A, Nelson A. "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliat Care*. 2014;13(1):1-10.
10. Sales CA, Silva MRB, Borgognoni K, Rorato C, Oliveira W. Cuidados paliativos: a arte de estar-com-o-outro de uma forma autêntica. *Rev enferm UERJ*. 2008;16(2):174-9.
11. Le Breton D. A sociologia do corpo. 4.ed. Rio de Janeiro: Vozes, 2011.
12. Boff L. Saber Cuidar: ética do humano - compaixão pela terra. Petrópolis: Vozes, 1999.
13. Bardin L. Análise de conteúdo. São Paulo: Edições 70, 2011.
14. Pereira NAC, Fortes RC. Autoimagem corporal de pacientes com câncer gastrointestinal. *Com Ciências Saúde*. 2015;26(1/2):29-44.
15. Queiroz ACCM, Mota DDCE, Bachion MM, Ferreira ACM. Úlceras por pressão em pacientes em cuidados paliativos domiciliares: prevalência e características. *Rev Esc Enferm. USP*. 2014;48(2):264-71.
16. Hines D. Cultural competence: assessment and education resources for home care and hospice clinicians. *Home Healthc Now*. 2012;30(1):38-45.
17. Goldzweig G, Baider L, Andritsch E, Pfeffer R, Rottenberg Y. A Dialogue of Depression and Hope: Elderly Patients Diagnosed with Cancer and Their Spousal Caregivers. *J Cancer Educ*. 2016 [acesso em: 14 abr 2016];1-7. Disponível em: <https://doi.org/10.1007/s13187-015-0975-0>.
18. Devik SA, Hellzen O, Enmarker I. "Picking up the pieces" - Meanings of receiving home nursing care when being old and living with advanced cancer in a rural area. *Int J Qualitative Stud Health Well-being*. 2015 [acesso em: 10 jun 2016]; 10. Disponível em: <http://dx.doi.org/10.3402/qhw.v10.28382>.
19. Rahnama M, Khoshknab MF, Seyed Bagher Maddah S, Ahmadi F, Arbabisarjou A. Religion as an Alleviating Factor in Iranian Cancer Patients: a Qualitative Study. *Asian Pac J Cancer Prev*. 2015;16(18):8519-24.
20. Haddad VCN, Santos TCF. A teoria ambientalista de Florence Nightingale no ensino da escola de enfermagem Anna Nery (1962 - 1968). *Esc Anna Nery Rev Enferm*. 2011;15(4):755-61.
21. Santos CA, Ribeiro AQ, Rosa COB, Ribeiro RCL. Depression, cognitive deficit and factors associated with malnutrition in elderly people with cancer. *Ciênc saúde coletiva*. 2015;20(3):751-60.
22. Gomes DRG, Próchno CCSC. O corpo-doente, o hospital e a psicanálise: desdobramentos contemporâneos? *Saude soc [online]*. 2015;24(3):780-91.
23. Ferreira MV. Michel Henry e os problemas da encarnação: o corpo doente. *Psicol USP*. 2015;26(3): 352-7.
24. Horta WA. Processo de enfermagem. São Paulo: EPU, 1979.
25. Holm M, Carlander I, Fürst CJ, Wengström Y, Årestedt K, Öhlen J, Henriksson A. Delivering and participating in a psycho-educational intervention for family caregivers during palliative home care: a qualitative study from the perspectives of health professionals and family caregivers. *BMC palliative care*. 2015;14(1):1-10.
26. Pesut B, Hooper BP, Robinson CA, Bortorff JL, Sawatzky R, Dalhuisen, M. Feasibility of a rural palliative supportive service. *Rural Remote Health*. 2015;15(2):3116.

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