



## Meanings of nursing care for the family of patients in palliative care

Significados do cuidado de enfermagem para familiares de pacientes em tratamento paliativo

Significados de la atención de enfermería para familiares de pacientes en cuidados paliativos

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**Objective:** to understand the meaning of nursing care for the family of patients in palliative care. **Methods:** field, descriptive, and exploratory study with qualitative approach conducted in secondary general hospital in the State of Ceará, Brazil. The participants comprised eight family members of patients in palliative care, with the conduction of semi-structured interviews and direct observation. For data analysis, we used the thematic category analysis. **Results:** data revealed the construction of three thematic categories. The meaning of nursing care for the family of patients in palliative care is anchored in the physical presence of these professionals, the performance of technical procedures, and teamwork. **Conclusions:** we verified that the nursing care highlighted by families aims at a humanistic care, established in the presence and based on human interaction. **Descriptors:** Nursing Care; Palliative Care; Family.

**Objetivo:** compreender o significado do cuidado de enfermagem para família de pacientes em tratamento paliativo. **Métodos:** estudo de campo, descritivo e exploratório, com abordagem qualitativa, realizado em hospital geral secundário do Estado do Ceará, Brasil. Participaram da pesquisa oito familiares de pacientes em tratamento paliativo, sendo realizadas entrevistas semiestruturadas e a observação direta. Utilizou-se a análise categorial temática no tratamento dos dados. **Resultados:** os dados mostraram a construção de três categorias temáticas. O significado do cuidado de enfermagem para a família de pacientes em tratamento paliativo está ancorado na presença física destes profissionais, na realização dos procedimentos técnicos e no trabalho em equipe. **Conclusões:** percebe-se que o cuidado de enfermagem destacado pelas famílias caminha em direção a um cuidar humanístico, estabelecido na presença e pautado na interação entre as pessoas. **Descritores:** Cuidados de Enfermagem; Cuidados Paliativos; Família.

**Objetivo:** comprender el significado de la atención de enfermería para familiares de pacientes en cuidados paliativos. **Métodos:** estudio de campo, descriptivo y exploratoria, cualitativo, llevado a cabo en hospital general secundario del Estado de Ceará, Brasil. Participaron ocho familiares de pacientes en cuidados paliativos, siendo realizadas las entrevistas semiestructuradas y la observación directa. Se utilizó el análisis temático de categóricas para tratamiento de los datos. **Resultados:** datos señalan la construcción de tres categorías temáticas. El significado de la atención de enfermería para la familia de pacientes en cuidados paliativos está anclado en la presencia física de estos profesionales, en la realización de procedimientos técnicos y n el trabajo en equipo. **Conclusiones:** se percibe que la atención de enfermería para las familias camina para el cuidado humanístico, establecido en la presencia y basada en la interacción entre las personas. **Descritores:** Atención de Enfermería; Cuidados Paliativos; Familia.

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## Introduction

Human care has always been present in the history of humanity<sup>(1)</sup>. It is considered that the care was and remains essential for the growth and development of the human species. The care, seen as an ethical attitude towards oneself and others, would lead to inclusion of a greater whole, society, environment, and respect for people<sup>(2)</sup>. Care encompasses several theoretical and philosophical dimensions: an attitude; feeling; necessity; process; action; and a presence.

In fact, human care is essential for life. From professional experiences, we verify that care is inherent in human beings and is present in daily life, family, work, and social life, strengthening feelings and preserving the relationship between caregivers and care-receivers. In this context, care is the foundation of nursing professional practice, constituting a specific area of nursing. Nursing emerges from the recognition that people demand physical, psychological, social, and spiritual care throughout life.

Nursing, as a human science<sup>(3)</sup>, is committed to care of people and has two aspects: one technical and other expressive. With regard to the technical, we highlighted interventional, technical, and instrumental care. As for the expressive, there is the relationship established between professionals and users, in other words interacting with individuals participating in care through verbal and nonverbal communication. Therefore, care should be seen not as a task or activity, but as a form of expression, relationship with oneself, with others and the world. It cannot be prescribed, cannot follow rules, rather must be lived, felt, experienced<sup>(1)</sup>.

We observed that care, as interaction, is expressed through communication established in care. Even during institutionalized care, with advanced technological resources, such as in intensive care unit, one must think there is much more than technology, once relationships, dialogue, respect, individuality, among others are imperative for care.

