

Existential feelings expressed by users of the house of support for people with cancer

Sentimentos existenciais expressos por usuários da casa de apoio para pessoas com câncer

Sentimientos existenciales expresados por usuarios de una casa de apoyo para personas con cáncer

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ABSTRACT

Objective: To understand the meaning of hosting in support houses for users with cancer during antineoplastic treatment outside their cities. **Methods:** Based on the Heideggerian phenomenology. 15 users of a philanthropic support house located in the northwest of Paraná were interviewed. The field stage occurred from June to July 2012, and the users were interviewed from the guiding question: "How does it feel staying in a support house during your cancer treatment?". **Results:** Through exploration and discourse analysis, three categories emerged: "Recalling his former force" "Experiencing being welcomed in the present" and "Experiencing true satisfaction of being cared". **Conclusion:** We understand that experiencing an authentic welcoming based on a sympathetic and humane way, besides approximating professionals of a comprehensive care, awakens on care ones feelings of gratitude and empathy.

Keywords: Neoplasms; Comprehensive health care; Social support; Quality of life.

RESUMO

Objetivo: Objetivou-se compreender o significado do acolhimento em casas de apoio para os usuários com câncer, durante o tratamento antineoplásico fora de suas cidades. **Métodos:** Embasado pela fenomenologia heideggeriana. Foram entrevistados 15 usuários de uma casa de apoio filantrópica localizada no noroeste do Paraná. A etapa de campo ocorreu de junho a julho de 2012, sendo os usuários entrevistados a partir da questão norteadora: "Como você se sente ao permanecer em uma casa de apoio durante seu tratamento para o câncer?". **Resultados:** Por meio da exploração e análise das falas emergiram três categorias: "Recordando seu vigor de ter sido", "Experimentando ser acolhido no presente" e "Vivenciando satisfação autêntica ao ser cuidado". **Conclusão:** Compreendemos que vivenciar uma acolhida autêntica baseada em um modo solidário e humanizado, além de aproximar os profissionais de um cuidado integral, desperta nos entes cuidados sentimentos de gratidão e empatia.

Palavras-chave: Neoplasias; Assistência integral à saúde; Apoio social; Qualidade de vida.

RESUMEN

Objetivo: Comprender el significado del acogimiento en casas de apoyo para los usuarios con cáncer durante el tratamiento antineoplásico fuera de sus ciudades. **Métodos:** Basado por la fenomenología heideggeriana. Fueron entrevistados 15 usuarios de una casa de apoyo filantrópica ubicada en el noroeste de Paraná. La etapa de campo ocurrió entre junio y julio de 2012, siendo los usuarios entrevistados a partir de la pregunta guía: "¿Cómo usted se siente al permanecer en una casa de apoyo durante su tratamiento para el cáncer?". **Resultados:** A través de la exploración y el análisis de los relatos, emergieron tres categorías: "Recordando su vigor de haber sido", "Experimentando ser acogido en el presente" y "Viviendo satisfacción auténtica al ser cuidado". **Conclusión:** Recibir una acogida auténtica basada en un modo solidario y humanizado, además de aproximar a los profesionales de un cuidado integral, despierta en los pacientes sentimientos de gratitud y empatía.

Palabras-clave: Neoplasias; Atención Integral de Salud; Apoyo social; Calidad de vida.

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INTRODUCTION

Currently, living with cancer is a concrete fact within many families. It must be remembered that this disease is considered, by far, the second leading cause of death in Brazilian population¹. This reality implies social reorganization, particularly with regard to the necessary support to families and individuals who directly experience the disease.

Nevertheless, antineoplastic treatment is considered highly complex and requires technological and scientific resources for its realization. This characteristic limits the number of hospitals or clinics that have the necessary infrastructure for such procedures, restricted to large cities. Therefore, patients in small towns, to begin their fight against cancer face with another barrier in particular: the lack of accessibility to treatment. Thus, these individuals live with the requirement of frequent transportation to specialized cancer centers, which further complicates coping with the disease, by causing significant physical, financial and emotional exhaustion.

