

Therapeutic Actions Promoted to Terminal Patient: Professional Experience at Home Care Service.

ORIGINAL

Indiara Carvalho dos Santos Platel¹, Patrícia Serpa de Souza Batista²,
Solange Fátima Geraldo da Costa², Maria Eliane Moreira Freire³, Maria Emília Limeira Lopes²,
Jaqueline Brito Vidal Batista², Marcella Costa Souto Duarte⁴

Abstract

Objective: To investigate the experience of professionals in a Home Care Service with regard to the therapeutic actions promoted to the patient in terminal illness.

Method: Exploratory research with qualitative approach, guided by the Reporting Qualitative Research – COREQ, held from February to May 2015, in the Home Care Service of a Northeast capital city, in Brazil. The participants were 20 higher level professionals, members of the Multidisciplinary Teams of Home Care. Data were collected through interview technique.

Results: From the analysis, it emerged two categories: “Therapeutic actions directed to the biological needs of the terminally ill to promote comfort and quality of life” and “Therapeutic actions promoted to meet the psychosocial and spiritual needs of terminally ill”.

Conclusion: The interventions highlighted by the professionals were essential to meet the biological, psychosocial and spiritual needs, and reduce the suffering of the terminally ill stigma in the home context.

Introduction

Building new paradigms in caring production has been transforming the technical care model and demanding of them new strands contributing to overcome the hegemonic model, innovating the attention to health in order to provide qualified assistance with integral and continuous care. [1, 2]

- 1 Nurse. MSc. Federal University of Paraíba, João Pessoa, Paraíba, Brazil.
- 2 Nurse. PhD. Teacher pos graduacion of Federal University of Paraíba, João Pessoa, Paraíba, Brazil.
- 3 Nurse. PhD. Teacher graduacion Federal University of Paraíba, João Pessoa, Paraíba, Brazil.
- 4 Nurse. PhD. Teacher of the Nursing Course of the João Pessoa University Center, Paraíba, Brazil.

Contact information:

Indiara Carvalho dos Santos Platel.

Address: Avenida Oceano Atlântico, 80 - Intermares, Cabedelo-Paraíba, 58102-252, Brazil.

✉ indiaracs@hotmail.com

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In this perspective, the Home Care stands out in Brazil, which includes unique, integral and humanized care directed to the users of the Unified Health System (SUS) and their families. This new type of health care is realized through the Home Care Service (SAD), named by the Ministry of Health, from 2011, as "Better Home Program", which institutionalization happens through the SUS. Currently, it follows legal principles regulated by ordinance n. 963 of 2013.

The SAD aims to provide comprehensive and continuous care; restore and maintain the health of the user; promote autonomy through function adaptation and coparticipation in care; reduce the frequency of hospitalizations; facilitate the deinstitutionalization, by improving the quality of life of the patient and support the family and/or caregiver, accompanying him and enabling him to perform daily care functions. [3, 4]

As a new logic of care qualification, the SAD stands out from the other health care networks by having its Multiprofessional Teams of Home Care (EMADs) and Support Multiprofessional Teams (EMAPs) that receive and assist the patient with pathologies, and often needing care and continuous health resources. In this attention, chronic diseases of progressive and incurable evolution are considered as, inevitably, they induce the condition of the terminally ill. In this sense, it is of fundamental importance to offer a humanized assistance based on the Palliative Care philosophy.

There is no denying the value of this philosophy of care because its therapeutic approach permeates the conventional treatment, transgresses the aegis of the disease, adapts the assistance to the multidimensional needs of the patient and the family, and does not attack their beliefs, values, customs and religious practices. In the meantime, it emphasizes several therapeutic actions directed to the patient in terminal life, such as: communication, music therapy, pharmacology, spirituality, among other. [5-7]

Within these possibilities, the Home Care Service is an important strategy that can be employed to expand care for the user and his family, and that stands as a mainstay of fundamental relevance to qualify health care and humanize the assistance to the terminally ill, especially in the reality of countries with limited resources in health and scarce institutional possibilities for caring at the end of life. [4, 8]

Studies show home as a potentiating space in the care given to the patient in the finitude of life and emphasize the importance of therapeutic actions designed by multidisciplinary teams to alleviate the suffering of the patient and his family [9-12], with the central focus on Palliative Care. However, at the national level, there is an incipient quantitative of studies related to the themes mentioned. The research approaching therapeutic care in terminally ill hardly contemplate the SAD and the activities of the multidisciplinary teams, as these are restricted to therapeutic actions promoted in hospitals with healthcare approaches aimed at individual professional categories.