The several care situations, with relation to

the hospital environment, involve human bonding. Studying nursing care to users requires understanding the care itself and the subjects it involves. Various conditions can cause a person to require nursing care. In such cases, the treatments and resources that biomedicine can offer are helpful, but not enough. So, it is worth mentioning the humanistic approach in health care relationships<sup>(4)</sup>.

Nursing care approached in this study must be available to all people in need of it, from birth to death. In this context, palliative care emerges as non-curative measure, applied in patients whose disease progression entail signs and symptoms debilitating and causing suffering. These are global health interventions, in which health, human, and social sciences professionals work in various fields, from the patient's home until his admission to the Intensive Care Unit<sup>(5)</sup>.

Palliative care does not intend to cure and can be implemented regardless of the disease prognosis, this form of care may be used along with other forms of treatment.

Palliative care focuses on offering the best possible quality of life for patients and their families<sup>(6)</sup>. This specific type of care is designed particularly for three moments: 1) period shortly after the disease diagnosis, whose curative treatment is still possible and the side effects and sequelae arising from interventions (such as chemotherapy and radiotherapy) may be at least minimized; 2) period characterized as without therapeutic possibilities, when curing proposals will not offer any benefit in terms of patient survival or quality of life, and interventions are now directed to the full comfort of patients. This stage seeks to relieve physical symptoms, alleviate psychological suffering, and develop a coping attitude by celebrating its whole story in life; 3) presence of non-communicable chronic disease in progressive phase, in which palliative care will be playing a role equivalent to the abovementioned<sup>(7)</sup>.

In this context, the family emerges, since patients undergoing palliative care have specific

demands that end up affecting the family dynamics. For this reason, we applied the following question: What are the meanings of nursing care for the families of patients in palliative care admitted to hospital?

The questions presented in this study are significant because when working with family members, seeking their perspectives, values, feelings and beliefs, aiming to understand the meaning of nursing care for them, and its actions, it contributes to the profession development, whether in developing theoretical concepts that support daily actions, or in establishing practical attitudes. We believe that professional practice needs to be studied in the context of meanings that the experiences have for people who are constantly interacting.

Additionally, nursing professionals, in their professional practice, deal with people experiencing unique situations, and by apprehending the meanings produced by the family, nursing can search ways for applying this knowledge in practice, qualifying the assistance reality and education. When focusing on nursing care, there is need to rethink human beings, actors in this care scenario, emphasizing its uniqueness and comprehensiveness.

This study is justified by the need to investigate the practice in order to understand the care phenomenon in the performance of nurses, nursing technicians and assistants. With this purpose, we established the research objective of understanding the meaning of nursing care for the family of patients in palliative care.

## Method

This is a field, descriptive, and exploratory study with qualitative approach. The qualitative approach represents a support for the object of study. The study was conducted at the Dr. Waldemar Alcântara General Hospital, located in Fortaleza, Ceará, Brazil, managed by the State Health Department and treating patients from the 184 municipalities of Ceará. All the services provided by that state health unit occur via the Unified

Health System.

Dr. Waldemar Alcântara General Hospital is a secondary care institution within the public health system. It was the first public hospital in the North and Northeast Regions of Brazil to be accredited level 2 hospital by the National Accreditation Organization. It is a support hospital for the tertiary care network of the Ceará State, treating exclusively the clientele from the National Health System. It offers 336 beds to the population, distributed in medical, surgical, and pediatric clinics; Special Care Unit, adult, neonatal, and pediatric Intensive Care unit, and medium-risk nursery. It also develops programs of outpatient and home care, as well as special and personalized care with multidisciplinary teams to patients with chronic diseases, such as diabetic foot and stroke.

This site was chosen due to the fact that the hospital is a local, state, and regional health care reference institution, among the major ones in the State of Ceará.

Data collection occurred from March to April 2015, after registration on the Brazil Platform and favorable opinion of the research ethics committee of the Public Health School of Ceará and the hospital internal research committee.

The Special Care Unit was the hospital sector chosen for the study. It has 66 beds receiving medical patients with chronic degenerative diseases staying for long periods of hospitalization. Ischemic Stroke was the predominant pathology among hospitalized patients. There are also other chronic diseases such as heart, kidney, and lung diseases.

Among the patients admitted at the Special Care Unit, there are those who given their chronic diseases, associated with several comorbidities and degree of physiological impairment, are often assigned to palliative care. Among these patients without any therapeutic possibility of cure, physical comfort and pain relief are the priorities. Such characteristics configured the unit as ideal for this research.

