CONTRIBUTIONS IN THE ASSESSMENT OF THE DEGREE OF SATISFACTION OF THE PERSON IN PALLIATIVE CARE

Contributos na avaliação do grau de satisfação da pessoa em cuidados paliativos

Contribuciones en la valoración del grado de satisfacción de la persona en cuidados paliativos

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ABSTRACT

Background: the degree of satisfaction is an important indicator of the evaluation of the quality of palliative care. Satisfaction, being a complex concept, defines the different reactions that patients and families have, with regard to the experience of palliative care. Knowledge of the degree of family satisfaction is a benchmarking factor regarding the planning, implementation and monitoring of care. **Objective**: to assess the degree of satisfaction of relatives of patients in the palliative care unit. **Methodology**: in 2020, a project for continuous quality improvement was elaborated through the qualitative, exploratory study through a telephone survey with the relatives of patients hospitalized in the palliative care unit using dimensions presented on a likert scale. **Results:** from the data analysis it was found that 95% of the reference family members characterize the work of the team as excellent and 4.69% as very good. Respondents considered themselves very satisfied 7.81% and with the result of 92.19% they felt totally satisfied. **Conclusion**: palliative care promotes the satisfaction of the needs of the end-of-life person. The promotion of dignity and respect for human life is the result of constant reflection in providing excellent care considering the assessment of the degree of satisfaction.

Keywords: palliative care; health care quality indicators; patient satisfaction

RESUMO

Enquadramento: o grau de satisfação é um importante indicador da avaliação da qualidade dos cuidados paliativos. A satisfação, sendo um conceito complexo, define as distintas reações que doente e família têm, no que respeita à experiência dos cuidados paliativos. O conhecimento do grau de satisfação do familiar é fator de *benchmarking* no que concerne ao planeamento, implementação e monitorização dos cuidados. **Objetivo**: aferir o grau de satisfação dos familiares de doentes da unidade de cuidados paliativos. **Metodologia**: no ano 2020 foi elaborado um projeto de melhoria contínua da qualidade através do estudo qualitativo, exploratório por meio de inquérito telefónico junto dos familiares de doentes internados na unidade de cuidados paliativos recorrendo a dimensões apresentadas em escala de likert. **Resultados**: da análise de dados verificou-se que 95% dos familiares de referência caraterizam o trabalho da equipa como excelente e 4,69% como muito bom. Os inquiridos consideraram-se muito satisfeitos 7,81% e com o resultado de 92,19%sentem-setotalmente satisfeitos. **Conclusão**: os cuidados paliativos promovem a satisfação das necessidades da pessoa em fim de vida. A promoção da dignidade e respeito pela vida humana é fruto de constante reflexão ao prestar cuidados de excelência tendo em consideração a avaliação do grau de satisfação.

Palavra-chave: cuidados paliativos; indicadores de qualidade em assistência à saúde; satisfação do paciente

RESUMEN

Marco Contextual: el grado de satisfacción es un indicador importante de la evaluación de calidad de los cuidados paliativos. Satisfacción, al ser un concepto complejo, define diferentes reacciones que tienen los pacientes y familias, con respecto a experiencia de cuidados. El conocimiento del grado de satisfacción familiar es factor de referencia en planificación, implementación y seguimiento de atención. **Objetivo**: evaluar el grado de satisfacción de familiares de pacientes en unidad cuidados paliativos. **Metodología**: en 2020, se elaboró un proyecto de mejora continua de la calidad através del estudio cualitativo exploratorio con encuesta telefónica con familiares de pacientes internados en unidad de cuidados paliativos utilizando dimensiones presentadas en escala likert. **Resultados**: a partir del análisis de los datos se encontró que 95% de los miembros de la familia de referencia caracterizan el trabajo del equipo como excelente y 4,69% como muy bueno. Los encuestados se consideraron muy satisfechos 7,81% y con el resultado de 92,19% se sintieron totalmente satisfechos. **Conclusión**: los cuidados paliativos promueven la satisfacción de necesidades de persona al final de vida. La promoción de dignidad y respeto por la vida humana es resultado de reflexión en prestación de atención teniendo en cuenta la evaluación del grado de satisfacción.

Palabras clave: cuidados paliativos; indicadores de calidad de la asistencia sanitaria; satisfacción del paciente.

