Feelings shared by companions of cancer patients staying in hostel accommodation: a phenomenological study

**ABSTRACT**

**Objective:** To understand the feelings of companions of cancer patients staying in hostel accommodation during treatment. **Methods:** This is phenomenological research founded on the thoughts of Martin Heidegger. Between May and July 2015, ten cancer patient companions lodged in hostel accommodation in the south of Brazil were interviewed. **Results:** The analysis identified three ontological themes: a feeling of concern for the other; worries about the distance from home life and the feeling of being welcomed in their home-away-from-home. **Conclusion:** It is understood that being-with-the-other lodged in hostel accommodation produces mixed feelings of worry about the patient's future and anxiety about the distance from daily life and future plans on behalf of the other. **Implications for practice:** While hostel accommodation represents a protective factor, the feelings experienced by caregivers can produce important emotional demands that should be considered in the planning of nursing care throughout the care network.

**Keywords:** Neoplasms; Caregivers; Social support; Qualitative research; Nursing.

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**Resumo**

**Objetivo:** Compreender os sentimentos do acompanhante do doente com câncer, hospedado em casa de apoio. **Métodos:** Pesquisa fenomenológica fundada no pensamento de Martin Heidegger. Foram entrevistados dez acompanhantes, entre maio e julho de 2015, hospedados em uma casa de apoio no sul do país. **Resultados:** Da análise, emergiram três temáticas ontológicas: desvelando o sentimento de preocupação para com o outro; preocupando-se ante o distanciamento de seu mundo vida e sentindo-se acolhidos como em sua própria casa. **Conclusão:** Depreende-se que estar-com-o-outro abrigado em uma casa de apoio produz sentimentos ambíguos entre preocupar-se com o porvir do doente e inquietar-se por se distanciar de seu cotidiano e planos de vida em prol do outro. **Implicações para a prática:** Ainda que a hospedagem represente um fator protetor, os sentimentos experimentados pelos acompanhantes podem gerar importantes demandas emocionais a serem consideradas no planejamento dos cuidados de enfermagem em toda a rede de atenção.

**Palavras-chave:** Neoplasia; Cuidadores; Apoio social; Pesquisa qualitativa; Enfermagem.

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**Resumen**

**Objetivo:** Comprender los sentimientos de los acompañantes de pacientes con cáncer, admitidos en casas de apoyo. **Métodos:** Investigación fenomenológica basada en el pensamiento de Martin Heidegger. Participaron diez acompañantes de pacientes admitidos en una casa de apoyo al sur del país, entre mayo y julio de 2015. **Resultados:** El análisis reveló tres temas ontológicos: evidenciando el sentimiento de preocupación con el otro; preocupándose con el distanciamiento de su mundo vida y sintiéndose acogido en su propia casa. **Conclusión:** Se comprende que estar-con-el-otro admitido en una casa de apoyo produce sentimientos ambiguos, de preocupaciones por el futuro del paciente y por quedaren alejados de sus vidas y planes a favor del otro. **Implicaciones para la práctica:** Aunque la internación representa un factor de protección, los sentimientos experimentados por los acompañantes pueden generar importantes demandas emocionales que deben ser consideradas en la planificación del cuidado de enfermería en toda red de atención.

**Palabras clave:** Neoplasias; Cuidadores; Apoyo social; Investigación cualitativa; Enfermería.
INTRODUCTION

Historically, human beings have always feared diseases that evoke memories of death, such as cancer, an illness that has long been inseparable from humanity. Today, the diagnosis of a malignant neoplasm causes not only fear and insecurity due to its severity, but also difficulties related to the healthcare system regarding availability and accessibility of diagnostic, follow-up and treatment services as well as concern about the quality of the assistance provided and outcome.¹

Public policies recommend organizing a care network for the person with cancer to enable the integrality and continuity of care through the articulation of the different points of attention, anchored by support systems, logistics, regulation and governance. It is up to each government sector to articulate in the implementation of this assistance in the basic, home care, specialized and/or emergency settings.²

It is important to remember that cancer treatment is highly complex, requiring technological, scientific and specialized human resources.³,⁴ This reality limits services to hospitals and clinics with the necessary infrastructure for procedures most of which are found in highly populated cities.⁵,⁶