The Special Care Unit offers physicians of several specialties, nurses, nutritionists, physical therapists,

speech therapists, social workers, pharmacists, psychologists, and technicians from different areas of health to treat these users. The service is able to meet the clinical and surgical demands required for the survival of patients. Transferring the patients to other services is also very feasible. The team work performed seeks an interdisciplinary approach, as the team has weekly meetings to discuss the situation of each patient.

Diagnosing palliative care is not easily established, there are formalities to be followed. Initially, the interdisciplinary team accompanying the patient, after careful evaluation, decides for palliation. It is noteworthy that the patient usually comes from a long period of hospitalization and various measures have been tried to recover their health. After this stage, the team requests an opinion to the palliative care team of the hospital. This team, composed of several professionals, attends the requests from the entire hospital, and states through a report whether the palliative care should or not be implemented. After the favorable opinion of the palliative care team, the interdisciplinary team from the unit establishes palliation, noting that the family is always consulted in decision-making.

Initially, we defined that 10 relatives of patients admitted to the palliative care unit would participate in the survey. After beginning data collection, we observed that during the period (March and April 2015) there were eight patients in this situation. For this reason, the relatives of all the patients who were in palliative care participated. The names of patients who were in this situation were properly listed and posted at the nursing station so the team could be guided on the clinical condition of the patient in the case of some complication. This very list guided the researcher to select the families to take part in this study.

The inclusion criterion applied was: the relative must accompany the patient hospitalized at least three times a week – believing it to be a necessary time for the family to get accustomed to the ward and be able

to talk about the nursing care they observe.

For data collection, we used two techniques: recorded semi-structured interview and direct observation, in order to understand the reality and achieve the proposed objectives.

Semi-structured interviews were recorded with multimedia resources and subsequently transcribed. They took place in a private room, with only the researcher and the individual participant. Interviews were moments of great emotions, in which relatives were able to express their feelings and opinions on what was being researched.

To preserve the subjects' identity in the transcription of semi-structured interviews, we chose to use the letter F, from the word family, then the number of the interview conducted, for example F8 means the eighth interviewee.

The material collected through direct observation was used to complement the collection of empirical reality. This observation led to an approximation of reality, of the context of the researched group. There were eight observation sessions. When collecting an interview, the researcher remained in the unit making the necessary observations.

After data collection, the interviews were transcribed and analyzed through the thematic category analysis<sup>(8)</sup>.

Procedures adopted for this research were in accordance with the Resolution 466/2012 of the National Health Council, concerning ethics in research involving human subjects. All participants signed a free and informed consent form. The research ethics committee approved the study under protocol number 1,014,857.

## Results

After the material transcription and analysis, three thematic categories emerged, created by a posteriori categorization, once they arose from the context of the answers from research subjects. This

form of content categorization requires the researcher an intense back and forth to the material analyzed. Furthermore, it was always linked to the main objective of the research: understand the meaning of nursing care for the family of patients in palliative care.

### The care from the nursing staff as presence

The individuals described nursing care as the professional's presence facing the situation. It is the physical approach, the touch, a conversation that professionals have both with the patient and the family, as seen in the statements: *It is very important how the professional comes to solve a problem. Wishes a good day, treats us well... Talking to us is very important because it calms us... Often we cry when getting something off our chest... we're seeing this all happening* (F2). *Whenever I need someone from the nursing team, they come. If the patient is sick, they treat them very quickly, call the doctor, if needed. They are always present. I realize that the doctor comes only once in a while, but nurses are always in the ward to assist people* (F6).

Besides the presence as care, there are still the care from nursing technicians, as described in the reports: *...it is giving a bed bath, administering medications, serving the food, making the dressing. All this happens daily. Some take longer in the dressing, others take less, but it occurs every day. If the patient is dirty, they clean them right away and change the sheets* (F3). *Nursing care are directed to hygiene, comfort, nutrition, and cleaning as a whole. For the patient and also the environment... They do so much for the patients...* (F4).

It is worth mentioning that the way the procedures take place are very meaningful to the family. This matter is closely associated with the main theme of this category (Care as presence). Behind the technical care, there are people taking action, and people receiving these actions. Thus, they highlighted the way the actions occur: *Before giving the bed bath, they arrive, wish you a good day. They ask how we spent the night. Some are careful not to speak out loud the patient's situation, that they are terminally ill. Though they are always sleeping, but one cannot know if they are listening or not. I think they hear it. And a care I've*

*learned here on a day-to-day was not talking about the issues around the patients* (F2). *The way they give bed bath is very important for the patient and the family who is there watching the whole situation. They demonstrate affection, talk to the patient without even knowing if the patient is listening* (F6).

