THE FAMILY AS A MEMBER OF PALLIATIVE CARE ASSISTANCE
A FAMÍLIA COMO INTEGRANTE DA ASSISTÊNCIA EM CUIDADO PALIATIVO
LA FAMILIA COMO INTEGRANTE DE LA ASISTENCIA EN CUIDADO PALIATIVO

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ABSTRACT
Objective: to analyze the nurses' perception about the participation of family members in palliative care.

Method: qualitative, exploratory, descriptive study, with the participation of ten nurses. Semi-structured interviews were conducted and the reports were submitted to thematic and content analysis procedures.

Results: the importance of welcoming the family, and their inclusion in the care process represent one of the structuring axes of palliative care. The participants' discourse refers to the participation of the family in palliative care assistance either as an active member of the team, or as a passive one, as the object of care of the team. Conclusion: the family is one of the structuring axes of the care of patients outside therapeutic possibilities of healing, occupying the place of a protagonist and being integrated with the care team. While its collaborative attitude favors patient care, it also helps to keep it as an object of care. It can also be understood that the humanized approach to palliative care allows the Nursing team to encourage activities that were once part of the routine of the patient. Descriptors: Palliative Care; Nursing care; Humanization of Assistance; Family; Terminal Patient; Family Health.

RESUMO
Objetivo: analisar a percepção dos enfermeiros acerca da participação do familiar na assistência em cuidados paliativos. Método: estudo qualitativo, exploratório, descritivo, com a participação de dez enfermeiros. Realizaram-se entrevistas semiestruturadas e os relatos foram submetidos aos procedimentos de análise temática e de conteúdo. Resultados: a importância do acolhimento da família e a sua inclusão no processo de cuidar representam-se como um dos eixos estruturantes da assistência paliativista. O discurso dos participantes faz referência à participação da família na assistência em cuidados paliativos seja de forma ativa, como integrante da equipe, seja de forma passiva, como objeto de cuidado da equipe. Conclusão: a família é um dos eixos estruturantes da assistência a pacientes fora de possibilidades terapêuticas de cura ocupando um lugar de protagonista e sendo, ainda, integrada à equipe de cuidados. Enquanto a sua atitude colaborativa favorece o cuidado do paciente, também ajuda a mantê-la como objeto de cuidado. Pode-se, ainda, apreender que a abordagem humanizada dos cuidados paliativos permite que a equipe de Enfermagem incentive a realização de atividades que outrora integravam a rotina do paciente. Descriptores: Cuidados Paliativos; Cuidados de Enfermagem; Humanização da Assistência; Família; Doente Terminal; Saúde da Família.

RESUMEN
Objetivo: analizar la percepción de los enfermeros acerca de la participación del familiar en la asistencia en cuidados paliativos. Método: estudio cualitativo, exploratorio, descriptivo, con la participación de diez enfermeros. Se realizaron entrevistas semiestrucuturadas y los relatos fueron sometidos a los procedimientos de análisis temático y de contenido. Resultados: la importancia de la acogida de la familia y su inclusión en el proceso de cuidar se representan como uno de los ejes estructurantes de la asistencia paliativista. El discurso de los participantes hace referencia a la participación de la familia en la asistencia en cuidados paliativos sea de forma activa, como integrante del equipo, sea de forma pasiva, como objeto de cuidado del equipo. Conclusión: la familia es uno de los ejes estructurantes de la asistencia a pacientes fuera de posibilidades terapéuticas de cura ocupando un lugar de protagonista y siendo, además, integrada al equipo de cuidados. Mientras su actitud colaborativa favorece el cuidado del paciente, también ayuda a mantenerla como objeto de cuidado. Se puede, además, aprehender que el abordaje humanizado de los cuidados paliativos permite que el equipo de Enfermería incentive la realización de actividades que outrora integraban la rutina del paciente. Descriptores: Cuidados Paliativos; Atención de Enfermería; Humanización de la Atención; Familia; Enfermo Terminal; Salud de la Familia.