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INTRODUCTION

The degree of patients' satisfaction is an important indicator for assessing the quality of health care provided to the population. The results of this evaluation reflect the contribution to the continuous improvement of the services provided by the healthcare teams, revealing the effectiveness of the organizations. For Capelas (2014), palliative care are the care procedures that improve the quality of life of patients affected by life-threatening health problems, and their family, through the prevention and relief of suffering through understanding and early identification, assessment and control of pain and other physical, psychological, social and spiritual problems. These represent an important public health need, a human right, requiring experts to deal with these situations, due to the universality of death, being associated with suffering that is usually avoidable, because of the impact on survivors, family members and socio-economic issues. Communication plays a key role and, as a pillar of palliative care, it constitutes an essential instrument for the transmission of information between the person's relatives and/or caregivers and the different healthcare professionals (Reigada *et al*., 2021). The main goal for carrying out the study is the mapping of the patient's/family's perception of satisfaction regarding the provision of health care. The care team develops a constant reflection on the concepts of quality translated by the degree of satisfaction of the person or significant person. It is so relevant to measure the feeling of well-being as a response to care, representing the subjective sensation by which life is viewed and influenced by aspects of personality and social, economic, cultural, religious, and spiritual factors. Similarly, the balance that dictates the quality levels and satisfaction of the person is identified in the conception of needs, aspirations and connection with the environment. Palliative care has a vision of adjusting all these variables by bringing aspirations closer to what is possible regarding the condition of the person at the end of life (Twycross, 2003).

BACKGROUNG

Despite the complexity inherent to the perception, patient and family satisfaction in palliative care is one of the indicators of patient care procedures and its assessment is essential. The family, as a pillar, is responsible for helping the individual to overcome the difficulties that arise throughout life, with illness being no exception. Therefore, in order for the family to play its role, it is essential for professionals to properly acknowledge and assess its needs, so that the family can be informed and adjusted to the constant recurring changes in the disease situation which almost always ends with the death of the patient. This is an enabling factor for improvement in care planning, implementation and monitoring of care delivery (Almeida, 2014). Neto (2012) considers that the family also becomes ill when its relative is affected by an irreversible disease, thus shaking its entire social structure. Perceptions, despite their possible subjectivity, have in health professionals, doctors, nurses and psychologists, the best users for decision-making with their patients and families (Areia *et al*, 2017). It is in the therapeutic relationship that the family and especially the reference family member assume the role of liaison to care through the healthcare professional (Neto, 2022). In the ideological agreement, that it is part of the nurses' role to perceive and record the suffering of the person at the end of life, the regular assessment of the patient and family's degree of satisfaction is highly recommended, particularly regarding the responses to their needs and the provision of care by the team. The aim of this study, as part of a plan for continuous quality improvement, is to assess the degree of satisfaction of patients and/or relatives admitted to the palliative care unit of a hospital in the central region of Portugal. With this purpose in mind, it is possible to identify several aspects for improvement and contribute to the introduction of quality indicators in the palliative care area, which is still insipient. During the development of palliative care, it has become important to create and apply tools that allow assessing the quality of the services provided. In effect, according to the guidelines of the *National Consensus Project for Quality Palliative Care* and the *National Quality Forum*, as well as Capela (2014), there are eight representative domains of the key quality indicators: Structure and process of care; Physical aspects of care; Psychological and psychiatric aspects of care; Social aspects of care; Spiritual, religious and existential aspects of care; Cultural aspects of care; Care of the patient in imminent death; Ethical and legal aspects of care. For this purpose, regarding the implemented study, the following are highlighted: satisfaction of the in-patients and their family concerning: care/response to the needs/problems of the patient; human care applied in the approach to the patient; methodology of information transmission; availability of the team to speak with the patient and family; keeping the patient and family informed about the clinical situation; coordination of care; satisfaction of the family on the continuity of the information transmitted concerning the patient’s clinical state evolution and concerning the therapeutic approaches for controlling the patient's symptoms, at the end-of-life stage.

Although studies are scarce, there is already a wide range of tools for the quality monitoring area. As it turns out, the CCFSS -*Critical Care Family Satisfaction Survey* scale and the FAMCARE scale are intended to assess the health care provided to the family member, while the CADI - Caregiver Difficulties Index scale, the CASI - Caregiver Satisfaction Index scale and the ESC scale (Zarit Caregiver Overload Scale) aim to assess the informal caregiver's overload and its satisfaction as a caregiver. However, studies on satisfaction with the palliative care provided are not frequent. The results of this research are intended to support, not only, the decision-making process of hospital management, but also, all professionals in the ward, to increase contact with patients and their families and knowledge of their perceptions and expectations, thereby increasing their satisfaction and, consequently, the quality of health services (Capelas, 2014).