Administering pain medications (analgesics) is among the nursing care highlighted as most important, as verified in the interviewees' speeches: *The medication has to be given at the right time, so the patient does not feel pain. When the patient feels pain, for example, at bath time you have to turn them, it even seems that we also feel that pain. Then the nurse comes immediately to give the medication* (F1). *It is very sad to see the patient in that situation and still be in pain. I think my dad does not feel pain, because he is always on medication* (F7).

Another aspect highlighted by the study subjects was teamwork, as confirmed in the following reports: *They always help each other. Sometimes the patient is heavy, so they call a colleague to raise him up. When someone is sick, others come to help...* (F2). *I realize that day and night go by and there is always someone to help. No matter when, morning, afternoon, evening, or night. It's a whole team working to improve the patient's condition* (F3).

### Changes in family context facing the situation of palliative care

Chronic diseases affect the dynamics of each family in a different way, it may represent an opportunity for development and redefinition of roles in the family system. Establishing palliative care for hospitalized patients resulted in many changes in the family context, as highlighted: *We have to stay a long time here in the hospital, accompanying the patient, so we put aside the family and work a little, to devote to the patient who is in the hospital. It's a difficult situation, but there is no other solution. We cannot leave our father (the patient) alone* (F3). *The whole family got sick. We are six in total, three sons and three daughters... Everyone has to come help, stay with our father. We have to take turns. Everyone works, and is difficult for all* (F1).

The following interviews reveal that they highlighted the difficulties the family faces when having a loved one in the situation of palliative care: *It*

*is very sad to see my mother in this situation, really sad... (crying), but we can do nothing, just wait. Now, the most difficult is always having to have someone here with her. At home, we are only two daughters, myself and the other. And then you have to pay someone every time one of us cannot be with her... and we do not have enough money, sometimes she has to be alone (F2). The greatest difficulty is money. We are not a wealthy family. I survive on minimum wage and still have all the expenses the disease requires (F8).*

Through direct observation, we identified that for each relative there is a plastic chair and a lounge chair so they can rest. Each companion receives three meals. When the relatives arrive at the hospital, they receive a key to a locker so they can store their belongings, and specific clothes that identify them and still serve to prevent the risk of contamination with their personal clothing. There are cohabitation spaces for families, with several chairs and TV, which stays on from 5 am to 11 pm every day. Some use these chairs to sleep. There are bathrooms equipped with various showers, taps, and mirrors so they can bathe or maintain personal hygiene anytime during their stay in hospital as companion. All relatives receive clean towels when they wish and, at nights, they get a sheet to protect from the cold, because the unit has air conditioning.

Usually the companion is also inserted into the patient's routine care. So meals are scheduled during the change of shifts, when there are no procedures taking place in the wards. During the collection phase, the researcher often had to wait for the completion of the patient's bed bath to conduct the semi-structured interview, since the accompanying relative participated in the procedure along with the nursing technician. The family takes part in all procedures performed with patients. Sometimes they participate only as observers, such as in drugs administration, other times they participate along with the nursing staff, as in the bed bath, while others they do it alone, like performing decubitus change.

Each ward has four beds and, since it is always crowded, four patients and four companions. We noticed a very strong interaction between companions

who stay in the infirmary. They organize themselves so the infirmary never stays without a companion. This way, only two of them go out to lunch, and the other two remain in the unit providing support for the four patients. Whenever one of them cannot go to the hospital to directly accompany the patient, the relative standing next is accountable for calling the person if necessary or assist the nursing staff in the proper procedures.

It is noteworthy that patients in palliative care wards share the space with other patients who are not in the same treatment regimen. Therefore, during data collection, only once a ward had two patients in palliative care. All the other times, there was just one patient in palliative care and three in non-palliative. It is believed that this form of organization is unintentional on the part of the team, but ends up diminishing some environmental stress and for those around. It is also important for the family to realize there is support care for patients who are hospitalized there, and that something can be done for patients and families.

