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ORIGINAL ARTICLE

ASSISTANCE TO PATIENTS IN THE FINAL PHASE OF LIFE OR UNDER PALLIATIVE CARE IS INADEQUATE: NURSES VIEW ASSISTÊNCIA AO PACIENTE NA FASE FINAL DE VIDA OU EM CUIDADOS PALIATIVOS É INADEQUADA: OPINIÃO DE ENFERMEIRAS ATENCIÓN AL PACIENTE EN LA FASE FINAL DE LA VIDA O EN CUIDADOS PALIATIVOS ES INADECUADA: OPINIÓN DE LAS ENFERMERAS

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ABSTRACT

Objectives: evaluating patient care in the final stage of life under Palliative Care from the perspective of nurses, and verifying the influence of the death and dying process on the provided nursing care. **Method:** an exploratory and descriptive study of a qualitative approach, in which 37 nurses were interviewed at a large public hospital in Recife (PE). The information was recorded and organized by similarity of answers, taking into account the central ideas of the statements, resulting in three analytical categories. **Results:** assistance to these patients was considered inadequate by most nurses, due to the scarcity of material resources, human resources, physical and humanizing structure. **Conclusion:** the continuous evaluation of the assistance provided to patients in the final stage of life and under Palliative Care in hospitals makes it possible to reshape reactions, attitudes, feelings and behaviors in relation to the care provided. **Descriptors:** Nursing; Assistance; Death; Palliative Care; Care at the End of Life.

RESUMO

Objetivos: avaliar a assistência a pacientes na fase final de vida em Cuidados Paliativos sob a ótica de enfermeiras, e verificar a influência do processo de morte e morrer sobre a assistência de Enfermagem prestada. **Método:** estudo exploratório e descritivo, com abordagem qualitativa, em que foram entrevistadas 37 enfermeiras de um hospital público de grande porte do Recife/PE. As informações foram gravadas e organizadas por similaridade de respostas, levando-se em consideração as ideias centrais das falas, originando três categorias analíticas. **Resultados:** a assistência a estes pacientes foi considerada inadequada pela maioria das enfermeiras, devido à escassez de recursos materiais, recursos humanos, estrutura física e humanização. **Conclusão:** a avaliação contínua da assistência oferecida ao paciente em fase final de vida e em Cuidados Paliativos no âmbito hospitalar torna possível reformular reações, atitudes, sentimentos e comportamentos em relação ao cuidado prestado. **Descritores:** Enfermagem; Assistência; Morte; Cuidados Paliativos; Cuidados no Final da Vida.

RESUMEN

Objetivos: evaluar la atención al paciente en la etapa final de la vida en Los Cuidados Paliativos desde la perspectiva de las enfermeras, y la influencia de la muerte y el proceso de morir en la atención de enfermería proporcionada. **Método:** este es un estudio exploratorio y descriptivo con un enfoque cualitativo, en el que se entrevistó a 37 enfermeras de un hospital público grande en Recife (PE). La información fue registrada y organizada por la similitud de las respuestas, teniendo en cuenta las ideas centrales de los estados, lo que resultó en tres categorías analíticas. **Resultados:** la asistencia a estos pacientes se consideró insuficiente por la mayoría de las enfermeras, debido a la escasez de recursos materiales, recursos humanos, estructura física y humanización. **Conclusión:** la evaluación continua de la asistencia proporcionada a los pacientes en la etapa final de la vida y en Los Cuidados Paliativos en los hospitales permite remodelar reacciones, actitudes, sentimientos y comportamientos en relación con la atención recibida. **Descriptor:** Enfermería; Asistencia; Muerte; Los Cuidados Paliativos; Cuidados al Final de la Vida.