Given the above, the research is considered relevant, by contributing to propagate the issue addressed herein and enhance the promotion of humanizing therapies in caring for the terminally ill. In this perspective, this study aimed to investigate the experience of professionals in a Home Care Service with regard to the therapeutic actions promoted to the patient in terminal illness.

Methodological Course

This is an exploratory study with a qualitative approach, guided by criteria established in the Qualitative Research Reporting –COREQ– an instrument intended for qualitative research consisting of 32 criteria that describe the research method, the context of the study, the results, analyses and its interpretation. [13]

The setting of the study was the Home Care Service (SAD), also named by the Ministry of Health as

'Best Home Program', located in the city of João Pessoa, the capital of Paraíba State - Brazil. The study was carried out with a sample of 20 top-level professional members of the Multiprofessional Teams of Home Care (EMADs) and Support Multiprofessional Teams (EMAPs).

The investigated multiprofessional teams were represented by the following categories: six nurses, five physiotherapists, two nutritionists, two doctors, two psychologists, two audiologists and one social worker. According to the realization sequence of interviews, professionals were identified with pseudonyms representing the following feelings: attention, affection, anxiety, motivation, love, compassion, happiness, hope, dignity, respect, joy, sadness, courage, impotence, sensitivity, gratitude, disability, satisfaction, peace and mercy.

The criteria established for the inclusion of the sample were: being active during the period of data collection and having at least one year of experience in SAD. As a criterion of exclusion: not having experienced the care of a terminally ill patient from the admission in the SAD.

The approaching to the participants happened upon previous contact with the coordinators of that service, as the responsible researcher had no relation to the surveyed professionals before the study. Through this intermediation, the first meetings with the professional teams were scheduled in order to explain the research project and the ethical aspects, and invite the professionals who met the inclusion criteria for participation in the study.

Data were collected during meetings of the EMADs and the EMAPs, respecting the shifts and days of weekly meetings of each team. Data collection was carried out by the researcher in charge of the project which ran this survey, in the period from February to May 2015. The interview technique was employed, lasting about fifty minutes each. This technique was guided by a semistructured script, composed of two parts: the first was composed by demographic data, and the second followed

this guiding question: What is your experience as a Professional at Home Care Service in regard to therapeutic modalities promoted to the patient in terminal illness?

In line with the ethical observances considered to the conduction of studies involving humans, this investigation was guided by Resolution 466/2012 of the National Health Council in force in Brazil. [14] The research project has been approved by a Research Ethics Committee, under CAAE nº 39989514.0.0000.5188.

A Consent Form was presented to professionals selected for the study, to consent their participation. In order to preserve the anonymity and confidentiality of research participants, a pseudonym was assigned to the professionals representing a sense of free choice of the participant at the time of the interview.

To seize the empirical material, a recording system was used in mp4 appliance. It should be noted that the decision of the participants regarding the use of this technology was respected, which was accepted by all of them. The reports were transcribed in full, read and legitimized by each participant in the study. Subsequently, the data generated were analyzed qualitatively, through the technique of content analysis proposed by Bardin. [15]

Results and Discussion

The sample was composed of twenty participants - 19 female and 13 aged over thirty years. With regard to professional information, fifteen of the participants said they had ties to the Home Care Service since its introduction, more than three years ago. Regarding the formation procedure, fifteen of them completed the course in private higher education institutions; five of them finished undergraduate course at the Federal University of Paraíba; seventeen declared themselves experts, and nine had studied lato sensu graduate in the area of Family Health, and eight of them has studied in different areas of hospital performance.

As regards the professional experience of a Home Care Service, the therapeutic actions employed in care with terminally ill have enabled the construction of two categories, listed below:

Category 1. Therapeutic actions directed to the biological needs of the terminally ill to promote comfort and quality of life

This category emerged from statements of the participants of the study, in which they emphasized the interventions employed to meet the biological needs before the clinical progression of the terminally ill. In this perspective, the professionals have addressed needs related to pain relief, as the control of gastrointestinal and nutritional symptoms, and skin care, as factors for the comfort and quality of life in the confrontation of terminal illness.