This situation is compounded by the side effects of therapy, which may cause limitations requiring residing in the city where they perform the treatment. To do so, these patients need a place of residence in municipality of treatment - which is not always easily found. To assist these individuals, there was the urgent need of a place that would house, welcome and supply the needs of those in this sensitive and difficult phase they are experiencing. With that the support houses came up, "aimed to provide a resource of assistance and care to a clientele that, particularly, is experiencing a situation of great emotional and/or physical vulnerability"^{2:170}.

So, in face of cancer treatment, the patient needs care, preferably in an environment that suits him, and it will give him comfort and peace, similar to those found in his home. So-called support houses "provide a familiar environment, away from the hospital aspect and approaching the context of domestic routine"^{3:97}. Then, it is reiterated the importance of these institutions, since pain, disfigurement, social isolation and impending death are part of the feelings experienced by most patients undergoing cancer treatments⁴.

The support houses have the function of employing the holistic and humane care to those who are in it and to provide physical and emotional well-being. This service is implemented by multidisciplinary teams that perform the union of diverse knowledge to provide comprehensive and continuous care. Following this thinking, this research led us to seek an understanding of the phenomenon: how users perceive such support houses where they are staying this time in their lives?

Thus, uncovering the meaning of temporary homes in the users' lives during treatment becomes important, especially for believing in scientific increment that such feat could bring in the qualification of social support resources for prolonged treatments. In addition, many people still have no knowledge about the responsibilities of these institutions, or do not recognize their influence on chemo/radiotherapy.

In our view, research on this scope are justified, since there are few studies that address the feelings of users that treat away from their city, especially those staying in support houses. This reality demonstrates the need for reflection by health professionals, especially nurses, about the condition of these beings so that they may harbor in their daily lives, care for these people. This requires the identification of their bio psychosocial needs, which should be assessed and taken into consideration in the planning and development of activities focused on their health and well-being.

Thus, this study aimed to understand the meaning of the host in support houses for users with cancer during their treatment out of their towns.

METHOD

This is a qualitative study that used the Existential Phenomenology proposed by Martin Heidegger⁵. The choice of this approach allowed focusing the phenomenon trying to understand the other in its facticity, considering it in its uniqueness, i.e., man in his existential totality⁵.

The study was conducted in a support house established in 1983 and located in a county regional center of the northwestern state of Paraná-Brazil that serves patients of both sexes in cancer treatments. The institution offers nursing, physical therapy, psychology, pharmacy, social work and legal advice services. The house also offers home hotel services (bed, bathroom and food) and transport for free to all patients undergoing treatment away from, i.e., those from other municipalities.

Survey participants were adult patients in antineoplastic treatment, which were duly registered in the home support and hosted at the time of this interview. Moreover, it was include as an inclusion criterion residing in one of the cities belonging to the 15th Regional State of Paraná, except the host city, where patients have their treatment. From this criterion, the study involved the participation of 15 subjects.

The interviews took place in the period June-July 2012, at the institution. The tool consisted of a questionnaire containing demographic questions and the following question: "How does it feel to stay in a support house during your cancer treatment?".

The interviews were recorded in full, with the aid of a digital recorder and then were transcribed by the authors. Moreover, to maintain the anonymity of the interviewed participants, it was adopted pseudonyms, regarding virtues of patients because they demonstrated the qualities during the meetings and made themselves unique in the eyes of the researcher.

It was then started, the trajectory starting from the ontic to the ontological, and close readings of each interview were conducted in order to separate the sections or units of meaning that have shown as fundamental structures of existence. Subsequently, the units of meaning of each statement were analyzed, and performed phenomenological selection of each participant's language, because a unit of meaning, in general, consists of feelings revealed by the interviewees that address the ontological

question⁶. Thus, the ontological issues arose, analyzed in light of some of Heidegger's analytic ideas, some assumptions of palliative care, and authors that deal with these issues.