METHODOLOGY

The implemented methodology follows the guideline of continuous quality improvement projects of this hospital, which in this unit started the evaluation by quarters in 2020. The option was taken for a descriptive exploratory study based on the comprehensive phenomenology of the palliative care ward reality having as example the last quarter of 2020 (Vilelas, 2020). The telephone survey was proposed as a technique, with the dimensions that we considered important for the study. This technique was chosen because it gave us the continuity of a previously existing approach with the patient's significant relative and whom we informed would be contacted later. This relative was always the one chosen by the patient or, in his cognitive impossibility, the one who would be our contact during hospitalization for the management of the therapeutic regimen. The sample of these family members was randomly built, having its number based on the total number of hospitalizations/discharges per quarter, making a choice of 25% of this total, distributed by each month until saturation. Patients who died within 48 hours of admission were excluded as contacts with the relative/significant person were too low for the introduction of an individual care plan. In this survey, the patient's previous and general data were known, such as age and gender, for their characterization, family member/significant person for contact, diagnosis and reason for hospitalization, presence of a family member at the time of death and the nurse's perception of suffering at that moment, using the Edmonton Scale Score with information on whether the patient was under the effect of sedation. These data were collected in a digital clinical documentation environment. The questions asked to the family member were the identification of the symptoms (physical, social, emotional and spiritual) that were decompensated and the degree of improvement until death; the degree of satisfaction regarding the adequacy of information and the professionals' willingness to communicate; the degree of satisfaction regarding the conditions of the facilities and the degree of satisfaction regarding the team's work. The information given by the family member was reversed on a Likert scale from one to five, from "not at all satisfied" to "totally satisfied". At the end of the survey there was space for other statements that the person would like to convey. The ethical issues of the study had as a starting point the protection of the person. Ethical values were respected within the institution, especially respect for the rights and dignity of the patient and significant person, within the scope of healthcare provision and regarding the behaviour of the providers. The research practice and clinical themes allocated to the development of this research, which involved people, had a bearing on the ethical principles by which society and professional healthcare organizations are ruled, in conformity with the principles of the European General Data Protection Regulation of 2019 for healthcare research. It should be noted that a request was made to the hospital's ethics committee, as well as the non-use of biographical data identifying the study population. The classifications by age, gender and degree of kinship between the patient and the significant person/family member of reference, were defined in order to frame and classify groups in data analysis. The ethical component was also safeguarded in terms of recording the agreement to answer at the time of the phone call on a voluntary basis. Participants received full information about the survey (aims, methods, data use). The issues of confidentiality and anonymity were explained. From a statistical point of view, we opted for a quantitative analysis of the data, insofar as it allows to perform a frequency analysis of the answers, as well as a descriptive analysis. For the expressions used in the free text, we used content analysis according to Bardin (2011).

RESULTS

The results here presented refer to the last quarter of 2020 and are divided into two areas. The first relates to the collection process and the second to the results of the survey itself. The most significant data relates to the number of surveys used for analysis, 64, i.e., 25%

