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Palliative care: knowledge of cancer patients and their caregivers

José Humberto Belmino Chaves[1], *Laura Marques Angelo Neto*[1], *Viviane Maria Cavalcante Tavares*[1], *Lícia Pereira da Silva Tuller*[1], *Criselle Tenório Santos*[1], *Jorge Artur Peçanha de Miranda Coelho*[1]

1. Universidade Federal de Alagoas, Maceió/AL, Brasil.

Abstract

The objective of this study is to verify the perception of palliative care, advance directives of will and do-not-resuscitate order of patients and their caregivers, as well as their relationship with health professionals. This is a quantitative descriptive research, carried out between 2018 and 2019 at the Center for High Complexity in Oncology of a Brazilian university hospital. The sample included 200 participants (100 cancer patients and 100 informal caregivers). The collected data were stored in Microsoft Excel and processed in the SPSS software. It was possible to observe the participants' lack of knowledge about issues related to the end of life, as well as the paradox of disagreeing with dysthanasia and agreeing with obstinate resuscitation. The results also attest to the importance of health professionals in the perception of caregivers about their own capacity to exercise this function.

Keywords: Palliative care. Living wills. Resuscitation orders. Patient care team. Caregivers.

Resumo

Cuidados paliativos: conhecimento de pacientes oncológicos e seus cuidadores

O objetivo do estudo é verificar a percepção sobre cuidados paliativos, diretivas antecipadas de vontade e ordem de não reanimar de pacientes oncológicos e seus cuidadores, bem como a relação destes com os profissionais de saúde. Trata-se de pesquisa descritiva quantitativa, realizada entre 2018 e 2019 no Centro de Alta Complexidade em Oncologia de um hospital universitário brasileiro. A amostra contou com 200 participantes (100 pacientes oncológicos e 100 cuidadores informais). Os dados coletados foram armazenados no Microsoft Excel e processados pelo software SPSS. Foi possível observar o desconhecimento dos participantes sobre questões ligadas à terminalidade da vida, bem como o paradoxo entre discordância em relação à distanásia e concordância com a reanimação obstinada. Os resultados também atestam a importância dos profissionais de saúde na percepção dos cuidadores sobre a própria capacidade de exercer essa função.

Palavras-chave: Cuidados paliativos. Testamentos quanto à vida. Ordens quanto à conduta (ética médica). Equipe de assistência ao paciente. Cuidadores.

Resumen

Cuidados paliativos: conocimiento de los pacientes oncológicos y de sus cuidadores

Este estudio pretende comprobar la percepción sobre los cuidados paliativos, las directivas anticipadas de voluntad y el orden de no reanimar de los pacientes oncológicos y de sus cuidadores, así como su relación con los profesionales de la salud. Se trata de una investigación descriptiva cuantitativa, realizada entre el 2018 y el 2019 en el Centro de Alta Complejidad en Oncología de un hospital universitario brasileño. La muestra incluyó a 200 participantes (100 pacientes oncológicos y 100 cuidadores informales). Los datos recopilados se almacenaron en Microsoft Excel y se procesaron con el software SPSS. Se pudo observar la falta de conocimiento de los participantes sobre temas relacionados con la terminalidad de la vida, así como la incoherencia entre la desaprobación de la distanasia y la admisión de la reanimación obstinada. Los resultados también confirman la importancia de los profesionales de la salud en la percepción de los cuidadores sobre su propia capacidad para ejercer esta función.

Palabras clave: Cuidados paliativos. Voluntad en vida. Órdenes de resucitación. Grupo de atención al paciente. Cuidadores.

Research

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Technological and scientific advances in the post-Industrial Revolution era changed the pattern of population illness, with an increase in life expectancy and a consequent growth of the older adult population[1]. This demographic and epidemiological transition was associated with a reduction in infectious and contagious diseases and an increase in the incidence of chronic-degenerative diseases, which today account for 70% of all deaths, totaling 41 million deaths per year worldwide[2]. Examples of diseases in this group are cardiovascular, endocrinological, osteoarticular and neoplastic diseases.

Despite the progress technological resources developed for early diagnosis and treatment represent in mortality reduction, they are also being used to interfere in the final stages of human life. In this sense, death has been understood not as part of the natural cycle of life, but as an undesirable event, an accident caused by a disease that could have been predicted or the result of failures in medical practice[3].

Faced with the impossibility of curing certain illnesses, many health professionals, especially those who work in intensive care units (ICU), face the ethical dilemma about the extent to which the principle of beneficence justifies prolonging the life of terminal patients[4]. One of the answers to this dilemma is therapeutic obstinacy, a practice based on a biomechanical view of health, which focuses exclusively on treating the disease at the expense of comprehensive care for the individual.

Opposing this view, in the 1960s, the work of Cicely Saunders resulted in palliative care, a new form of care that considered biopsychosocial aspects in the care of terminal patients[5]. Initially, this care was specifically aimed at cancer patients. Later, however, in the 2000s, the concept was expanded to encompass other life-threatening illnesses, whether neurological, cardiac or renal.

Although palliative care is already well established in some countries, in Brazil this type of care was only officially recognized in 2018, by the Resolution 41 of the Ministry of Health[6]. Among the main goals of palliative care established by the World Health Organization and the International Association of Palliative Care, the following stand out: prevention, early identification and management of physical, psychological and spiritual suffering; the maintenance of the patient's autonomy, with respect to their cultural and religious values; the improvement in quality of life, positively influencing the course of the disease; and providing support to family members and caregivers during the illness and at the time of mourning[7,8].