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Palliative care is defined as an assistance methodology that aims to improve the quality of life of patients and their families in facing the problems associated with both the disease, which compromises the continuity of life, as well as the symptomatology resulting from curative treatments and / or procedures for the relief of suffering. It is imperative that there be early identification, reliable assessment and treatment of pain and other possible physical, psychosocial and spiritual problems.\(^1\)\(^2\)

Through the philosophy of palliative care, it is shown that a humanized, integral and individual care is necessary not only for the patient, but also for their family, who must be assisted in the process of mourning, their fears, anguish, and anxiety. The family tends to suffer both from the possibility of imminent loss and from the inability to resolve the situation, as shown in figure 1.\(^3\)

![Figure 1. Representation of care for the family in the process of illness and death. Brasília (DF), Brazil, 2018.](https://doi.org/10.5205/1981-8963-v12i10a234575p2399-2406-2018)

It is understood that the family must be accompanying the patient, since the hospitalization removes him from his social environment, which he considers to be safe and constant, and is inserted in another environment that presents itself cold, unknown and fearful, and the family represents a refuge for the patient and his connection with the outside world. The nurse must respect the importance of the family as well as their values and beliefs in order to understand their thinking and acting.\(^4\)

It is observed that one aspect of the palliative philosophy is the holistic care for both the patient and the relative. In this sense, the family member also needs to be assisted in order to contemplate the physical, psychological and spiritual aspects, guaranteeing comfort through adequate accommodations, support in the confrontation of their fears and permission to freely express their creeds and dogmas facilitating, whenever possible, performance of rituals characteristic of their religion.\(^5\)

It is important to remember that one of the important aspects regarding the valorization of the quality of the actions in palliative care is the assistance offered to the family member, who must be continuously accompanying the patient, both of whom should receive appropriate treatment and comfort. There is a change in the social role of the subject who is now patient, but within the social-family context they are still a father / mother, husband / wife, son / daughter, and the nursing staff acting in an active and effective way, encouraging positive attitudes.\(^6\)

It is understood that assisting the family with a sick relative outside the therapeutic possibilities of cure requires a great deal of sensitivity from the nurse, since she has many concerns regarding care and attention to her relative. It is also incumbent on nurses to train family members with the purpose of helping them to understand more about the future responses of the disease and the diversity and possibility of care.\(^6\)

It is reported that the possibility of imminent death affects the entire family structure causing great suffering. Therefore, the family and the patient should be considered as a unit of care, since the assistance offered to one of them also significantly affects the other. Ensuring the dignity of the patient while experiencing the termination of life process is the main objective of the palliative care team in order to reduce the impact of the disease.\(^6\)

The family often feels unprepared to participate in the caring process by crediting importance only to the actions of the medical and nursing staff and relegating their importance to a lower level. The family's awareness of its importance in health care, as well as the motivation for it to remain with the patient during the treatment, is one of
the fundamental actions for the quality of care.5

It is considered that a constant factor in the care of terminally ill patients is the incessant requests of family members for continuity of procedures and interventions in order to extend the life of the patient, although in most cases these interventions do not correspond to the quality of life. The investment of unnecessary therapies, promoted by professionals pressured by family members who do not accept the condition of the patient, is considered the easiest way, instead of guiding and working with the familiar confrontation and the condition of the termination of life.7

It is observed that sporadically, family members use their influence in the decision-making process regarding the conduct towards the terminal patient and impose on the health team an intense ethical dilemma. The team, for its part, does not have knowledge about the legislation related to the subject. Nevertheless, a large part still observes the lack of clarity of such laws, generating, in the team, considerable anguish for not being able to deal with such complex situations.7

It is considered that the insertion of the terminal patient’s family into the care process is a way of respecting bioethical principles such as autonomy, justice, beneficence and non-maleficence. The family is important within this process, which even directs the actions that are offered to the patient, so that when the family still does not accept the condition of finitude of the patient, it tends to insist on unnecessary investments of the team and, thus, often prolongs the patient’s suffering.8

Palliative care is pervaded throughout the family context in order to assist in the reestablishment of a true communication between both parties. An open dialogue between family members, staff and patients fosters understanding of the emotions that are going on and those that need to be adjusted. Both the patient and his / her family members tend to decrease their anxiety when perceiving the answers of their questions about pain and fear.