of the total number of patients admitted and who died in this quarter. The calls were made between four and six weeks after the patient's death. The majority answered on the first call. These calls were made between 9am and 7pm on days chosen by the researchers, within the expected timeframe of four to six weeks after discharge/death. Patients who were discharged died at home. The number of patients who died and whose relatives answered the survey follows the percentage of deaths in the quarter of 71.8%. The next step was to characterise the patients by gender, of which 31 were female and 33 male. The distribution of patients by age group ranged between 31 and 95 years, with the largest number of patients in the groups 66-70 years with eight patients, 71-75 with 10 patients and 81-85 years with 13 patients. The lowest limit of patients was in the age group 31-35 years with one patient and in the age group 91-95 years with three patients. In most cases, the reference family member is the daughter, identified in 28 situations, followed by the husband/wife in 12 cases and then the son in eight cases. Other degrees of kinship are the daughter-in-law, brother, mother and one case in which the contact was established with the institution where the patient lived. In order to understand the impact of the diagnosis leading to hospitalization, we referred the main one in a clinical diary and/or to the one validating the presence of symptoms/reasons for hospitalization. Therefore, 92% of oncological situations were identified as admission diagnosis, such as 10 people with Colon/Rectum tumours, 7 situations of Haematological tumours and also 7 Breast tumours, 6 of Lung and also Gastric, 5 of Prostate, 4 of Pancreas. With three cases each we identified Dementia, Hepatic, Laryngeal and severe CVE/TBI. With the designation of brain and ovarian/uterus two cases were identified and only one case of bone tumour. There are various reasons for hospitalization, the majority being symptom control. In the organization of care, 14 situations were described as caregiver's rest, and the management of care so that the caregiver could continue to collaborate with the ill family member. In 34 situations, pain was identified as a reason for hospitalization, dyspnoea and agitation/confusion in 14 cases and nausea/vomiting in 10 cases. Another reason was end-of-life care for 13 cases. With less expression, reasons such as anorexia, asthenia, pruritus, cough, fever, haemorrhage, insomnia, malign wound, ascites, intestinal obstruction and two cases of sialorrhea. Despite the constraint of the Pandemic, that poses the need to decrease/control/avoid visiting the patients, eight family members were identified who were present at the time of their patient's death. Seven relatives also came to the unit at the time of discharge for possible follow-up of the patient that died in a short period of time at home. Nurses are the professionals who mostly accompany patients and their relatives at the time of discharge or death. Therefore, we wanted to identify these professionals' perceptions of the existence of suffering at these moments. Thus, the perception of the patient's suffering at discharge or death was 100% "no suffering" according to the Edmonton Scale, which associated the non-existence of symptoms of discomfort. This interpretation may be helped by the fact that 29 patients were under the effect of subcutaneous infusion of sedation-inducing drugs and the average score of the Edmonton Scale was 25. The perception of the relative or significant person about the physical symptoms that the patient presented was verified, the three most prevalent symptoms expressed by the relative were pain, mentioned by 50 people, agitation symptoms mentioned by 21 and vomiting 16. Dyspnoea and wheezing/phlegm were among the intermediate symptoms perceived by family members. The symptoms with a lower incidence of reference by the relative were constipation/diarrhoea and dry mouth. In 20 results the relative does not know/does not answer/other. The results for the perception of the psychological, emotional and social symptoms, such as sadness were verified in 21 situations of sensitivity on the part of the relatives and anxiety in 19 situations. The less expressive ones refer to revolt, denial and resignation. In 10 cases, the perception of the relative was not presented. The perception results for religious and spiritual symptoms show aspects of disbelief in two cases, absence of meaning in five cases and, above all, uneasiness in 10 cases, or even a bad relationship with God in seven cases. It should be noted that 40 people do not know or did not answer about the religious and spiritual symptoms of their relatives. The degree of satisfaction of the relative of reference with the above-mentioned symptoms denotes how they cause discomfort or suffering to the person. It should be noted that the quantification of suffering was presented as much discomfort in 6.25% and intense discomfort in 93.75%. The observation of the family member's perception about whether "the symptoms presented were relieved through the care provided by the team" was that 1.56% of the sample mentioned that there was no relief after care. In opposition, 14.06% said they were much relieved and 84.38% agreed that there was a relief of all symptoms and discomfort. Regarding the aspect of the perception of the serenity concept, which is widely used as a terminology in the end-of-life phase, it was investigated that one family member understood that there was no serenity during hospitalization. While for five people there was a feeling of great serenity, and finally for fifty-eight people there was a feeling of complete serenity. Regarding the clarity of the transmission of information by means of communication, which may have taken place in person or by telephone, we analysed the clarity of this transference in 91.31% of the respondents. And 4.69% of the people refer that they did not feel clarity of information. As far as the availability of the professionals to listen and inform is concerned, 84.38% felt that the professionals were present and in 15.62% of the cases they present a negative response to the availability of listening and information. In this way, the classification of communication by the team is evidenced as being very adequate in 6.25% of the cases and 93.75% as completely adequate. Concerning the infrastructures, facilities and conditions of health care provision, relatives assessed the place of hospitalization as completely adequate in 92.19% of the cases. Within the scope of the assessment of satisfaction with the team's work concerning the person who was hospitalized, from the perspective of the relative/significant person, this was considered very good in 4.69% of cases and excellent in 95.32% of cases. All in all, the value of the survey that reflects the satisfaction of the relative/significant person in the overall care provided, on a quantitative scale ranging from "not at all satisfied" to "totally satisfied", was 7.81% as very satisfied and 92.19% as totally satisfied. At the end of the survey the respondents were proposed to give some information that would reflect their feelings and support the improvement of the clinical activity. We highlight the manifestations that ended the carried-out survey, emphasizing the use of expressions translated here in free text, during the telephone interview that were important for the relative, which can be understood as a moment of relief in the post-hospitalization period, namely in the period of mourning for the loss of the person. Thus, there is a great emotional content that is reflected with the caution and dignity implicit in the context of the person's end-of-life, which is evident in table 1.