Among the clinical manifestations reported by most terminally ill patients, there is pain, recognized as one of the most frequent and persistent symptoms reported by these patients. It is a sensory and multidimensional experience, unpleasant from the physical and emotional point of view. For this reason, it is necessary to make an accurate assessment of pain, since it is the cause of suffering and undermines the quality of life of patient [16-18], as demonstrated in these lines:

..., the symptom that often appears is the pain, and this is considered by many patients as unbearable. At this point it is important to evaluate its intensity for being a subjective and personal symptom.

Distress.

..., she always complained of pain and whenever we evaluated it, its intensity was the maximum,...

Attention.

For this, it is necessary to evaluate the causes and pain intensity...

Hope.

In the mentioned reports, participants conceive pain as one of the most common symptoms in terminally ill patients and they stressed the importance of evaluating its intensity to provide the proper therapy. Studies suggest that pain must be incorporated in the context of health care as the fifth vital sign, which must be measured and recorded accurately through pain scales, in order to apply appropriate therapeutic and humanized care. [19-21]

Thus, the assessment of pain is predominant in the choice of therapeutic approaches in the treatment and control of this symptomatology. In this sense, there is a numerical visual unidimensional scale and the Wong Baker faces pain scale, that most used because they are quick and easy to be applied. However, its measurement quantifies the intensity and severity of pain, without involving the multidimensional aspects. [22] In the specificity of the terminally ill, the applicability of these scales can be complex because it depends on clinical status, physical condition, age and communication condition. [23]

To meet this biological need, the participants emphasize how interventions followed by evaluation of the intensity of the pain, the analgesia, having morphine as first-choice drug, in order to provide comfort and relieve symptoms arising from terminally stage, as highlight these reports:

...we work a lot with the pain, the discomfort on the evolution of the clinical picture, and this generates a lot of suffering [...], drugs are given for analgesia or other symptoms...

Sensitivity.

Every patient cites as the cause of discomfort, we treat and after all we prescribe morphine!

Anguish.

If a painkiller is prescribed, I have the hope that this will be effective.

Hope.

Many times I had to administer morphine

Attention.

Seconded passages emphasize pharmacotherapy as an approach adopted by professionals in relieving pain and they mention morphine as a drug to be used for relieving this symptom. In accordance with the effectiveness of opioid, studies indicate the morphine as the first drug to be administered to the patient in the critical phase of the illness to relieve his pain. [12, 24-25] However, the World Health Organization recommends that the analgesia directed to the patients without prospect of cure must obey clinical criteria, the intensity of the symptoms and the approach of "WHO's analgesic scale". [22]

Concerning the analgesic scale, this is a proposal that adapted the use of analgesics according to the intensity of the pain, that must be evaluated by following three steps: the first one is directed to the treatment of mild pain, using non-opioid analgesics and anti-inflammatories; the second one is recommended for patients with moderate pain with the use of weak opioids, combined with non-opioid analgesics and adjuvants; and the third one is reserved for patients with severe pain, in which the weak opioids are replaced by the strong ones, like morphine, methadone, oxycodone and fentanyl, associated with non-opioid analgesics and adjuvants. [22]

Treat pain in terminally implies meeting other dimensions of the human being, since this symptom goes beyond the physical dimensions because it is an experience that involves emotional, affective and sensory factors. Its complexity is directly related to the suffering, which converges caring for various areas of knowledge. [18] Corroborating this assertive, there are some participants' reports:

...the pain extends beyond the physical dimension. Caring of the terminally ill patient is to go beyond, is watching people, human beings, and not just the symptoms of the disease...

Hope.

...we try to relieve pain and promote comfort [...]. In the sense of trying to get him to live in the best possible way, without suffering...

Love.

...after the pain, the discomfort is related to gastrointestinal symptoms...

Sensitivity.

...Medication for pain, nausea, vomiting and diarrhea was prescribed, all in order to promote comfort and improve the quality of life ...

Dignity.

The circumstance of terminal illness generates caring that transcends the physical dimensions. In this subjectivity, the pain is still described as a relevant symptom, especially with regard to its relief, but when associated with the symptoms of gastrointestinal tract, it causes discomfort. As a result of this suffering, the participants aggregate pharmacological assistance interventions focused on the patients' needs. In this respect, the comfort is considered as central focus, demonstrated in individualized care, with multidisciplinary or humanized interventions, in order to improve the patients' quality of life.