In this sense, it is proposed, in view of the challenges posed for the insertion of the family member in the caring process, either as an active agent or as an object of care, the following question: What is the nurse’s perception about the participation of the family member in the care in palliative care?

**OBJECTIVE**

- To analyze nurses' perception about the participation of family members in palliative care.

**METHOD**

Article extracted from the dissertation << Nurses’ perception about the meaning of palliative care >>. Master in Nursing at the University of Brasilia - UnB. 2017.

This is a qualitative, exploratory, descriptive study carried out in the palliative care ward of the Brasilia Support Hospital (BSH), from January to March 2015. The BSH is part of a network called Hospital Foundation of the Federal District and specializes in the palliative care of advanced cancer patients.

In this study, ten nurses selected from the observation of the inclusion criteria were: 1) To be a nurse; 2) Act in the Palliative Care Ward for a minimum period of six months. As exclusion criteria, they were listed as follows: 1) Being on vacation or a license in the period of data collection; 2) Do not carry out assistance activities, ie, exercise only administrative functions in the two fields of study.

A semi-structured script was used to guide the interview technique performed using a tape recorder. Data collection began only after approval by the ethics and research committee and occurred at the participants’ own workplace.

The collected data was transcribed and the corpus of the interviews was analyzed using the ALCESTE software. Subsequently, the results obtained by the textual statistical analysis were submitted to the thematic and content analysis procedures.

The analysis of content is particularly used to study and analyze qualitative material, improving the understanding of a communication, as well as deepening its grammatical characteristics and organizing the most relevant ideas.9

It is reported, however, that the thematic analysis is developed in three stages: the pre-analysis, the exploitation of the material and the treatment of the obtained results and interpretation. This technique consists in discovering the nuclei of meaning that form a communication in which the presence means something to the objective. The presence of certain themes denotes reference values and present patterns of behavior.10

The participants of this study were oriented about their right to privacy and individuality and to refuse or even to give up participating in this research, and for each deponent, a fictitious name was attributed to preserve anonymity. This research was
approved by the Research Ethics Committee of the Faculty of Health - FS of the University of Brasilia - UnB under CAAE no. 46837215.5.0000.0030.

RESULTS

It was verified that, among the ten (100%) nurses participating in this study, three (30%) were male and seven (70%) were female. As for age, there was an average of 41.4 years, in which four (40%) participants had ages between 36-40 years; four (40%), between 40-50 years and two (20%) presented more than 50 years.

Nine (90%) participants were declared Catholics and one (10%) was Spiritist. When analyzing the time of action with the assistance in palliative care, it was observed that two participants (20%) had a duration of action ranging from one to five years; four (40%), between five and ten years and four (40%) presented more than ten years.

As for the professionals’ discourse, the family's participation in the palliative care assistance is either actively, as a member of the team, or passively, as the object of care of the team.

I think it's important, yes, someone's participation. Nobody wants to die alone, right? I think it's an important part and needs care, and the person needs attention. (BSH 9)

So, the presence of the family is fundamental until the last day of life. And it is very interesting, it has happened, so, some that only in the hour that passes away, you see the difference, right? The difference of the two, that which is accompanied. (BSH 2)

It is much worse for him to go through that process alone. It's worse. With family support, even the treatment is different. Very important. (BSH 1)

It is seen the importance of the family mainly in the emotional support to the patient and in facing the process of illness and termination of life. The simple presence of family members conveys to the patient a sense of security, non-abandonment and comfort with something or someone who presents themselves with a meaning that goes beyond their illness.

It is revealed that the coexistence with a patient outside therapeutic possibilities of healing, besides modifying the daily routine, entails anxieties and tensions that are attributed by the relatives to the constant care with the patient. Some families tend to assume the roles that were once performed by the patient, generating an accumulation or even interrupting their own roles due to their care.

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One can assimilate this reorganization of tasks, when it occurs in a short time, by family members, but when there is a need to prolong this new organization, some family members are overloaded and new adaptations are necessary.