Today, in Brazil, there are 284 specialized cancer care institutions distributed around the country, with referrals from the network of government healthcare clinics being the responsibility of state and municipal health departments.⁷ In a large country such as Brazil, this structure constitutes a social, economic and psychological barrier as the frequent visits to therapeutic centers have a substantial impact on the lives on both the patient and their family.⁸ This creates a need for support for people being treated outside their hometown with free hostel accommodation⁹,⁶ and food and whenever possible transport to referral centers.⁹

A caregiver, usually a family member, remains with this patient to give support in respect to the fatigue caused by the disease and intensified by antineoplastic therapy.¹⁰ It is worth remembering that, in the face of the aggressiveness of cancer in a household, the entire family reorganizes their lives in favor of the treatment and the well-being of the sick person. This is particularly true for the caregiver, who, devoted with affection, renounces his/her personal life to be with and support the patient.¹⁰

Caring for the cancer patient may also increase the caregiver’s insecurity in his/her actions to care, and cause feelings of loneliness, fear and sadness associated with physical exhaustion and suffering linked to the distance away from other family members; this can result in functional stress and, consequently, carelessness.¹¹

Considering the difficulties faced by these caregivers, the present study was based on the question: what are the feelings of relatives of cancer patients who are treated outside their hometowns and need to stay in hostel accommodation? It is worth emphasizing that by giving voice to these companions, who relinquish part of their lives to care for another, creates an opportunity for the real feelings and needs of these people to be heard.

This existential condition suggests paying attention to the care environment that is established in the hostel accommodation where patients and their companions are distant from their homes and inserted into a new context. In this setting, the caregiver starts to play a fundamental role in the care dynamics by cooperating with the health team. Therefore, further needs for care may arise for both the patient and the caregiver, forming a suitable environment for the implementation of nursing care focused on the caregiver.¹¹

Hence, the objective of this study is to understand the feelings of the companion of cancer patients lodged in hostel accommodation.

METHODS

This is a phenomenological study. This type of study seeks to understand the demands of individuals by analyzing their awareness of their experiences and the meanings they attribute, allowing rearrangements of assistance. Thus, it allows reflection on the different contexts of care that contribute to the condition of nursing.¹² Existential Phenomenology of Martin Heidegger proves to be fundamental in this, since it leads to immersion in the everydayness of individuals and to an analysis of their speech and their experiences, making it possible to arrive at an understanding of the phenomenon that we wish to reveal.¹³

Thus, in an ontological-existential sense, the region of inquiry or ontological region is not constituted by a physical place, but by the feelings of the relatives who accompany cancer patients for treatment outside their hometown.

The present study was developed in a philanthropic institution located in the northwest of Paraná State, Brazil. This institute is a nonprofit social organization that provides social and health support to cancer patients of any age who demonstrably do not have good financial conditions and reside within the city of the institute or neighboring towns. In this sense, in addition to lodging and food, whenever possible, the institution provides transportation to the clinics and hospitals where the patients are being treated.

The caregivers were contacted individually in the institution at which time the purpose of the study was described and they were invited to participate in the research. In order to do so, they had to be at least 18 years of age, living in other municipalities, due to the financial restrictions related to time and distance they needed to stay with the cancer patient in hostel accommodation close to the treatment center.

Those who stayed only for the examinations were not included in the study. All the relatives lodging in the hostel accommodation during the data collection period who met the inclusion criteria were approached by the researcher and invited to participate in the study. None refused and so ten people participated in this research.
The period of data collection was interrupted as the contents of the interviews became repetitive, and no new findings appeared. In this regard, it was considered that the content of the reports had sufficient meanings in relation to the objective proposed by the study, that is, during interviews the relatives were able to reveal their feelings regarding their stay with the family member with cancer in the hostel accommodation. It is important to emphasize that in phenomenological research generalization of the data is not important to the results; it is essential that participants have exposed their experiences accurately.

In the phenomenological approach, the researcher explores a particular question in order to gain a good understanding of the circumstances. For this, uneasiness must present itself to the researcher as a phenomenon, that is, as something that must be exposed, “enlightenment.” Therefore, the following question was used as a guide: how is it for you being lodged in hostel accommodation while you accompany your relative with cancer?

The interviews took place from May to July 2015 in a place with privacy such as a bedroom or consulting room in the hostel on days and at times chosen by the caregiver. Interviews lasted 30 minutes on average and were recorded using a digital recorder and subsequently transcribed.