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INTRODUCTION

Despite being part of life, illness and death have always been the main enemy of humanity. We live in a society that discusses and dramatizes the death, which ended up delegating the technologically equipped institutions to prolong life, and where death is a loss to their interests and responsibility for their care.¹

Experiencing death and terminal illness, then, is everyday event for healthcare professionals and assist patients with end-stage of life ends up becoming one of the most uncomfortable, embarrassing and unpleasant situations from day to day of the professional.² And the nurses are who suffer most from this situation. The patient who is dying is coldly, a contradiction to the commitment to the life and health and a failure on their skills and competencies, despite new modalities of care whose main focus is on care, not cure, such as Care Hospice.³

Much progress has been made in this meanwhile with the advent of palliative care, which in addition to care when a cure is no longer possible, it is a philosophy that strives for active, integral and flawless control of pain and other symptoms that cause suffering in a multidimensional spectrum, beyond support for family members through a qualified interdisciplinary team and to ensure the maintenance of the dignity and autonomy until the time of death;³⁻⁵ however, often attend the terminally or caring for patients in palliative care imposes a flow nursing activities, pleasant or not, that go beyond the technical procedures, which require continuous exercise settings and emotional adjustments to the performance of these actions. It creates another conflict: the continuing clash between the high level of responsibility and low resolving power regarding this patient.^{2,6-8}

The care of the patient with an incurable disease and dying becomes then one of the most tense and demanding situations for nurses: it has to be strong and hopeful, true and ethical; its performance has to be objective and scientific; one has to show affection and personal; one needs to strive tenaciously to care and often save lives; you are responsible for yourself, for your team, for its Code of Professional Ethics, the community, by their peers, by patient and family.⁹ It is the nurse who takes responsibility of assistance in times of trouble: hygiene, hydration, medication, pain relief and other threatening symptoms and comfort; it is the professional who is gracious, concerned with the suffering, deals with the feelings of the patient and his family, and when

the patient dies, is who takes the first steps for the preparation and release of the body; you do what is in their power to keep the patient alive while maintaining a high standard of quality care while struggling to maintain the dignity of this at death.^{10,11}

In recent years, several studies²⁻¹¹ about the quality of care and professional qualifications in the care of terminally and Palliative Care were performed and showed numerous professional limitations. On the other hand, these studies have also shown many aspects that have contributed to the development of assistance related to the whole of the profession, to be a nurse, be patient and be interdisciplinary team. However, the literature that deals with the binomial nursing/patient at the end of life still leaves gaps in knowledge, discussions and reviews of the efforts dispensed in caring for such patients, making it relevant to new studies.

Thus, this study aims at evaluate the care of patients at the end of life and paliative care, from the perspective of nurses, and the influence of the death and dying process on the provided nursing care.

METHOD

This is an exploratory and descriptive study of a qualitative approach, in which nursing assistants of a large university hospital in Recife, Brazil, reference in the North and Northeast of Brazil, who worked in clinics of adult admission and neopediatric in both rounds (day and night) in the year 2012 were invited to participate. Of the total population, 37 nurses agreed to participate and met the eligibility criteria: age above 18 and not be on vacation or leave during the survey period.

There was built up a semi-structured interview guide with questions aimed at identifying the meaning, feelings and reactions to death and dying for the studied nurses and evaluate the care provided by health professionals to patients in the final stages of life and paliative Care, in the opinion of the interviewees, by checking the influence of the former over the latter.

Participants were recruited in their duty shift and the interviews individually, in reserved place, days and hours previously marked, according to individual availability, registered in the recorder or not, respecting the decision of the respondent to such a procedure. At that agreed to participate was made explaining the study's objectives, risks and benefits and collection procedures, and signed the Informed Consent two-way, staying with each other and researcher with the interviewee.

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Study participants were identified by codes, in order to protect their identity, and speeches in each group of items were grouped by similarity of answers from the theoretical and methodological basis of the content approach, taking into account the central ideas of lines, making it possible to identify categories and subcategories.

All ethical and legal aspects of research with human beings were contemplated, according to Resolution 196/96 of the National Health Council, and obtained approval of the Research Ethics Committee with Humans of the Health Sciences Center of the Federal University of Pernambuco, and was approved under Protocol 014/2010-CEP/CCS.

RESULTS AND DISCUSSION

Variables such as age, gender, religion, time since graduation, time of work and time in the industry were collected and underwent descriptive analysis. Of the 37 participating nurses, the majority were female (82,9%), Catholic (40,6%), aged between 25 and 40 years old (83,4%), active in clinical adult admission (89,1%) during the day shift (59,5%), with over 10 years of experience (48,6%) and packed in the current performance of the industry for about 5 years (97,3%).