We clarify that this study is part of a wider range of research entitled: "The applicability of palliative care in primary healthcare by promoting better quality of life to patients with malignancy, their families and caregivers". This project was undertaken in accordance with the Resolution of the National Health Council Nº. 196/96, in force at the time of data collection, revoked by Resolution 466/2012 of the Ministry of Health and approved by the Standing Committee on Ethics in Research Involving Human beings, State University of Maringa under the number 435/2011. All participants signed a consent form in duplicate.

RESULTS AND DISCUSSION

Among the 15 patients interviewed there were eight women and seven men, mostly married (eight) who had income below a minimum salary (six). Of these, six had incomplete primary education and three were illiterate. The age ranged from 40-77 years old and the types of cancers most often found among those surveyed individuals were breast, prostate, bowel and cervical metastases. The time of treatment for most participants (eight) was up to six months, and hence the residence time in the house varied between 1 week and 7 month host.

We also point out that the approximate distance of the municipalities where the patients lived to the city they performed the treatment was on average 131.1 km. For these distances, the travel time by bus varies from 40 minutes (to the nearest town), to four hours to the farthest municipality. Currently, 15.5% of Brazilians live in cities located more than 150 km away from a city where it can be performed the treatment⁷.

From exploration and analysis of the interviewees' statements, three categories emerged, as follows:

Recalling his former force

In his work *Being and Time* (Part II), the *Being-there* and temporality, Heidegger exposes the interpretation of authentically existing human, i.e., being in the world in its temporality⁸. To the thinker, in anticipation of death, i.e., in the original and authentic way of caring, man reveals all its power-being, and this power-being is manifested in a temporal constitution. It is a primitive temporality that temporalizes as three ecstasies: the future, the force of having been (past) and the present⁹.

In this temporality, the *being-there*, understanding to be an entity unto death, is perceived released in the world and experiencing the facticity of existence, i.e., being with cancer. The temporal movement by which he makes his return to his *being-released* is the past. In Heidegger's thinking, it is projecting itself into the past that man can take his sight and *being-in-world*. "Human being can return to the past, because life is compact, crystallizes in significant ways, of meaning and value"^{9:137}.

From the above, we realize from the descriptions of users that being hosted on a support house does not erase the

memories of the vicissitudes faced during his pilgrimage in search of healing. "The past has always sense only insofar as it is seen from a present"^{9:136}. The time of transportation stands out from the others, as being of the greatest impact, since the vicissitudes experienced enliven the ill feelings of distress and anger at his existential condition. These feelings are expressed in the statements below:

[...] because we leave our city at 4am, then I had to stay until 19pm, I had to wait until this time... So it was too late, I could not stand it, I still had to go back [...] (Generosity).

[...] I used to have chemotherapy once a month and used to go in the morning; I used to get up at 4am and came at 5am. We stayed without eating, not to be sick. Some days, I got home at 17:3 pm or 18pm and it was very tiring. I stood there, waiting, sitting, waiting... And though we went by van, we then had to wait other patients [...] (Perseverance).

[...] and one that brings us, Mrs. B., she cannot leave early because she came with a full van... All patients. Then we had to wait to eat lunch, and we could not sleep because we had nowhere to sleep [...] (Prudence).

[...] When I did the treatment and had to go back, I came back feeling bad, I laid there and I was dropped like I was giving a reaction. I went back in that bad, hard and full of sick bus... You need to see, really [...] (Faith).

It is noteworthy that the quality of care and especially the completion of treatment in appropriate period may be hampered by the complexity of access. Because when they are depending on the transport provided by the city hall, users must adjust to the times and modes of it, which requires by patients too much patience, facing the busload, discomfort and extreme schedules that do not allow their rest⁷.

In Heidegger's analytics, disposal stands about the past, when the man eventually retracts into the world of oblivion, to his *have-been-released*. The philosopher says that the disposal is characterized in mood or affectivity, representing the ways in which man expresses himself to the world. In this temporal analysis of the mood, the author refers to the fear.

For the philosopher, fear is characterized as an improper disposal, because fear finds its opportunity in ones that come to meet him revealing a "*malum futurum*". The existential and temporal meaning of fear constitutes a self-forgetfulness. Fear provides the removal of *Being-there* of his own power-to-be, and in this forgetfulness, he does not recognize himself anymore in his surrounding world and do not see the various possibilities around him because with fear, man is disturbed before the world, becoming tormented and disturbed⁵.