With regard to gastrointestinal symptoms, mentioned in two testimonies, studies show that nausea, vomiting and diarrhea are frequent in terminal phase, as well as loss of appetite, dysphagia, constipation and fatigue. [11, 18, 27-28] The severity of these signs and symptoms should be the professionals' focus of attention, by compromising nutritional standard and the patients' quality of life [29]. The lines following confirm this assertion:

She was a physically weakened patient, she did not eat anymore and she had trouble when swallowing [...]. The support multidisciplinary team had to be involved in this care, at the moment that she was accompanied by nutrition, speech therapy and psychology.

Affection.

The nutritionist evaluated the malnutrition profile and supplements were prescribed...

Dignity.

...she was already making use of antineoplastic, then I noticed her feeding [...], and on the next visit I took her some supplementation ...

Gratitude.

...we have to resort to a nasogastric probe, in order to preserve his water and nutritional status. The intention is that this survey is temporary, until the phonoarticulatory organs regain their mobility...

Satisfaction.

The above speeches highlight some factors that affect the nutritional status of the terminally ill, which are cited by a symptomatology cast that include physical weakness, poor appetite, dysphagia, cachexia and malnutrition. These significant factors, associated with dehydration, decrease the survival of terminally ill. [29] In the confrontation of this juncture of signs and symptoms, professionals stress therapeutic actions focused on evaluation of the nutritional pattern, adequate diet, state water control, nutritional supplementation, rehabilitation of the phonoarticulatory organs, nasogastric survey and use of antineoplastic therapy.

In this context, the importance of professional nutritionist and the adjacent multidisciplinary team performance was highlighted, since nutritional disorders in terminal illness involve multifactorial causes, and the set of these interventions will contribute to improving the quality of life of the terminally ill and provide well-being.

Authors show that the nutritional disorders related to lack of appetite reduces lean body mass and adipose tissue, conditions that compromise the integrity of the skin. Another factor to be considered is that these nutritional disorders result in deficits in absorption of nutrients essential to the

immune system function and tissue angiogenesis. These phenomena result in physical weakness and walking difficulties, limiting the patient to the bed, skin lesions and increasing the risk of pressure ulcer. [30-31] Such conditions require multidisciplinary team interventions to prevent and/or minimize the repercussions arising from the increase of terminal patients, which was highlighted by the participants of the study, as demonstrated in these testimonials:

We must have maximum skin care with the terminal patient, [...] have associated with any frame of dermatitis or pressure ulcer. The change in decubitus, moisturizing and massage prevents it! [...].

Impotence.

...we used hydrocolloid, his skin was always hydrated, he was a patient who had as much concern for the skin, since he couldn't be much hydrated because of his heart failure...

Courage.

We performed the bandage, [...] I wanted at that moment to make the best healing of my life, so that she doesn't suffer, doesn't feel pain [...].

Compassion.

wanted her wound to heal, to offer better quality of life and decrease her suffering

Attention.

The statements above point out that nutritional disorder reflects the functional capacity and the completeness of the skin, which causes suffering to terminally ill at home, by favoring the development of pressure ulcers. So, in order to promote comfort and improve the quality of life of these patients, the professionals of SAD bring to their approach interventions such as healing, change of decubitus, massages, moves to improve venous return, hydration, in addition to the nutritional interventions already reported. A study on nutrition and healing confirmed these findings and concluded that the proper absorption of nutrients stimulates the hea-

ling of pressure ulcers and improves the standard of patient comfort. [30]

This category was set up with interventions that sought to promote the comfort of clinical symptoms in the critical phase, in order to bolster the biological needs and reduce the stigma of suffering of the terminally ill at home. The therapeutic actions contemplated by professionals concentrated in relieving pain and other symptoms of the disease progression. Furthermore, the importance of nutritional support, the skin care and pressure ulcer prevention were highlighted with a view to improving the lives of the terminally ill.

Category 2. Therapeutic actions promoted to meet the psychosocial and spiritual needs of terminally ill

In this category, fragments of testimonies from the pros entered in the study were presented on psychosocial interventions promoted to the terminally ill in home care. Therapeutic actions referenced gave emphasis to communication, listening, spirituality and religiosity as careful actions spread by the Palliative Care philosophy. A priori, communication is emphasized, as mark these parts of the testimonies of some participants:

I consider the communication very important, even in the most difficult moments in which the patient feels a lot of pain [...]

Tranquility.

The logic of relieving the suffering of the patient, to have good communication with him, to have a good interaction, providing pleasant moments at very end of life.