We get them where we have an approach with the relatives, right? A type of interview, a round table, where the principal relative who is aware of the whole illness, of the whole history of the patient is called? (BSH 2)

He has the initial meeting, when he arrives, and then when he sees that he is not flowing very well, he calls his relatives and has a well-detailed meeting, so very specific, right? (BSH 8)

How did evolution begin, what was done about treatment, how it is at the moment, and if it is aware of the disease, right? If he knows what the disease is, the severity of the disease? (BSH 5)

The importance of welcoming the family and their inclusion in the care process is observed, being represented as one of the structuring axes of palliative care. The family has a crucial role to play, as it has therapeutic and care information that the patient has participated in. In this sense, the whole course of palliative care occurs through the participation of family members about their experiences that are not restricted to the approaches that occurred during the process of illness.

[...]the doctor comes and talks like that, hey, he's being referred to the palliative care because the illness of his son, his relative, there is no more therapeutic possibility of cure. Seventy percent get here scammed. (BSH 7)

Patients and family members often come here, they do not get targeted. They think it's a referral hospital, but they do not understand what palliative care is, and it's up to the staff here, it's up to the nurse to explain to the patient, familiar, that the disease is already at an advanced stage. (BSH 5)

Many chaperones have that fright when we say, “No, there is no more possibility of healing. Here, we treat your so-and-so, not the cancer anymore.” There has to be a way. Many fall, many cry, many. So I had to have this preparation before I got to the Support Hospital at the Clinic, right? (BSH 10)

The need and importance of communication between the health team and family members is perceived as a difficult task, although it is essential to define the
next steps in the care process in order to redefine the objectives and expected results of care.

There is a negative repercussion when patients and relatives are referred, believing in the possibility of therapeutic interventions. Explaining the meaning of palliative care, and the reasons for abandoning curative care, delay acceptance and hamper care actions.

It is noted that, however, when the family is oriented to be actively involved in the care of the patient, it perceives the improvement of the symptoms, as highlighted in the extracts of the following speeches.

Aren’t they doing anything else for him? You gotta get this sick from the hospital! But the family member who participates in the process, this, no. This one understands everything very well. Things work well. (BSH 9)

Do we wait to die? Very quickly, they realize that this is not so. Sometimes, several times, they come home. And that time they spend in the hospital is different. That patient who was bedridden with pain all the time starts circulating in the hospital. (BSH 6)

It is added that the change of actions in curativist assistance to palliative care is often perceived by the family as abandonment and death sentence. Initially, family members do not perceive the difference between palliation and cure, however, with the approach focused on improving the quality of life, they begin to observe that something positive is being done.

It is inferred that the need for support to the family by the palliative team, at that moment, is indisputable, since it occurs the development of negative feelings that go from anger, not having received the information, passing through despair, with the idea of the proximity of death, the impossibility of returning to the hospital of origin, and the conflicts for not understanding the discrepancy between the idea of the hospital structure, where there are no therapeutic interventions of cure, as can be seen in the excerpts from the speeches of the participants.

After starting palliative care and, consequently, improving the quality of life in the face of imminent death, the relatives begin to observe that something is being done, even if they cannot understand what is happening.

It is evidenced that the changes in the clinical picture of analgesia, physical and emotional comfort bring an aspect of improvement to the patient. This often generates unrealistic expectations of healing in family members. The Nursing team is still constantly working to help discern the difference between palliative and curative care.

It is emphasized that, even if the family can understand the meaning of palliative care, there are cultural factors that will inevitably affect the course of this assistance.

I have faith in God that my father will heal, that my son will be healed. Of course we will never say, “No, it will not heal”. (BSH 4)

There, the family, his sister said, that, with faith in God, he will heal. So, as much as they find it, let them know that it is palliative, they still have a lot of hope that it will recover and that it will leave here. (BSH 3)

It is understood that the assistance to the spiritual aspects of the patient, when it is limited simply to the absence of repression to the exposition of his beliefs, represents as a lack of preparation of the professionals when offering spiritual care.