While reading the testimonials, it was realized that having to stay in a support house initially causes feelings of dread at the prospect of having to live through difficult and often unknown times.

[...] I thought we would get into the wrong place; I was afraid (Temperance).

[...] So we thought... We live far away, when we go out there, it will be terrible, I had never been away from home, I thought it would be weird, but I like it here (Hope).

[...] I cried at home last night, I thought, now what do I do?! [...] I would not continue the treatment; I would not bear it, to come and go back in the condition I was. If it was not for this place to stay, I do not know how I would do the treatment. I would not bear it. (Faith).

Considering the speeches, we apprehend that the break of routine and the chance to step into an unknown place arouse in these individuals feelings of fear before the probability of not adapting to the new temporary home. And these feelings of hopelessness are evident in the language of the subjects when they express fears about leaving the protection of their homes and leave for the sake of life, for a so far totally incognito place for them.

In Heidegger's existential discourse, on the one hand the man relates the fear to a "*malum futurum*", on the other hand he conceives in the hope to develop a "*bonum futurum*" because hope brings to man the strength to emerge from its anguish and glimpse new possibilities. "He who has hope loads, so to speak, himself into the hope, in contrast to what is expected"^{8:143}. In this thinking, we infer in the language of Faith that becoming familiar with the support home brings hope and make it emerge from its existential angst and strengthen itself to face treatment.

It is noteworthy that a support network may grant two instances of assistance to their patients, instrumental and emotional. The instrumental assistance is financial aid, including the distribution of overhead and conducting instruction to the subject. The emotional assistance is guided in empathy, care for others, and ultimately provide the feeling of being welcomed by the caring staff¹⁰. Thus, it is possible to observe that the support network comprises a remarkable paradigm of promotion, prevention and restoration of health, since it has focused attention to all these aspects, providing oncology patient in a dignified care in this fleeting moment of his life.

Experiencing being welcomed in the present

On Heidegger's meditation, the last ek-stasis of temporality is the present. It does not represent the current time of colloquial temporality, but as an existenciary indicates the movement by which the being-there, projecting himself to his own power-to-be and assuming his existence-the-world, discovers a world that is his, that is, his own situation. The presentification of the authentic man, Heidegger calls is-tant (Augenblick), i.e., the moment he becomes free to experience his world and find ways to cope with cancer and its treatment⁵.

The path to freedom was expressed by users through the joy of feeling welcomed, because in all the interviews we noted

that they carry in them the belief that someone is looking for them, helping them to cope with the illness and its treatment. Users have the perception that the support network is that help and needed light to dispel this cloud of fragility that the patient and family are, supporting them after disclosure of diagnosis and being a support throughout the disease cycle. In the speech to follow patients reveal the importance of support home in their lives, highlighting the minutiae that make this place their second home.

[...] It is very important, and it is helping me because we do not need to go back to town on the same day, we can stay here, we have food, we can rest, take the radiotherapy and come back, it is very nice... I am enjoying it. [...] And now here on the Net is much quieter, we can rest, lie down, eat... It has been really cool to stay here (Perseverance).

[...] It is helping me a lot. [...] Here we have good food, good sleeping bed... We can rest, and everything is clean. I learned a lot... I liked it very much. Each one has its room here (Prudence).

[...] we rest enough and do not get stressed... We eat on the right time and sleeps tight... Here everything is all right, everything is good. I do remember my house... It is so good here, they treat us well, we have shower whenever we want, we sleep. They leave us in the hospital and bring back Here is a very, very good (Charity).

[...] Here is good, it is great, it is really great for me, because here is like my home. [...] For me it was good. Here is really great, we feel like home [...](Temperance).

As we can see through the speeches, the support network tries to keep the routine of each subject, respecting their individuality, and meeting all their basic needs. And with that, though far from home, patients feel at home, that is, one less difficulty to be overcome: the longing for the comfort and warmth of their home. Thus, the health care provided by the support home goes beyond the action on the disease, seeking to rescue and build social bonds in an environment that is similar to their home, in a biopsychosocial view of health².