### **Palliative care: death as a relief from physical suffering**

The situation of palliative care, after months of hospitalization, is very stressful for the family. It is worth noting that, in six of the eight interviews conducted, the subjects were moved and cried during the questions. After so long time and so much struggle for survival, the family is beginning to realize that death is a way for ending the suffering, as seen: *I do not want a miracle, I just want the care, I want her to be well, do not feel pain, and that this ends soon, because we already know that there is no more cure. There are many diseases. The kidneys have already stopped, the lung is collapsing, and so the heart (F8). I know that when that day comes it will be a relief to everyone in the family, but I hope it takes a little longer, because at least we still have him here with us (F3).*

It is known there are technologies that can be used for prolonging life, but not with the same quality.

Palliative treatment should direct care to pursue the quality of life of patients and their families. During the terminal illness of a patient, the actions are full of feelings and emotions experienced by family members, as described in the statements: *I get anxious all the time... I fear his death, but I know that there will be no other way* (F7). *I've cried a lot, very much, but now I see it is too much suffering for one person* (F3). *I take responsibility to accompany my father during this final phase of his life* (F1).

They also emphasized in the statements the professionals' communication to the family and clarification of the patient's clinical situation: *Every day the doctor asks me if I understand my father's situation, he will not be resuscitated if he has a cardiac arrest. We are already aware, yet she always makes it clear* (F4). *My sister and I already know of my father's situation. He might pass away at any moment. The doctor has explained us that there is nothing to do. The priority now is to comfort him and he will feel no pain* (F1).

## Discussion

The act of care implies human bonding, between professional and client<sup>(3)</sup>. It is considered that the intersubjective space established between them is permeated by emotions, meanings, and feelings. In this context, care is presented as a relationship, interaction between subjects.

The nursing staff being present when patients and their families are in pain and suffering, in the hospital environment, represents a diverse and multifaceted playing field. Physical presence becomes a rich intervention tool in professional practice, and there can be many actions or even none, depending on the demands of patients and their families. In this sense, nursing care consists in conducting individual and collective efforts from one person to another, seeking to protect, promote, and preserve the human being. Attention and physical presence as fundamental care are expressed in the dialogical relation between clients and the hospital nursing staff, being imperative for human care and important in valuing what is needed and the customer interest<sup>(9)</sup>.

Based on the interviews, we verify that technical procedures performed by the team are important and essential for recovering the health of patients. In the hospital context, there is no nursing practice without procedures. Bathing, sanitizing, puncturing, administering, and installing are verbs present in the daily vocabulary of the nursing team. Similar to this research, other studies conducted with patients in the postoperative period of cardiac surgery<sup>(10)</sup> highlighted nursing care directed to the technical dimension. Highlighting the technical or instrumental dimension of care is not uncommon. Research on the meaning of care for nurses in the hospital context emphasized the technical dimension of nursing care<sup>(11)</sup>, corroborating the above findings.

Technical procedures alone are actions that prioritize some biological need. The way this procedure takes place reveals the real dimension of nursing care. Instrumental dimensions (techniques) must converge in care actions, that is, designing comprehensive care built in relation to the other<sup>(12)</sup>. Thus, the success of nurses' actions, and their team, will depend, not on the technical procedure itself, rather on the way it is done. From the statements observed, research subjects have designed these principles as fundamental for conducting any care.

Among the technical procedures mentioned, we highlight analgesic administration, a very relevant action in the context of palliative care. In patients without any therapeutic possibility of cure, one of the goals is to establish comfort, and administering analgesics is one of the tasks to be performed with this purpose.

A recent survey with nurses in the context of palliative care<sup>(13)</sup> emphasized that nursing actions should prioritize the promotion of comfort, referring the comfort in its physical dimension, associated with nursing procedures aimed at relieving pain and physical symptoms. In this context, the nursing performance is imperative, as the comfort emerged as the main staff action in relation to hospitalized clients<sup>(12)</sup>. As regards palliative care, this comfort can

be achieved by administering analgesics, along with other technical procedures. Moreover, nursing care must direct comfort to four dimensions: physical, psycho-spiritual, environmental, and socio-cultural<sup>(14)</sup>. Among the technologies implemented in the physical context there are pain control and relief.

We identify that teamwork also relates to the main object of this study, as highlighted by families, from the moment there is continuity of care. Palliative care is established in chronic situations without any therapeutic possibility of cure. Therefore, death becomes something present and commonly discussed and experienced in the research site. Thus, teamwork assumes another meaning: working together in mutual aid. The unit nursing professionals work in scale regime shifts, so that scale staff changes do not involve discontinuity of care.