In the analysis of these characteristics of the sample considered appropriate score some issues that can contribute positively or negatively to the question of terminally life. Age and religion are extremely important for the perception and interaction of the individual with the finitude in their daily lives. Phases of adult life between 30 and 40 years old the human being is closely linked to the life and future achievements; death is an unreal and distant chance of being understood and accepted.¹² All this is permeated by acquired and followed religious teachings in life. The way man relates to the Divinity, which directs and controls the course of nature and life, determines attitudes and concrete behaviors in the face of death, redefining it as synonymous with punishment or forgiveness or transition to a broader state of spiritual development.²

Although the nurses interviewed possess familiarity with the routine and the particularities of each clinic, while exercising the profession, units like intensive care and hemodialysis death can be a routine.^{5,13}

[...] It is already part of day-to-day [...] death is already a routine (7.75)

However, some areas of knowledge such as surgery and pediatrics, nurses aim to save lives, not considering death as a real possibility, and rather painful and frustrating

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the meeting of professionals working in this area with them. Dealing with death can be having to deal with moments of great stress, suffering and pain, and with the certainty that sickness and death do not choose gender, age or social class; it is the realization of one's own death or finitude.^{8,14}

It's hard [...] those mothers, that family, you cannot conform. Death is not for children. (32.9N)

For purposes of discussion about the quality of care during the analysis of the content of the interviews, there were stipulated 03 categories believed to build and base the evaluation of the assistance: Feelings on the terminally as professional experience and perception of care dedicated to phase in patient end and paliative care; Influence of terminal illness and healing is not possible in reactions to the death of the patient; and evaluation of patient care at end of life stage or palliative care.

♦ Category 1 - Feelings on the terminally ill as professional experience

Health professionals are prepared for keeping patients alive. Dealing with situations where this is not possible can be a problem. Mean and reframe death, the human terminal illness and healing impossibility becomes daily task and directs the quality of care being provided. The confrontation does flourish numerous feelings and can manifest itself in several ways; however, never without consequences.

Nurses are mostly professionals who show human and sympathetic. There are few who seem distant and cold and who believe that there must be a relationship between dissociated patient and health care professional. However, the proximity and daily experience with patients who are dying are not enough for the acceptance of death. Impotence, failure, guilt are death denial of consequences and bring much suffering to the professional.^{6-7,9,11}

The feelings described by nurses interviewed proved sometimes symmetrical, sometimes ambiguous, sometimes conflicting and antagonistic. Most described, as well as in other studies^{2,5-11,13}, feelings of impotence and incapacity. Rest, respect, acceptance and indifference have also been mentioned. However, for some nurses, the awakened sense will depend on other factors such as patient age, condition, hospital stay, among others.

[...] I feel impotence, because after all, the whole effort was employed, to no avail. Could have done something, maybe we could save [...] (13.85)

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I feel like a human being. Respect for the time that is passing. Respect for family. (8.9S)

Will it be the end of a torment, a rest (20.5S)

Depending on the patient, on the age, and on the reason, I feel regret and sometimes even sadness. In other times, I feel some relief by the end of the patient's suffering. (19.5S)

I think I'm insensitive. Will you escape from death? I will? No, we'll all live, like it or not we have to go. (33.7N)

[...] I encounter and I have no reaction [...] do not know whether defense [...] I know, I'm sorry, but do not show. I feel numb. (3.5S)

The ambiguity of feelings reflects the conflicting relationship of man with terminal of life. Death is considered ruthless; it brings pain, sadness, loss. But, as you cannot leave it, its acceptance can make it less painful.¹⁵ Additionally, the type of care under his responsibility and proximity to patients and their families, the nurse is in an intermediate position between the objectivity of performance and everyday nothing heroic in the face of physical and psychological needs of the patient at the end of life and paliative care, ranging from technical and dedication, science and low power of decision.^{6-11,13} Keep the clean patient, fed and comfortable, prevent complications and choose between beneficence and non-maleficence, maintain the autonomy and dignity of the patient, prevent contamination and other characteristic and unique care nursing practice, or working with families living under the stress of an impending death, are part of a dynamic and not easy everyday. However, they do not fit the decision on the interventions that will be made or not to that patient^{10,11,15}, reinforcing the sense of powerlessness and incapacity:

It is disability, hands tied: I have all the features of Medicine at my disposal, all the technology, for the time I want, and nothing they serve me, I can do nothing. (29.5S)

However, in Palliative Care, nursing is a growing area of expertise, able to question, evaluate, analyze and decide what care, and nurses' actions, along with other members of staff, is essential in preserving the integrity and dignity of patient in his last moments of life. And this can be extremely beneficial and reduce the inconvenience caused by close contact with death.¹⁶

Understanding the feelings aroused by living with the patient at the end of life and paliative care, fostered understanding of the second category of analysis: how to care for a

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patient in the final stages or whose cure is no longer possible to influence the reactions that this professional is when the patient dies.