In Heidegger's analytic, the being-with reveals ways of being in his encounter with the other, passing between occupation and concern. Occupation is guided by the disdain and neglect in dealing with other beings around you; whereas, if he cares, establishes the mode of co-relation, and an ontic-ontological privilege, becomes being-with-others¹¹. This relationship with others in a compelling and expressive manner is called solicitude¹². This has as primordial characteristics "having consideration for others" and "being patient with others". Both are related to temporality, as the consideration is referred to the past, to the experience that has been, i.e., it has a look to the past; while the patient is seen ahead, due to the hope of what might still be in the future¹².

So, for presenting diligent and humanized, features employees who accept other users are admired by users, who demonstrate through speeches, gratitude for the affection and consideration received.

[...] Now the home here, Our Lady!... Helps us too much. [...] Nothing is missing for us. An educated people, good people, who treats us well. We are treated well here. Here we can rest peacefully, we eat well. They take and bring back [...]. One cannot say anything, not a bad thing about the house... It has everything for us; nothing is missing for us here (Hope).

[...] good people, they caring, have consideration, treat us with respect and with love. Devout people. Here I watch the Mass, the rosary. [...] The Network is helping a lot, it is very well. [...] The staff is very religious, very polite, I like it here (Humility).

[...] Now taking chemotherapy here is better, there is a nurse, there is everything in here, anything we need, we have people to help (Generosity).

Related to this issue, authors express that when a support house is composed of quality services and exemplary employees, it results in guest satisfaction, helping them in coping with treatment, or even disguising the difficult experienced reality, which provides quality life to the hosted subject. This is achieved by the application of other essential characteristics to individuals, such as family assistance, a proper nutritional diet, mastery of emotions, tranquility, respect for their principles and history among others¹³.

The institution of support, since having experienced and trained professionals who remain available to their patients, refers to the guests safety and tranquility, as shown in "Generosity's" discourse. Therefore, these employees are considered as a safe haven for their importance during the diagnosis of the disease, and support during treatment¹⁴. Moreover, the attitudes of professionals working in the house refer to comprehensive care practice, since professionals treat the patient as the center of interest, considering his subjective aspects and experiences when performing care¹⁵.

Therefore, it is essential that professionals involved in these institutions are prepared to welcome these beings and offer them the support and care they need at this very special time of their life, so as not to be a greater injury to their physical and mental health.

Experiencing true satisfaction of being cared

In Heidegger's meditation on one hand inauthentic opening affects the moment of encounter between people, on the other hand the true opening reveals itself the capacity of the being-there to manifest attitudes of companionship and care for oneself and other ones around¹⁶.

The cancer patient who performs treatment away from home is in a situation of dependence to the neighbor to achieve satisfaction in day-to-day life and quality of life during this journey. In this perspective, the protection offered at the time of eminent need has an immeasurable value to those who receive it. Faced with so many obstacles, the support of the institution is the assurance of a secure future, which animates the struggle and gives strength to face a new journey. Thus, the vicissitudes that accompany the person during cancer treatment are diminished by the availability of the neighbor.

[...] The importance of the network... I have no words to say, because it is such an important thing... it is even difficult to speak. It is so important in our situation [...]. The importance of this is speechless... so good... so good... a wonder [...]. (Patience).

[...] Look at me, in my view it was the best thing that ever happened in my life [...]. They are doing everything possible and impossible for me. [...] I am very happy to be in this house (Strength).

[...] Very important to me [...]. Here everything is good. [...] It is very, very good here. All good here, no comments... I love it. (Charity).

Paying attention to the language of the interviewees, we noted the unique importance that each guest expresses about the home. It must be considered that these sites help the quality of life of cancer patients, since they offer residential care for people who need to carry out health care outside the home and who have no financial means to afford a particular support house. Also, they provide the expansion of the guests' informational universe, through the guidance and referral they perform, with a view to enforcing rights.