In Heideggerian analysis, in their being-in-the-world, human beings reveal themselves through their ontological characteristics, where ontic refers to the fact, that is, to the concreteness of the phenomenon being studied. On the other hand, ontological refers to the meaning of the phenomenon and the comprehension of the meaning by the living being.

In this respect, the analysis of the language of the interviewees happened at two distinct methodical phases. In the first, the reports were read in order to understand, albeit with vague and moderate comprehension, the experiences of the relatives accompanying a loved one under cancer treatment. In the second phase, the essence contained in the statements was sought by rereading and using significant structures to reveal the subjectivity and intersubjectivity of the state of being-with. Thus, the essential structures constituted the Units of Significance (US) that composed the ontological themes.

As this research involved human beings, all the ethical and legal precepts regulated by Resolution No. 466/2012 of the Brazilian National Health Council were followed. The study project was approved by the Standing Committee on Ethics in Research involving Human Beings of the State University of Maringá (COPEP nº 1.028,728/2015 - CAAE 43114815.6.0000.0104). The request for participation in the study was accompanied by two copies of an informed consent form, which includes information about the purpose of the research, the type of participation desired and the probable duration of the interview. Moreover, to guarantee the anonymity of the participants, they were identified by codes (C1, C2, ... C10) followed by the degree of kinship with the patient.

RESULTS

The degree of kinship was mostly first degree and nine of the study participants were women with five daughters, three wives, one mother and one son-in-law. The time of their stays ranged from 20 days to four months in the institution.

The interviews revealed the experiences of caregivers lodged in accommodation while accompanying cancer patients giving rise to three ontological themes that are presented below.

The feeling of concern for the other

In general, the companions of family members with cancer who stayed in the hostel accommodation were able to express themselves about the feelings that come with caring for a sick person and staying away from home. This demonstrated their commitment to be with their loved one, as illustrated by the declarations below.

[...] as I am here with him and, people with the same problems are here, we go through the same difficulties, one learns from the others ... It is something that has to be done. [...] That is, only a mother knows, and I have already said, you can stop moaning, let’s do this and this [...] (C1 mother).

[...] but I need it, it's necessary, so we have to understand, because even he did not tell me: if I were not here he would have died already, because he has already been like this, not knowing me, do you understand?! ... There's no way I can get out of here, leave him the way he's alone, there's no way, because how can I leave here and go there to take care of things? There is no way [...] (C4 wife).

[...] I cannot stop to do this, I have to come, I know I have to come ... I have to go through this. You have to try, and try everything you can. [...] (C2 daughter).

Worrying about the distance from his/her worldliness of the world

When experiencing a moment of intense transformation, it is possible to observe that the participants, besides the care they give to their relatives with cancer, are concerned about who remained behind and with everything that is in their hometown, that is, the family and work.

[...] So it's difficult for me as grandmother, here I'm worried about him there, I cannot forget them there [cries], if my daughter was better controlled, it would be possible, but it is impossible. (C5 daughter).

[...] there is also my mother who is bed ridden because of a spinal problem; she fell and hurt herself and so she cannot do anything. I have to take turns. [...] it is complicated for
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The distance from home affects the caregivers not only because of the emotional attachment to their families that are far away or the comfort of their homes that they had to leave, but also due to the new reality that is imposed on their lives. This includes the need to adapt to a different city and the relinquishment of their belongings and the customs of their day-to-day lives.

[...] there I am doing this, alternating the days, when I am there I am solving problems and when I am here, what I can solve here, I do too, but it is difficult, it is complicated! But we are going to cope, even if we have to leave some things that we do and like to do and live through another situation, then it is difficult until you get used to this routine! But we are trying to reconcile one thing with another (C8 daughter).

[...] I just feel sad that I cannot go to church, which is something I really like (C9 daughter).

You know, before I was at home every day drinking beer with an appetizer and here now I'm not drinking because we feel bad too [...] (C10 son-in-law).

Feeling welcome as in your own home

In this theme, caregivers express their satisfaction of being welcomed. In all the declarations, it was observed that participants mentioned that the care they received helped them to cope with the process of illness and the treatment of their relative.