♦ Category 2 - Influence of the terminally ill and the impossibility of healing on the reactions before the death of the patient.

Death and die, even though they look the same, are different. Death is the final biological life. Dying is the process by which death occurs. Man can overcome their problems with death. But the die is attached to the extinct survival, preservation in dangerous situations, which can be healthy. But what can accompany this event causes great fear, both those who are experiencing death, and those who are around you and are responsible for their care.¹⁷

Death and dying are facts so feared by staff, patients and their families, which can create escape situations on these occasions. Trail brush with death, escape the questions of family, escape of care the patient needs, escaping own fears, their own death escape, escape and delegation of its responsibility to others.⁵⁻¹⁵ This was strongly observed when nurses questioned what the reaction of these before the death of the patient and how much the proximity of death or healing impossibility influenced these reactions:

The body shocks me. The lifeless body I do not like; run closely. What I experience is not always have more to do, I am very frustrated. (1.8N)

Rather run away from the situation, I do not like to see. As auxiliary here are very good, I delegate to them the most part of care, just do what they really cannot. (26.5N)

Professional experience in the face of death and dying, the same stages of denial, anger, bargaining, depression and acceptance described by Elizabeth Kubler-Ross.¹⁷ For this author, professional associate relationship with the patient and the professional experience of time with the intensity and the presence of feelings and emotions over the care of this and the preparation of the postmortem body, starting to consider these situations as rituals leading to reflection and maturation.¹⁸

Preparation of professional for what is to come. Dying prepares the professional to mature and better to accept the time. (23.9S)

[...] it is the natural process of life. We know when the patient will improve or not, and this helps a [...] helps deal also with family members. (28.5S)

Still, for the nurses interviewed, losing a patient is not easy and marks the professional

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career, as found in the literature.²⁰ They all cited the first professional experience with the patient in the final stages as something quite remarkable and which aroused feelings that are perpetuated to this day:

[...] I was in pretty hard time, but when I left I cried, I cried, I could only cry. It was tragic, even trauma. I was disoriented, did not know anything else. The worst part was the mother. Who would console that mother? To this day I want to cry [...] I could not save all lives! [...] I felt even more helpless. I was a student, still had much to learn. (13.8S)

I felt so much remorse [...] the patient was very dependent, arrived already thinking about the whole routine, bed bath [...] but had gone to death on the same morning [...] that sadness. (7.7S)

It was horrible. Everybody wants to save, get her out of the PCR and then, when I was preparing the body, I was afraid for her to return. I was thinking, my God, everyone wanting her back and I scared! It was shocking; it's all over for her. (18.8N)

The patient died and the helpers who prepared the body were talking about something else and sometimes laughed. I was sitting in front; she cried and could not understand how they were not moved by what happened. I suffered a lot, suffered a lot [...] (19.5S)

However, according to the testimony, if one can see that even marked by the loss of patient experience, over time, professionals can feel his alleviated suffering when appropriate the fulfillment of their role, function, guided in its technical-scientific preparation¹⁴, in the different stages of patient care process at the end of life and palliative care.

Even in difficult situations, I take into account what I can do to assist in assistance. I have much more respect for the patient, the family, the situation [...] I want the welfare of all (15.6S)

Before I thought I had done everything I could, today I'm sure we do everything we can [...] and we must: respect (33.7N)

From the knowledge of the influence that living with the patient in final demand phase and face reactions to this coexistence, there were requested nurses to assess the care provided to these patients by a multidisciplinary team, observing the following assistance: material resources, human resources, physical and humanizing structure.

♦ Category 3 - Evaluating the quality of patient care at the end of life and/or palliative care.