Table 1

Expression of the relative, significant person about the care provided

Expression of the relative or significant person about the care provided
- It's a pity I only went to you at that moment. I think it would have been better to have gone earlier
- My only regret is that my father's discharge have been forced so much
- I thought about taking him out of there but I saw afterwards that you work so well; the hospital... didn't say anything about sending him there, it's sad
- I have no words to say what I felt and what I feel for all of you. You are always in my heart
- In these very difficult times you were different for the better
- We wanted to visit more often but you didn't let us... too bad
- My wife is getting better and better thanks to your work
- You must improve the conversation you have on the phone
- After a year of suffering she found peace with you there
- You'll only have to improve on sincerity
- Could have stayed for another week to compensate for the symptoms
- It was the best thing that could have happened to my father
- My mother still talks to this day of your affection for her and if she has to leave let it be there
- What does the psychologist do, who I have never seen, despite your promises?
- I would like to know more about the evolution he had, what you have done to him because he solved many of the ills he had
- I am and will be eternally grateful to that team
- I would just like to have a better understanding about the reasons why you put my mother to sleep
- I never thought I would ever find professionals with your level of excellence
- The information that you gave me was very subtle and you could have been more open and honest
- Too much time was spent in hospital ... and as soon as the illness was known the transfer should have been carried out there
- You should pay more attention to have the family closer to the patient when he’s dying
- I only have good things to say about you. He's been in several places suffering. Not even IPO can get near you
- Thanks to you he died in peace but you should have let me in to say goodbye or to give the last kiss
- Unfortunately, she didn't spend much time with you, but I feel she was very spoiled
- She suffered too much and should have been with you much sooner but I know that the hospital ... didn’t allow
- Was discharged and died alone in the emergency room. No one should be treated like that
- The hospital of ... wasn’t able to do in so many days she was there what you did in half a dozen days when my mother was you
- I just needed to know more details about why he died
- I have the best memory of my wife who was comfortable until the final moment
- I'm just sorry it took so long to get to your hospital
- Despite the little information you gave me you were the only ones who were honest with me
- Always be who you are
- I just think you should talk to people. You should have called me and told me it was all the same
- My mother who is in heaven now tells me I have to be grateful to you forever
- I’ll only give one advice; you should talk more to the people or rather the families. Otherwise, you are fantastic
- Apart from some detail about the information you give, I must say that you are exceptional at taking care of people.
- My greatest anguish was that I was not told how he died, whether he suffered or not

Using content analysis, according to Bardin (2011), the following categories were identified with the justification of the registration units in Table 1: late referral, in which the family member's opinion is that he/she should have gone to the unit earlier; non-negotiated discharge, in which they felt that the family member should have been hospitalized for a longer period of time; communication/information deficits with lack of availability on the part of professionals; gratitude for the work developed, praising the professionals' attitude; quality of care developed in a different way from other units where their patient had been hospitalised; difficult visits but understandable because of the pandemic situation; positive comparison with other health services where the facilities and the quality of the professionals is different in a positive way; human resources deficits where they believe that if there were more professionals the quality of the dimensions under analysis could be more significant.