[...] after I found a place in this hostel it was much better, I'll tell you the truth, here we feel at home you know ... I like it, we talk, I help the girls, he stays there in the bedroom, he is relaxed, thank God we're treated well. Here I feel at home, if I could stay here even at weekends, I would feel good (C4 wife).

[...] Oh I feel so good here, I get along with everyone, I feel useful here, helping, washing, drying, storing, because who is in bed is my mother and not me, right. As we are treated well, it's the way to give things back, it's all for free, even transport, so it's a way of repaying, helping with things, like I was in my own house (C5 daughter).

The relatives also have the perception that the hostel is a light that illuminates their stay, highlighting details that make this place a home-away-from-home.

[...] I always say that this is a very blessed place for me because the staff welcomes us well. Many things are better than at home, because it is a place with much assistance, a very good staff. That was one reason that I was not very worried, thank God I'm feeling pretty good (C6 wife).

[...] but it's a good thing that there's this place, that is wonderful, here [the hostel] we are treated very well. I never thought there was a place like this to welcome sick people, I pray to God every night to bless this place, so that nothing is ever missing, so that it gives strength to these girls, to touch this house, because woe to us if this house did not exist (C7 wife).
DISCUSSION

By immersing themselves in the emotional role of caregivers accompanying cancer patients in hostel accommodation, facets are revealed that show the singularities of these family members who are looking after the future of the person suffering from cancer as well as everyone and everything back at home. This includes other family members, their homes and their daily routines. Without hesitation, the family chooses the patient as the primary focus of their care when it brings together all possibilities in favor of the other. In Heidegger’s meditation, the opening and closing of existence are founded on the phenomenon of having the capacity of being-in-the-world-with-others. This openness is called solicitude or care that comes when someone forgets themself and goes to help the other showing care and concern.\textsuperscript{13}

The process of cancer treatment experienced by a loved one intensifies feelings of uncertainty and fear within the family as well as concern for its future, awakening awareness about the necessity of reorganizing the daily routine as the demands of patients include fulltime attention and complex care.\textsuperscript{16}

However, the role of the caregiver does not always emerge from the real desire to accept this responsibility: values, beliefs, ethnicities, and family systems are related to this choice however the caregiver is a member of the extended or nuclear family that takes on the moral duty of care.\textsuperscript{17} In this study, it was found that the concern with the loved one emanates not only from family ties, but, above all, from the commitment that caregivers imposed on themselves, the obligation to care and be with the other during the course of the disease.

Caring as a mission gives rise to the desire to protect and help the loved one as this act is conceived as something that they were predestined for; it does not pass through their minds to refuse the task imposed on them by life. Their dialogue showed that, when worrying about the future of the sick relative, each caregiver accepted the responsibility to safeguard the patient’s health and life, taking on this role with tenacity and hope. A recent study reports that the companion of oncology patients staying in hostel accommodation actively participates in implementing care, modifying his/her life by relinquishing his/her daily routine.\textsuperscript{11}

The interviewees expressed their willingness to face a new and unfamiliar world full of fear, but clad in love and compassion, and thus, nourished by a thread of hope, they persisted in their primary goal, trying to give their best in order to support of the sick person. Heideggerian analysis suggests describing the experience of man as he gains awareness of his being-launched-into-the-world, and sees that the vicissitudes that have come his way, regardless of his desire, cannot be contained. However, he stresses that hope is an existential condition that returns the sensation of coming good \textit{(bonum futurum)} to the human being, as it carries with it the fundamental force that will rescue the being-in-the-world from anguish and will reveal the innumerable possibilities that come with existence-in-the-world.\textsuperscript{13}

On turning to the other with concern, companions revealed their power to be more themselves, willing to care with zeal and were confident that being together with a sick person is an important act that contributes to the transcendence of facticity experienced at the onset of cancer in the family. The literature reveals that homecare for a cancer patient, despite being permeated with physical and emotional exhaustion, carries with it positive consequences for caregivers, mainly in the sense of gaining control and meaning in their lives, the recognition of others and the redefinition of priorities after the death of the relative.\textsuperscript{18}

In their existence-in-the-world, human beings live in a constant state of concern, occupying themselves not only with themself, but also with other people and events around them. In respect to this, family members expressed that, in addition to the concern with their current condition, they felt apprehensive about what they had left behind such as their other relatives, their house and the daily life that they had had before the illness and the treatment of their loved one. Sometimes their memories made them relive the happiness of being in their own homes and in the sanctuary of their family, yet they always returned to the present, perceiving themselves immersed in a sea of anguish and unexpected transformations.