Further emphasizing contentment with the services of the house, users find it difficult to express the importance it plays in their lives. While becoming the target of so much zeal and dedication, they reveal the greatness of the institution through their gratitude, besides considering the site as predestined to assist them during the difficult journey.

[...] I praise God that this house exists. I got to give thanks to God, with so many things that happened in my life, there this support house for us to stay here. (Prudence).

[...] It is good here. Thank God! [...] Thank God, God enlightened this place to us, for us to be able to do this treatment, because if not, what we would do? The bus does not come. It is a wonder, God gave a blessing, this place here was a blessing, by the time I arrived and I saw it, I said: Oh my God... That white lady who was talking to

us here and I was looking at her and I saying, Oh my God, what a relief. She did not know how much I was thanking, while she was talking to me (Faith).

Religion is employed in comforting the patient during periods of vulnerability, pain and illness, because it grants to the Supreme Being the control of their experiences, helps to find tranquility and alleviation of distress and fear experienced¹⁷. Thus, for the patient who is faced with a malignancy, faith becomes a foundation of protection that serves to strengthen the individual and makes him stand the barriers imposed by the treatment, or even accept the opportunity of his terminally ill¹. The support home was felt as implementation of the care and, based on spirituality, seen as a blessing for the patients that were there.

Thus, with the same purpose of religion, the support network exerts its support and hope to people who seek it, providing comfort and peace, these feelings evidenced in reports of Prudence and Faith. About this issue, authors mention that "hope brings a portent of the future, allowing the patient and their family the strength to emerge from its anguish and envision new possibilities"^{18:30}.

And, in this friendly environment, users and escorts find the strength to overcome the vicissitudes of the present. Finding help at this time provides comfort as it gives the refuge needed to restore hope and strength that were shaken. In "Faith's" testimony it is clear the sense of gratitude and relief, emphasizing that the institution was crucial to restore her hopes on coping with cancer, and that it provided a new perspective on her life and existence, thus favoring the restoration of spiritual and physical balance, and achieving the quality of life of the guest during his stay in the house.

In our view, sometimes it is just needed a little light as an aid to this individual shine again. We glimpse the link patient-support home, and soon concluded that the strong bond existing between this pair causes the patient to have a great fascination with the care received.

CONCLUSION

As we enter the world of people with cancer who must undergo treatment away from their houses, we seek not only to glimpse the human being, but understand this being in his ontic-ontological primacy, where time is the horizon of understanding of being. In this situation the being-there with cancer manifests his way of being in a support house during his treatment, because while a person with possibilities, he unveils to the ones around him his joys, sorrows and mainly the needs covering ontic-ontological priority.

The existential phenomenological analysis allowed us to understand that being in a strange place initially awakens feelings of awe before the unknown. But we learn also that experience an authentic hospitality based in a supportive and humane way, besides approximating professionals to the comprehensive care,

it awakens in the cared ones feelings of gratitude and empathy. Such an attitude shows that they consider that the support homes represent important support, not only for their stay, but also to improve their quality of life during treatment.

In our view, these houses are benevolent archetypes for people with malignancy who perform treatment outside their home, and usually aim at the holistic dedication and prevention of health problems during care. Thus, the maintenance of support houses in regions that are benchmarks for cancer treatment deserves the attention and encouragement of government agencies, since, within this area of care, it is considered the possibility of countless people to follow up on their treatment and experience this moment feeling cared for. Furthermore, the study raises a reflection on the preparation of professionals who have the opportunity of being-in-world with these beings, because these are the ones who will accommodate these individuals, going beyond their physical needs, to enter into their bio-psicosocio-spiritual world.

This study unveiled the experiences of users with cancer who remain in a support home during their treatment. However, it has some limitations comprised in the fact that it had been developed in a specific setting and region. Thus, we believe that the results cannot be generalized, but may point to the fact that many institutions have been seeking to comfort others in difficult times. We hope this study will contribute and encourage further research that takes into account in its preparation, the complexity and diversity of these institutions, as well, seeking to understand the experience of people housed there, joining them as part of the premises for training nurses and other health professionals.

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