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At the moment, quality is essential to the development of any company; however, there is a significant difference between the quality of business-industry and company-hospital; the first to retrieve defective parts in the second there is hardly any opportunity and failure will result in suffering. Health care quality has been a recurring theme, and still quite controversial, and the quality of nursing care permeates many aspects that relate directly to be a nurse.¹⁹ Thus, with regard to the quality of care provided to patients in the final stage or in palliative care, for various reasons, this was considered inadequate by most of the interviewees:

The hospital environment is very hard, cold [...] In general, doctors are cold, coarse and rude; they speak with great cruelty about the patient's problems. (21.6S)

Understanding is low, the comfort [...] We do not understand sometimes what that family is going through; doctors are very cold, treat the patient as an organ, a piece of meat that is in need of repair; the human being disappears, what counts is his interest that, after his interest ends, that person shall not be worth anything. (34.8N)

Under technical procedures, assistance was considered partially adequate for a small portion of the respondents, as long as there is improvement in some aspects:

From a technical point of view, well. But far I can go and where should I stop? As far as we have security? As far as I'm killing or leaving rest? (9.5N)

I feel a great sense of professional success when I entitled to care where the prognosis is so bad, however I believe that every team should always be in the works as the humanization of care, for example, one must make allowances for the family to visit with most often the patient. (19.5N)

I think we have a lot of technical skill, but the humanitarian side we have yet to make much progress. (33.7N)

The care for human beings, which is formed by a complex interaction: physical, psychological, religious, social and environmental, has been restricted to the functioning of the body - a machine whose parts are analyzed, studied and any malfunction of a specific mechanism it is fixed physically or chemically. This model of care, although it started centuries ago, persists to this day.^{4,16}

On the other hand, care has been modified. Increasingly there are professionals interested in palliative care model of care, which includes physical, emotional, spiritual, social and environmental in their philosophy.^{3,4,16} Every day it has given more emphasis on the holistic nature of care and health, a fact that has required health professionals assistance not only

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of biological nature, but also seek to meet the psychosocial needs and religious patient and his family, realizing the importance of requesting the assistance of properly trained and qualified professionals, allowing the presence and participation of the family in care and respecting beliefs and spiritual and social needs of patients.¹¹

[...] a more humane environment, with background music, multiple phones to drive the family, for it for it be next to the patient [...] all a long way (4.8S)

On the other hand, institutions and care teams have not yet adept at palliative care seem alien to the hospitalized customer needs, stipulating a number of strict rules that must be met by all. Assistance is limited to the care (read technical) Medical and Nursing, getting other assistance relegated to the background.^{1,2,16,18} With regard to this study, only one of the clinics surveyed have routine psychological care and the visit of religious representatives can happen, since at times pre-established and controlled by the members of the team.

It is emphasized that care, to be made effective, requires the provision of adequate material and human resources, in quantity and quality. However, the reality is quite different.

The support, the affection, the pastoral care, psychology, social worker, sometimes it is forgotten and lies with the nurse, who ends up workloading and not realizing it. (26.5N)

What you see is too much effort in to possess the latest advances in medical technology, which will only be enjoyed by a small portion of the population, in contrast, needed materials for daily care, as gauze, cotton, gloves, solutions, mattresses suitable beds, among many others, are constantly missing. Not those technological advances are not important; however, should always be sought, but should not be in the background leave the primary resources of the assistance. This lack of materials directly affects the professionals working in inpatient services, since their daily work material is often not available, interfering with the quality of care that is offered.

Most of the time, the nurse is so troubled about her business, so much to do, lack both material, which has no time to talk to the patient, to hear him mainly because often he needs someone to listen to him. (24.4S)

Another important point is that the inappropriate design of nursing staff and high workload to which they are exposed is still faced problem. Made the calculation for the studied institution in accordance with the

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norms of Federal Council of Nursing²⁰, met a quantitative nurses 2-3 times less than ideal, resulting in workload, especially for nurse, who in addition techniques highly complex functions, takes various administrative functions, failing to hear, touch, support - inexorable care of the nurse-patient relationship. Hence the lack of time, staff and referred availability; however, we believe that even with this function workloading, care in nursing, based on respect and customer service, should never take a back seat, especially when it comes to the patient with a large burden of symptoms and care, like that at the end of life and paliative care, which requires redoubled efforts and attention from the health team.