**DISCUSSION**

It is believed that the family is understood as an individual or a group of people who act as social basis united to the patient by legal or consanguineous bond. Even in the context of impending death, where the family is sentimentally fragile, it still has responsibility and an active role in the decision-making process. 11

The family member / caregiver is considered a participant in this care setting, since, in the majority of cases, the complexity of the situation gives the caregiver a sharp look, being questioning, curious, insecure, which can often be interpreted as an inflexible, invasive and unwanted family member by the health team because they are asking about what is happening to the patient. 12

It is recommended that the family’s presence with the patient is part of the recovery process and it is imperative that the team also attend to their care needs. The family environment presents itself in different forms, organizations and meanings, which depends on several factors, including social, economic, political and cultural. Therefore, the family relationship is a complex subject that involves intimacy, the establishment of standards and concepts and the daily deal with various situations and peculiarities.13

There is often a crisis in the family, through the process of illness and, consequently, the changes imposed by this process in the dynamics of the family, and
may trigger a greater integration or even the disintegration of family relationships, which will depend on the existing ties, family members’ view of what happened, their experiences, their customs and beliefs, and finally, a range of factors internal and external to them.14

The experiences, experiences and culture of each individual are respected through the humanization of the host, which must be welcomed and classified according to their severity, and the professional should have discernment in their evaluation, reducing waiting in line service and promoting customer satisfaction.15, 16

The active participation of the family in palliative care is of the utmost importance, since they are the first caregivers of the patient during illness. Family experiences and knowledge of the patient’s lifestyle weigh heavily on therapeutic decisions.16

It is recommended, as essential, that the family participate, from the outset, in the care of the patient, especially when it still has its neurological functions preserved so that, in this way, the process of caring in an ethical way can be continued, respecting the autonomy of the patient, even when the disease reaches an advanced stage, making it impossible to answer for itself.11

It is noted that when a family member is affected by an illness, each member of the family may act in a different way in the face of what has occurred. Thus, everyone’s health is also affected as there is a disruption in their normal activities and often some plans and expectations, leading to the feeling of frustration difficult to be faced.13

It is necessary to adopt a cultural approach to care, that is, an approach in which professionals take into account the values, beliefs and ways of life that are standardized, learned and transmitted and that facilitate, to the individual or the group, maintain their well-being, improve their abilities and ways of life and face their loss.17

It should be emphasized that few professionals assume the responsibility of communicating the clinical state of the patient and this is perceived as a great difficulty on the part of the health team.5

It is understood that spirituality, a factor intrinsic to the human being, is quite present during the process of finitude of life. Hope and attachment to the deities should not be reprimanded, since they may be acting as coping mechanisms.18, 19

Through spiritual care, it is possible to examine the essence of the human being in order to perceive the fears, fears, and other emotions that technique will never be able to achieve. In this sense, spiritual care will enrich both the caregiver and the person under his or her care.19, 20

It is perceived that the influence of spirituality and dogmas is not restricted to patients and families. The confrontation of death may lead to a closer relationship with religion, which leads nurses to believe and ameliorate suffering in the face of terminality, generating a greater burden of responsibility and, in turn, creating this defense mechanism that will block affective involvement with later patients.21

One observes the human being in his multi-dimension, when spirituality is seen as a search for meaning and a purpose of life, and this multi-dimension must be assisted by means of prescriptions of care aimed at meeting the spiritual needs of the patient.22 This study was limited by the fact that the interviews included only nurses, since palliative care is performed as a team.

CONCLUSION

It was possible to reach the objective proposed in this study in order to analyze the nurses’ perception about the participation of the family member in palliative care. It is concluded, then, that the family is one of the structuring axes of assistance to patients outside therapeutic possibilities of healing occupying a place of protagonist and being still integrated to the care team. While its collaborative attitude favors patient care, it also helps to keep it as an object of care.

It is known that the palliative approach is built from an integral care to the patient and their families through actions developed by a multi-professional team anchored in effective communication in order to control the symptoms that cause suffering. It was verified the inexistence of information strategies for the family unit. It was observed that relatives consider the information received as limited, which leads to the conclusion that the nurses in this field of study do not understand that communication constitutes a therapeutic assistance action.

With this study, we could see that the humanized approach to palliative care allows the Nursing team to encourage activities that once integrated into the routine of the patient conferring self-esteem and adding the necessary therapeutic character that should be valued.
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