Joy.

I value communication, [...], I encourage the patient when he is able to talk, if he can't, as the communication can be carried out through a smile, a glance, the touch and gestures of affection

Disability.

The above narrative denote the sensitivity of professionals to mention the use of communication as a relevant intervention in the care of the patient facing terminal illness. In the area of health, interpersonal communication is understood as a complex process, expressed through contact between the patient and the professional, whose representation involves the perception, understanding and the transmission of messages through speech or writing (verbal communication) or signs (non-verbal communication). [32]

Considering the dimensions of the verbal communication, it is noted that the participants brought to talks, also described as conversation, a strategy to address the situations of uncertainty and suffering of the patient in his finitude. Such relevance confirms the studies developed in the context of the terminally ill, who defend the communication as one of the foundations for the care dispensed to the patient without prospect of cure, since its essence conveys attention, compassion and emotional comfort, minimizing the fears and anxieties experienced by the patient in terminal illness. [16,23,32]

Nonverbal communication is described as any manifestation of human behavior that is not expressed in words. Its systematization was proposed by Knapp and Hall in 1972, that defined in fields of study, announced by kinesics (body language, gestures, facial expressions); the proxemics (use and organization of personal and physical space); the paralanguage (the characteristic sound of the voice); the language of touch and the physical characteristics (shape and appearance of the body). [33] Among the studied fields, kinesics and language of touch, represented by the smile, the look, the gestures of affection and by touch, were cited by participants of this study, associated with verbal communication.

Non-verbal strategies, also mentioned by the participants, were pointed out in study [31] as important in the context of the terminally ill, once they denote interest on the other person, they are essential

premises for the approach and the establishment of ties of trust with patients. In this approach, there is a reverence to therapeutic listening, which requires from professionals the association of all non-verbal fields of studies already presented, proclaimed by some participants of the study:

...in terminal illness the principle of care is established by listening, hearing what this patient wants to say, what he feels, what are his sorrows, fears, that we try to work,...

Tranquility.

But there were cases that the hearing already improves his anguish or suffering. [...] and at that time the most important thing is to have someone to talk, than the intervention itself,...

Sadness.

...the strategy that I most value is the qualified listening [...], patients who have speech preserved, even the most debilitated of them, I let them talk, I go to the visits and just listen,...

Mercy.

In some situations, we realize that the technique of a procedure is not so important but, of course, there are the specifics. [...]. I realize that our presence, attention and mainly listening to them, offers an extraordinary therapeutic power...

Love.

In the fragments of the above statements, the professionals mention listening as an essential intervention in the caring of the patient in terminal illness. Mainly for patients with preserved speech ability, its therapeutic action strikes the invasive procedures by sensitizing professionals and directing them to new perspectives. On this premise, their fears, anxieties and sufferings are worked, and the family facing situations raised from the finiteness of life.

In this line of thought, some studies deserve mention that highlights the listening as a therapeutic intervention needed to alleviate suffering. Listen to

the patient means to extend a blanket of protection and care, touching him without invasive interventions. It's a way that directs new learnings. These insights demand a personal maturation of professionals so that they can understand the necessity of being and effectively direct therapeutic possibilities and the imminence of death. [7, 33-34]

So, recognize the interactions that pervade communication therapy is to respect the human being in its finitude. The talks, the smile, the look, the gestures of affection, touch and qualified listen promoted by professionals' caring actions, in the home context, reaffirm the potentialities of the multiprofessional interventions in promoting comfort and improves the quality of life of the terminally ill. In this understanding, therapeutic perspectives overlap the mistaken assumption that "there's nothing else to do" by the patient and direct new health practices while there is life. [34]

The care in terminal illness requires the health professional knowledge and skills that integrate biopsychosocial and spiritual aspects [16]. In this approach, the spirituality is inserted as a strategy for combating unanimous and transcendental death. It is important to point out that caring for the spiritual dimension is relevant because it can improve life to the terminally ill. [35] Such considerations are expressed in the following:

Spiritual dimensions have their importance, when the patient already has a religion or faith in God, we resort to these aspects, mainly to relieve the suffering...

Motivation.

I consider religious important, I always talk about God to the patient believes, but without interfering in religion. [...]. When it is allowed, I show that God is there and He is governing everything.

Sadness.

There are patients that I do prayer to, we talk, he cries, we sing. Regardless of religion or belief, I work their faith, the faith in life, the hope and the Supreme force. Many patients allow us to make our prayers.