DISCUSSION

The reflection that is now proposed enables more pragmatic conclusions to be developed in the palliative care unit of this hospital, in terms of its continuous quality improvement plan. It is important to retain the idea that numbers always require a more contextual analysis and taking into consideration all possible variables. In this case, a complex area of healthcare provision is addressed (Barbosa & Neto, 2016; Neto, 2022). Concerns reside in the satisfaction of relatives of hospitalised patients with regard to: care/response to the patient's needs/problems; human care with which the patient was approached; conditions offered to them; coordination of the available information; information transmission methodology; availability of the team to talk with the patient and family; keeping the patient and family informed about the clinical situation; respect for the patient's therapeutic preferences (Capelas *et al*, 2019:16). In most of the responses obtained, the outcome of the care process led to the death of the person in a total of forty-six deaths and the remaining eighteen people were discharged from hospital and died at home as a result. This result together with the age range of hospitalizations during this discussion may be explained by the progressive ageing of the population, with an average life expectancy that has an increasing trend (Neto, 2022). Also, Radbruch, *et al* (2020), in a reflection on a new vision of palliative care, points out that the end of life is perfectly expectable, being prepared to care for the person and family in an end-of-life situation with the most effective and efficient health responses of the health system. It is worth emphasizing the idea of the possibility of adapting the needs and problems of people in extreme vulnerability to the use of a palliative medicine and specialized palliative care nursing (Neto, 2022). In terms of the variables of sample characterization, these reveal close gender results that are in line with broad general health indicators in Portugal. A total of forty-eight patients aged over 65 years and a set of sixteen patients aged less than or equal to 65 years were cared for, thus a higher number of patients with advancing adulthood and heading towards the third or even fourth age flows in. One of the most important variables identified for the course of the study is related to the identification of the relative of reference, the nomenclature used for the patient's significant person who may be a relative or not. The largest expression of the reference family member is positioned within the family, as some authors (Fonseca, Peres & Scalia, 2020) also call the informal caregiver, although there is still room for the vestigial presence of institutions that assume this role of caregiver, thus the identification of an institution in the role of family caregiver remained in the study. It is essential to mention that the relative of reference will be identified as the main caregiver, being the link to health care and the person who has most closely followed the evolution of the disease. It is often seen as a capacitation process even by health professionals to assume the person's care, especially when the person's degree of dependence increases with the possibility of discharge or even at the approach of the end of life. The act of caring is always a demanding challenge that aims to meet the person's needs and whose perception of the physical, psychological, social and spiritual status encompasses the concept of satisfaction with the answers provided by the healthcare services (OPCP, 2018). Several family members of reference were identified, whose greatest expression identify the role of the daughter in a total of 28 people, followed by the figure of husband/wife. Such results mirror the social monitoring of the family identified in studies such as DenHerder, *et al* (2017) Fonseca, Peres & Scalia (2020). As a diagnosis at admission, it is important to consider on the results that show that most patients with palliative care needs come from the large group corresponding to oncological diseases. Looking at the internal records of this hospital it is possible to assume a continuity of these data. There is a higher incidence for colon and rectal cancer, followed by breast cancer and haematological neoplasms. The reason for admission defines the need that led the person to seek palliative care, and three large groups are analysed: control of symptoms (discriminated in an individualized manner), organization of care and support at the end of life, where two or even three reasons for intervention by the team may coexist. According to the study, most patients needed pain control, which is one of the most commonly described and prevalent symptoms in palliative care and one that generates greater disability and anguish not only to the person, but also to the family (Capelas et al., 2018) and more previous data on pain as found in Ferris *et al* (2007). In addition to pain, as a symptom leading to hospitalization and intervention by the palliative care team, dyspnoea and agitation/confusion stand out. Although the malignant wound does not represent a necessary symptom *"per se"* to control, it may lead to the presence of bleeding, dyspnoea and asthenia, in addition to encompassing a set of problems that interfere with the person's well-being and self-image. All the symptomatology described in this research follows the possibilities of symptomatology leading to suffering described in the various palliative care manuals, of which we highlight the one by Barbosa & Neto (2016) for their experience in this context. End-of-life support was described and inferred specifically since people with imminent death require intensive intervention by the team and whose outcome, despite being expected, requires an active and attentive presence care for the patient and family, with end-of-life management of physical condition, but also from rigorous psychological and spiritual issues. The complexity of the person at the end of life and their level of demand increases the range of interventions and their quality, based on the existence of well-defined and updated protocols. With regard to the organization of care, accompanying and helping the person and the family to collaborate in the patient's quality of life, it is expected that it culminated in the resolution or stabilization of physical symptoms and in the social preparation of the family/institutions in order to have proceeded to hospital discharge, however, there is no information that could confirm this reasoning. It is essential to reflect on the presence of teamwork, its relevance among professionals who complement their interventions in favour of the complex situation of the patient and family. The social difficulties found in this research follow other results that point to the need for a more sustained intervention of community support so that the person can say goodbye in the comfort space, or even death occurring at home (Baquet-Simpson *et al*., 2019; Seow & Brainbridge, 2018). For Barbosa & Neto (2016) and Neto (2022) family is a fundamental pillar to collaborate in the care negotiation process. Regarding the presence of the family member at the time of discharge or death, the inference emphasizes the context of the pandemic experienced in the quarter under analysis, very different from other moments in the past when the presence of the family was often effective within 24 hours. It is increasingly important to emphasise the need to favour the presence of the family member. In a study on the needs of the family in the follow-up of their patient in Palliative Care, Areia *et al* (2017) state: *"However, it is important to point out that many caregivers manage to derive positive gains from the follow-up of the terminally ill patient (e.g., attributing greater meaning to life)."* (2017:144).