Through their dialog, it was understood that caregivers distanced themselves from people who disturbed their thoughts, as they lived a relationship of interdependence with other family members, who amplified the feeling of helplessness for having left behind a part of themselves. This preoccupation with the other existences also aroused the agony of not being able to meet their demands, which made the emotional suffering experienced by caregivers evident. Hence, the distancing from the family, friends and future plans weakened the individuals that accompanied the sick family member, causing feelings of worry, sadness and anguish to rise in the face of all that they had left behind.

Family caregivers insert themselves as informal caregivers, becoming involved in all phases of the antineoplastic treatment with unconditional support for the patient, and intercessors for the health team, while accumulating responsibilities with the rest of the family, with work and with other commitments of private life.\textsuperscript{19}

Being absent from work was mentioned by the interviewees with deep regret, as the job represented not only the source of their income but, above all, their role in society, occupying much of their day. Thus, they found themselves unable to fulfil their obligations, which may also have intensified the emotional burden in respect to the demands they imposed on themselves. Therefore, caring for a family member with cancer has a substantial impact on the life of the caregiver, interrupts their plans and dreams, affects their self-esteem and causes them to be overburdened.\textsuperscript{20}

Being with a family member who suffers and distant from other loved ones and their daily routines causes the caregiver to experience an existential paradox, with loneliness, among other feelings, awakening in this existence.\textsuperscript{9} The participants in this
study felt their own detached reality, which they contemplated from an anguished viewpoint and with a restless spirit, which brought out the feeling of impotence in respect to the impending facticity.

“Abandon everything” and “having to live away from home” for companion C7 (wife), consisted in no longer being with everything that belonged to her worldliness of the world. Nevertheless, caregiver C5 (daughter) revealed that, after establishing a new context of life and a new world for herself that was now in the hostel, she no longer felt in her home when she was there. Thus, the companions revealed how impacting it was to be sharing the process of the illness of their loved one causing them to be absent from their homes and their realities.

In this way, it is convenient to reflect on to-be-with and being-with, an ontological constituent of being-in-the-world, of human existence. Moreover, because of this, the world is always something that the being-in-the-world shares with others, that is, the world of existence is a world ‘with’. Therefore, the renunciation of their own day-to-day life and their old habits and customs was implicit in their dialogues, depriving themselves of their existential needs in order to reestablish the health of their sick relative, as they understood that meeting the demands imposed by the disease was a higher priority than the other aspects of their lives. Relatives created new strategies not only to preserve the family structure within the network, but also to strengthen the whole family.

A study from Denmark showed that although family caregivers suffer the most from the accumulation of functions, financial difficulties and social withdrawal, they are the ones with the highest personal growth and the ones who least feel the need to return to their normal lives after exercising the function of caring and adapting to this condition.9

In his existentiality, the human being is a temporal being and this temporality is lived by him at every moment of his life. The last ecstasy (ek-stase) of this temporality is the present, yet it does not represent only the present moment in the daily life, but, as an existentiality, it indicates the movement by which existence projects itself as its power-to-be as such. By accepting being-in-the-world, the human being discovers a world that is his, that is, his own condition, and from that moment he is free to discover ways to face the facticity lived in this ecstasy of his life.13

Although they were experiencing a time full of worries about the future of their loved one and discomfort related to the changes in their lives, the companions felt thankful to have been welcomed in the hostel at a time they were passing through the torments imposed on them by the process of the disease.

In these moments, the hostel can mean a source of energy, presence, strength and guidance throughout the process of illness and treatment, in which the professionals who work in these institutions have a prominent place, exercising their supporting role with dexterity. This was confirmed in other settings, such as in a study carried out in Taiwan, which showed a lower burden on caregivers receiving social support and emphasized the importance of the health professional in supporting the caregiver of cancer patients.20

Man, as being-in-the-world, unveils himself as being-with (Mit Sein), in which the other (Mit Dasein) is similarly a being-in-the-world, a being for the other in a coexistence. Thus, it is by being-with-another that the human being perceives the possibility of being-with-the-other, not merely as the target of his care, but, above all, in an enveloping and significant way as, in sickness copresence does not occupy, but preoccupies about the other.15