Patients who remain hospitalized and receive palliative care are not isolated from the world, there is a family accompanying them and suffering a lot with all the situations experienced by patients. Consequently, emerged the changes in the family context of patients in palliative care. It is noticed that the disease requires families to give up on something, such as work, study, or romantic relationships. This way, understanding people's health-disease process involves seeking to know their different living and influence spaces. In this perspective, the family group acquires great importance as it reflects the complexities of relations among its members.

The family experiences all the changes and feelings that chronic diseases generate<sup>(15)</sup>. The impact of the diagnosis is the first moment of difficulty, requiring a positive overcome for coexisting with the disease. It is noticed that nursing care as presence intends to meet this demand created by families facing this situation.

We noticed that understanding the meaning of nursing care requires an ethical conception that contemplates the human being above all, as a valuable asset in itself, starting with respect for life in its complexity and choices. Therefore, nursing care

should respect family decisions facing the situation.

A serious illness not only affects the sick patient, rather extends to all the family universe, imposing changes, requiring reorganization in family dynamics to incorporate in daily activities the care the disease and the patient's treatment demand<sup>(16)</sup>. Thus, we verify that families struggle to deal with the situation, from adapting to the hospital routine to economic, social, and cultural issues.

It is worth mentioning that the precarious social and economic conditions of patients and family increases the social vulnerability imposed by the disease. For this reason, the nursing staff should also direct assistance to the family, through guidance, and include them in the care of patients in a holistic and quality perspective.

Pain relief and the end of suffering are something that families hope for. In a dichotomous way, there is the loss of a loved one and the end of a life. Many feelings are explored during that period and, after several months of hospitalization, everyone remembers the final destiny of people. Despite all the technological development and the available therapeutic resources, the best way to end the physical and spiritual suffering of terminally ill patients is the comfort with their families and loved ones<sup>(17)</sup>.

It is noteworthy that palliative care reaffirms life and sees death as a natural process, it does not intend to anticipate nor postpone death, and integrates psychosocial and spiritual care<sup>(18)</sup>. In this context, there is a multidisciplinary team that should provide a support system to help patients, family, and loved ones to feel encouraged throughout the disease process and in mourning.

## Final Considerations

Data revealed the construction of three thematic categories necessary to understand the meaning of nursing care for the family of patients in palliative care.

The first highlighted care as physical presence.



Furthermore, emerged the conduction of technical procedures; administration of analgesics; how the procedures occur; and teamwork.

In the second, there were changes in the family context imposed by palliative care. It highlighted financial expenses; non-adaptation to the hospital routine; and the need to spend long times with patients in detriment of personal projects, such as study and formal work. Additionally, we observed that the hospital offers a good infrastructure to receive these families during hospitalization of their loved ones in palliative care.

In the third category, after experiencing what this situation imposes on families, participating subjects revealed as necessary for patients: the pain relief; end of physical suffering; personal feelings facing the situation; communication with the multidisciplinary team; and doubt clarification.

It is worth mentioning that all the theoretical elements highlighted by relatives are associated. Nothing is isolated, and the search for understanding the meanings leads to a more comprehensive and nonlinear analysis of situations. Therefore, the meaning of nursing care for the family of patients in palliative care is anchored in the physical presence of these professionals. At the same time, technical procedures take place, such as bathing, sanitizing, feeding, among others. Noting that while performing these procedures, the way they are carried out is important in the family's conception. The families highlighted that administering analgesics so the patients can end their lives free of physical pain was crucial.

The meaning of palliative care is anchored in changes in the family context, as they need to have time and financial resources to accompany the terminal life of loved ones. They emphasized non-adaptation to the hospital routine and the infrastructure the hospitals provided to these families.

The relationship with the nursing and multidisciplinary team is also a theoretical element

permeating the meaning of nursing care and palliative treatment. Noting that this context involves personal feelings, revealing the complexity of meanings. We identified that the nursing care highlighted by families aims at a humanistic care, preserving life above all else. Physical presence shows a lot of that, representing one of the central elements of this study. Comprehensive health care must take into account all aspects analyzed and highlighted by families, and consequently, the family also becomes object of nursing care.

## Collaborations

Lima MPO and Oliveira MCX contributed equally to the conception and design, or data analysis and interpretation; drafting of the article, or relevant critical review of the intellectual content, and final approval of the version to be published.

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