The professionals' perception at the moment of discharge or death is considered as without suffering for the patient, associated to the value of the Edmonton Scale, whatever the result of the hospitalisation may have been, and the important data that twenty-nine people were under sedation or intensive perfusion for symptom management and control. When assessing pain as a general symptom, professionals may be able to understand its degree. In a study on the perception of care, Silva (2014) identifies a strong proximity between the references of professionals, caregivers and patients. Thus, it is suggested that, with the use of the Edmonton Scale with its result by *Score*, it is possible to assess, throughout the quality assessment quarters, the consideration of the professionals' perception as an important note. On the other hand, the perception of the family member, and even the patient, about the relief of suffering, in some cases is seen as an extremely important measure to assess care (Capelas, (2014)). This study highlights the aspects asked to the reference family member regarding his/her perception of the person's physical, psychological/emotional/social and religious/spiritual symptoms. As far as the aspects of emotional perception are concerned, sadness and anxiety are the ones that stand out. The idea that physical suffering is more easily observed and evaluated by the family than emotional issues and, above all, spiritual issues that remain in the background is corroborated by the results of this study. The reflection on the family member's perception of the symptoms that cause discomfort and/or suffering to the person reveals results of much suffering. The care provided by the team alleviated this suffering in its entirety, reaching the point where they believe in the total serenity of the person. These results confirm previous studies for a more comprehensive view of palliative care described in the work of Hasselar & Payne (2016). In the end-of-life context, information often changes the person's and family's perspective of life in relation to their future, in a negative and drastic way, with the need to adapt to constantly changing realities. The human act of communicating is covered with points of respect, dignity, sensitivity and empathy. Ultimately, it requires constant training and knowledge of protocols so that it develops in a natural and humane way. In relation to the results obtained in the points of the study "Clarity of information", it was noted that the team was able to convey clear information that answered the family member's questions and needs about the status, diagnosis or evolution of the in-patient's clinical situation, being completely adequate, leading the team to reflect once again on the importance of positioning itself within the palliative care strategy.