Humanized work is, therefore, one that is carried out with love, affection and kindness, making the receiver feel good and welcomed. In this way, the practices implemented in hostels take place and offer a differentiated treatment that promotes harmony and good relationships.5,6,9

The findings of the present study revealed that “being welcomed” and “treated well” by the staff of the hostel, made the caregivers feel as well as they would in their own homes, raising the spirits of those who were suffering and soothing their anxious hearts about the facticity of the disease. This made these individuals see the institution as an exceptional place that deserved to be protected and graced with divine blessings so that it would endure eternally and, thus, receive everyone who needed it.

The importance of this type of institution resides in the capacity to promote quality of life to its users as it opens its doors at a moment in which the patient and his companion most need assistance and helps them to face this process of illness and treatment.9 In addition, “it provides an authentic welcome to caregivers who accompany their loved ones, sharing moments of anguish, sadness and joy, especially when they are far from their homes “.4,13

In Heidegger’s meditation, affective disposition or tonality represents a fundamental behavior that the being-in-the-world employs to reveal himself to the world. The disposition leads man to open up to himself and to the world, receiving, in the dominion of encounter, the coming of other beings in his direction.13

It is worth remembering that, regarding the practical reality of the hostel accommodation, its structure is based on the need to offer support to the population during antineoplastic treatment. Hence, proper local healthcare planning should take into
account "the regionalization of care, the distances traveled by the population in search of care, and the number of patients involved in these journeys", in order to know the relationship between the place of residence of patients and their search for healthcare.8

In a network comprised of basic and specialized care, hostels are one more component of the network, which aims to integrate the different levels of care, and provide highly complex treatment with quality and resolution with humanized care.

It is understood, therefore, that the support given by hostel accommodation did not only cover the physical and social needs when it provided shelter, food and care and contributed to the access and continuity of cancer treatment, but, above all, extended its reach to essentially subjective aspects. The patient and caregiver were welcomed with care and commitment, which instigated them to report that the hostel accommodation is not something that represented the suffering experienced, but shelter and protection that appeared at a good moment as a home away from their own home.

FINAL CONSIDERATIONS

The daily life of family members who experience the course of cancer through the illness of a loved one revealed that they experience a range of feelings through being-with-the-other while lodged in hostel accommodation. As caregiver, the concern for the patient's present and future emerges from within, causing uncertainty, fear and sometimes loneliness.

The caregiver then starts to live with anguish at staying for long periods away from the people who are important, from home and the day-to-day life, that is, from everything that was part of their world. As a result, family members are forced to make adjustments in their own lives, worrying about giving up their routine, their obligations and even their life plans in order to meet the patient's demands.

In light of Heideggerian hermeneutics, it is understood that this path along the tortuous track of cancer enables the companion to experience the opening of his own self, to become aware of his existential condition as he recognizes the mission imposed on him by life, accepting the role as being-with the sick person. He then adopts feelings such as protection for the other, care and relinquishment of his own needs, incorporating his pilgrimage.

Reflection on their worldliness revealed that these family members experience ambiguous feelings in the face of the vicissitudes that they must make. However, a feeling of gratefulness emerges amid the storm, as they perceive themselves welcomed by the hostel staff. In the domain of this meeting, authentic care manifests through the practice of considerate professionals, who put themselves at the service of the other and consider their existential needs. In this way, the companions have the sensation of being protected similar to in their own homes with support that will help them to transcend their facticities.

It is recognized that the current research has limitations, as it was performed in a single institution and region of the country. However, this study may reveal the reality of many relatives who dedicate themselves to a cancer patient as it enabled the unveiling of dimensions in the daily life of those who accompany their sick family member while lodged in hostel accommodation, with a sensitive appreciation of the subjectivity and the uniqueness of this being.

Although the support of the hostel represents a protective element, the feelings experienced by the companions generate important emotional demands. Therefore, the evidence presented may inspire health professionals and, in particular, nurses to rethink their approach, with a view to qualifying assistance as humanized care, which must be offered throughout the support network as well as at all levels Health care. Nonetheless, it is hoped that this study contributes and encourages further research that will allow a better understanding of the feelings of those beings who relinquish their lives for the other.

REFERENCES