Respect.

The spiritual dimensions addressed in the statements of the participants relate to spirituality associated to religiosity. These findings are substantiated in studies that indicate that, in spite of the spirituality and religious practices being described as distinct modes, there is something intrinsic, especially for the individual who faces the completion of life. The religion leads to spiritual dimension, in order to provide comfort to the suffering and certain conformity in relation to the desperate situation. [35-37]

Spirituality is a practice that brings meaning and improves quality of life. It is an instrument of reflection, wisdom and balance, which helps patients to set up priorities in life and get straight to the things which are, in fact, essential and necessary for people. Studies show that spirituality, inevitably, is present in times of distress and it is notable especially in individuals with a disease that threatens life. [28, 38-39]

When it comes to religion, professionals who participated of this study highlighted the respect and religious diversity, and contemplated the faith as a crucial point to proceed with actions directed to the spiritual evolution of the patient, highlighting prayer as the intervention strategy. In this sense, authors recommend that health services offer spiritual and religious support, through institutional groups or Chaplaincy Service, without imposing religious preference, respecting the beliefs and values of the patient and his family. [35-36]

A study that sought to show the diversification of needs of Brazilian patients with reference to spiritual well-being in terminal phase state that religious manifestations are almost always present in the rituals of finiteness of life, even for individual

who didn't express any religion or belief. Inevitably these manifestations will be demonstrated by relatives or friends. Such practices govern the spiritual transcendence and the well-being of the patient, and comfort relatives at the time of mourning. [39]

The interventions that maximize benefits and promote the improvement of the quality of life of terminally ill are of great importance in the therapeutic context. So, it is very important that professionals pay attention to aspects involving the psychosocial and spiritual dimensions that make up the human totality, which arises in the course of the development of a chronic disease with no prospect of cure. The impact of the interventions highlighted by participants show that home is a potentiator space scope for the promotion of comfort and quality of life of the patient in condition of terminal illness.

Conclusions

This study investigated the experience of professionals in a Home Care Service with regard to the therapeutic actions promoted to the patient in terminal illness. It is noted that the interventions highlighted by participants support the proposals for widespread assistance in the philosophy of Palliative Care, that takes care of various forms, in order to respond to the peculiarities of the patient. Among the therapeutic actions mentioned in this study, it includes Pharmacology, by analgesia and the relief of symptoms caused by the progression of Pathology, nutrition, skin care, pressure ulcer prevention, therapeutic communication, spirituality and religiosity, therefore, different possibilities of care directed to the patient without prospect of cure.

In the development of this research, there was a paucity of current studies related to the theme of nutrition and terminally ill, a relevant intervention in promoting comfort and the terminally ill quality of life. The study revealed the national and international lack of research on skin lesions and terminally sores. The findings tended to oncology, but skin

lesions and the terminally ill are not only particulars of patients affected by cancer. It should be emphasized that there were no records of such thematic in research in the home environment. The studies found limited their investigations to hospitals.

Regarding psychosocial and spiritual dimensions, the participants stressed the verbal and non-verbal communication as interventions that can improve the lives of terminal patients. Regarding spirituality, its practice was associated with religiosity, however these modalities are distinct, since the first search the transcendence of being, and the second is associated with divine belief.

Although the experiences presented have no relation with a palliative multidisciplinary team, since SAD team does not provide assistance only to terminally ill patients, the promoted interventions demonstrate the capability and commitment of EMADs and EMAPs with respect to the patient's needs and families facing terminal illness. The essence that governs these actions, at the moment, is particularly relevant for those patients who are at home, whether because of the current circumstances of the health institutions, by clearing hospital beds for patients with no prospect of cure is a choice of the patient himself, to understand that home is a warm and dignified place to live with care until the last day of life.

In this context, it is suggested that further inquiries must be made, given the incipient quantitative studies about the subject. The research approaching therapeutic care in terminally ill hardly contemplate the SAD and the activities of the multidisciplinary teams, as these are restricted to therapeutic actions promoted in hospitals with healthcare approaches aimed at individual professional categories.

On the above, it is hoped that this study can arouse interests for further research, particularly as regards the promotion of humanizing therapeutic care dispensed to the terminally ill in the home setting, and give subsidies through which it is possible to qualify the assistance and enhance the human

and humanized care completeness, in order to promote the comfort and quality of life of the patient in the process of finiteness of life.

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