One of the aspects of patient and family satisfaction relates to the information and knowledge they have about their disease, so that they can exercise their principle of autonomy in relation to accepting or refusing proposed and appropriate interventions for their best quality of life and comfort (Calado, 2014). Regarding our findings related to communication, we have got the following: *"For them, the greater the communication, accurate information and good care by the home care team the lower the burden in the daily life with the cancer patient. Thus, the proposal of a multi professional care emerged, since the caregiver often feels unprepared to deal with a terminal disease, requiring support for the practice of care and emotional support."* (Fonseca *et al*. 2020:80). This was observed regarding the availability to listen and inform the relative, but the opinion of the professionals who did not show this availability is worrying. The relatives of reference characterised the work of the multidisciplinary team as excellent. Thus, the satisfaction degree of the family member, regarding the care received by the person in the unit, shows that, according to the expectations of satisfaction, 7.81% were very satisfied and to 92.19% was excellent. This result meets the expectations of the indicator proposed by Capela (2014), which is 90%. Also, according to Pinto *et al*. (2022), the satisfaction of patients and families with the palliative care provided is a monitoring indicator (process and/or outcome), which will have an impact on the quality of care in palliative settings. The expression of the family member shows emotions, feelings and is suggestive of various interpretations. Without making any value judgement, we merely highlight some concepts that have strong meanings within the scope of palliative care and that record sweet or fond memories of the provision of care to people in their vulnerability and close to their finitude. It should be emphasised that, in approaching difficult times of social distancing that were experienced by the care team, limiting the presence of family members, the farewells were maintained as far as possible, renewing the innovative character of ideas of closeness with resource to video calls and visits by the exterior or even in person for the necessary farewells to those who are close to the end of their lives. Even so, the distance was felt and manifested by the family as a less positive aspect, causing anguish and suffering. As a limitation of the study, beyond ethical questions, in the treatment and analysis of data, such as its subjectivity through the analysis of the observer, this survey and the entire methodological development were carried out by two professionals and reviewed by a third in later stage. According to the relevance and consideration of the data, these presented contributions from the team and the need for corrective or evolutionary measures resulting from the continuation of care and subsequent assessments of the degree of satisfaction per quarter. The need for information, already reflected throughout this work, is once again the object of analysis due to the relevance of people obtaining information, the need to know with sincerity, openness, detail, assertiveness and honesty: *“For the satisfaction of the service in the opinion of patients and caregivers it becomes necessary: more open communication; active listening; the presence of the doctor and the same clinical team; effective control of signs and symptoms; identification of priorities for patients and caregivers; alleviation of physical and mental suffering; reinforce the importance of resolving conflicts, holding farewells and valuing the family presence.”* (Fonseca *et al*, 2020:85). The translation of free textual expressions is part of the content analysis of this study and allows the manifestation of what may have marked in a positive or negative way, the care and communication during the provision of care. For the analysis of these expressions, it is essential to perceive the moment of vulnerability of the family member who utters them and, without judgment of ethical value, to understand that the expression of gratitude is part of the reciprocal process of caring (Neto, 2022). The findings in this very sensitive area, the word uttered by those who may still be going through their mourning period, will help to understand and intervene in the near future. In line with the stories told by Neto (2022), the expressions of gratitude mentioning the comfort of the people cared for, the rediscovery of peace, translates the feeling of undeniable importance of palliative care.

CONCLUSIONS

The study contributes to the description of satisfaction by the care provided to hospitalized patients in palliative care, from the perspective of two observers: the family member/caregiver and the healthcare professional. Quality in palliative care is characterised by the centrality of care for the patient/family, service management, and the fundamental role played by the team. An individual care plan must ensure continuity and quality of care, with the patient and family assuming a central, participatory role in the different decision-making processes in an environment of constant interprofessional collaboration. It is essential to monitor the satisfaction levels of both patient and family to promote continuous improvement. Recognition of the palliative care quality, through a continuous quality improvement program, allows for a better understanding of clinical practice in order to develop programs that respond to the real needs of each patient/family in particular. The results obtained must be interpreted with caution, since this study has its limitations. However, despite its small dimension, it is part of a knowledge area that is still very little explored, and it was intended to contribute to the analysis and evaluation of the quality care provided, in the process of monitoring the patient and his significant family member in the face of the experience of an incurable, progressive disease that inevitably leads to death. The limitations of our study, as far as the generalization of the results is concerned, must be considered. Due to the conditions of access to the studied unit, families that could be present 24 hours a day with their patients were not included. We can state that the implementation of scientific assumptions in the provision of highly specialized and intensive care, within the scope of palliative care, contributes to increasing family satisfaction (namely the figure of the reference family member) regarding the health care provided by the team. Taking into account the representative domains of the key quality indicators, we can conclude that: the identification and characterization of the reference family member are essential so that the degree of satisfaction of the family member can be evaluated; the outcome of hospitalisation can influence the perception of care and the degree of satisfaction of the reference family member; the communication processes, meeting one of the pillars of palliative care, are structuring of the entire care plan; there is an appreciation of physical symptoms to the detriment of psycho-emotional and spiritual symptoms in the perception of the family member. In coherence with the positive results, when considering that the reference family members are satisfied with the care procedures, it is important to perceive that the quality and training of professionals should continue to be a strong reason for investment, a priority for practices to be normalized with the goal of improving and/or maintaining results. The final vision of the authors seeks in a clear and sustainable image of the specialized practice of end-of-life care. It lacks a larger base of similar and validated studies in the current and national context of the action of professionals in the communicational and relational field for future inferences of patient and family satisfaction. The result of this work aims, in addition to mapping all the aspects previously mentioned, mainly the reflection by all the global concepts of care and communication that do not cause harm to the patient and family, as in particular another individual reflection that supports this continuous quality improvement plan. We believe that, in the near future, this work may also contribute for the establishment of a set of quality indicators in the area of palliative care for a systematic evolution monitoring in Portugal.

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