Evaluating other aspects of patient care at end of life phase, nurses were asked about how starded efforts, attention and assistance devoted to the patient who was dying. It was noticed a great ambiguity in the perception of the nurses interviewed on these aspects. On the one hand, a portion of them stressed again the feeling of powerlessness and frustration:

I try to provide all care, it has to die with dignity [...] There are times when you feel frustrated, helpless, sometimes the conduct is wrong, it is extreme, unnecessary both investment but is teamwork [...] (8.9S)

In contrast, most of the interviewees stressed as a priority the palliative philosophy of promoting comfort and dignity to patients. This search for comfort is the primary objective of nursing, which in its practice involves care with hygiene, hydration, medication, and comfort and pain relief. Aims to conserve the clean, fed and comforted patient.^{2,5-11,13,16} These concerns are also shared by the philosophy and principles of palliative care, making it the natural partner of nursing care. In this sense, in the words that follow, the nursing care was considered very important for patients in end of life stage:

Have to do the best for comfort, for us it is a privilege to be at someone's deathbed: my hand is the last that the patient holds, hear the last words, I see the latest looks, I am present in their last moments of life [...] (5.7N)

I think one of the great beauties of nursing is caring without necessarily depend on the diagnosis or prognosis. Of course, all my efforts are aimed at the recovery [...] however when all healing investments are no longer possible, I can give you pain relief, comfort, safety, meet your desires (if possible), try your minimiar suffering, I can even do a lot without necessarily using medications. Sometimes a bath, a position, a conversation, greater attention, attend a desire simple, but important. (19.5S)

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I see myself in their place, drains, edema, comfortless, everybody solving all about the life and death of them. You invest when you know you have return [...] but the comfort and respect at all I do not give up! To stay in that moment well; to be too uncomfortable, sweaty secretions [...] not! You Have to have dignity! (1.8N)

It seems to be clear in these reports that the nurses greatly value the basic nursing care, which is also closely linked to the basic principles of palliative care^{4,5}, which seeks to provide comfort to the patient, keep his dignity and humanization of care until after death and the grieving process. In this core, professionals can offer the patient at the end of life and paliative care, a death less painful for both parties through quality care based on humanization, respect and preserve human dignity.

Still, although the respondents have considered the important care provided in more than half of the lines, it is believed that they are not prepared to deal with patients and their families during the final stage of life or before the incurability of the disease, demonstrating that this issue still bothers raises fear, fear and distress, and interfere with the care provided to patients at end of life phase and Palliative Care.

Despite the positive findings of this research, some limitations were imposed, among which, the resistance of some nurses to accept participating in the study, claiming not to identify with the theme, resulting in loss of 26,2% of the sample. Larger samples, addressing other aspects of quality assurance (as quality indicators), concomitant evaluation of clinical patients (diagnosis, phase of treatment, Karnofsky Performance Status) and other actors involved in care can also provide diverse and broad spectra analysis.

CONCLUSION

This study showed fears and disorders arising from the representation that death has for nurses in everyday situations, feeling threatened and powerless, interfering in the care of patients with end-stage of life and palliative care.

The quality of nursing care that is provided to these patients was still considered short from the ideal, needing to improve it in many ways, especially in the context of humanization, the presence of other members of the interdisciplinary team and adequate quantity of nursing professionals. The perception of the precariousness of such assistance and where the faults lie, can be the start in the pursuit of

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changing attitudes and behaviors of nurses, as it contemplates what is most human in each care provided and where the synchronized and organized labor leads the success of the assistance.

It is recognized that care for these patients is not an easy task for nurses, given the range of technical procedures and specialized care which they need; and despite the feeling of helplessness and inability to be present and interfere negatively in the perception of care before the terminally process, nurses should rethink their fears and anxieties and help the patient and family acceptance and experience of dying and death.

While those hospitals should offer ways to make a more humanized care, this issue should be discussed during the training, preparing these professionals to deal not only with death, but with conflicts and loss of human pains, among others. It is believed that perhaps this is one of the possible paths to a less lonely and agonizing confrontation, allowing the professional to maintain the values of dignity, respect and humanization of care.

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