In the context of palliative care, it is important to emphasize that, unlike euthanasia, orthothanasia does not anticipate the death of a patient with incurable diseases, but only does not artificially prolong the natural process of death[9]. Under Brazilian law, euthanasia is considered a crime, whereas orthothanasia is recognized by the Federal Council of Medicine (CFM) through Resolution 1805/2006 and the Code of Medical Ethics[10].

Still on the legal aspects of the terminality of life, the CFM approved, in Resolution 1955/2012, the advance directives of will, a *set of wishes, previously and expressly expressed by the patient, about care and treatment that he or she desires, or not, to receive when they are unable to express, freely and autonomously, their will*[11]. The directives aim to guarantee, when necessary, the possible representation of the patient by someone who can reflect their autonomy through the power of attorney for health care providers.

This CFM approval followed the parameters of a similar document, regulated in the United States in the 1960s: the living will. In the present study, the terms "advance directives of will" and "living will" were used as synonyms in order to facilitate data collection and analysis. It should be noted, however, that Brazilian legislation does not have a specific determination that formalizes the living will[12].

Another document related to the care of patients with advanced chronic progressive diseases is the do-not-resuscitate order. This document consists of the written expression, signed by the still lucid patient, of the wish not to be resuscitated in case of cardiopulmonary arrest in a terminal situation. The order not to resuscitate is also not legally formalized in Brazil, but, considering the criteria for limiting procedures in general, it can be supported by provisions such as the *Health Users' Rights Charter*, of the Ministry of Health, and included in the advance directives of will[13].

Although there are already several documents that preserve the rights of patients with chronic pathologies of limited prognosis, studies show that most of these patients are unaware of terms such as "palliative care," "do-not-resuscitate order" and "advance directives of will" [14]. Such lack of knowledge is combined with the limitation of training for health professionals, given the absence of specific disciplines and the scarcity of specialization and graduate courses on palliative care [15].

The formation of a professional team is essential for proper care and is directly associated with a good physician-patient relationship and quality of life for both patients and caregivers. The latter provide emotional, social and financial support to terminal patients, helping them with daily activities and attending appointments and exams. Its performance is essential for adherence to treatment [16].

The manual of the National Palliative Care Agency (ANCP) defines the *family member or person responsible for the care of the patient as a caregiver, who is primarily responsible for receiving guidance and clarification from the team, as well as constituting a link between the patient and the team for some demands* [17]. The document also deals with the figure of the "main caregiver," who is more involved in care and, therefore, more subject to stress and overload, which in turn can trigger mood disorders such as depression, generalized anxiety disorder and insomnia [18].

Considering the fundamental role of caregivers in the therapeutic process and recognizing the importance of information for the exercise of autonomy, this study assesses the level of knowledge of cancer patients and their caregivers about palliative care, advance directives of will and order not to resuscitate. In addition, this research addresses the relationship of the professional health team with cancer patients and their caregivers after the cancer diagnosis.

Method

This is a descriptive survey study with a quantitative approach. The sample consisted of 200 participants: 100 patients and 100 informal caregivers. Patients known to be older than 18 years of age, with cancer, undergoing chemotherapy at the Center for High Complexity in Oncology (Cacon) of a university hospital in the capital of a Brazilian state were included. Along with them, their informal caregivers (not necessarily main caregivers), over 18 years of age, who accompanied the chemotherapy sessions on the days in which the research was carried out and agreed to participate in the study, were included in the sample.

Data were collected through questionnaires applied between August 2018 and March 2019. The survey questionnaire by Comin and collaborators [14] was used as a basis and the necessary adaptations were made according to the interests of the present study. Therefore, two models were used, one for patients and one for caregivers, with 21 and 20 questions, respectively (Appendix).

The responses to the questionnaire were registered by the researchers – previously trained to apply the instrument – or by the participants themselves, depending on their level of education and the willingness they expressed at the time of collection. Thus, 15 patients and 5 caregivers had their responses recorded by the researchers, while 85 patients and 95 caregivers responded to the survey in a self-administered way. Participants were approached in the Cacon's chemotherapy session room, and data collection took place cautiously, after creating bonds of trust for some moments.

The variables collected for patients were: sociodemographic data; type of cancer and presence of metastasis; life span forecast (if this information was provided by a healthcare professional); perception of quality of life after knowledge of the disease; decisions regarding the possibility of an incurable disease; physician-patient relationship; level of knowledge about palliative care, advance directives of will and order not to resuscitate and desire to carry them out; how you would like to be treated if you were in a situation of terminality in life.

For caregivers, the variables collected were: sociodemographic data; degree of kinship with the patient; whether or not you are paid as a caregiver; perception of their own ability to care for the patient and how long they have been doing it; how the care interfered in their life (overload, loss in her professional life, etc.);

relationship with the medical team; feeling about the patient's prognosis; level of knowledge about palliative care, living will or advance directives of will and order not to resuscitate, as well as the desire to carry them out and that their choices were respected if they had advanced chronic progressive disease.

Data were stored in spreadsheets created in Microsoft Excel and then processed in the SPSS software and analyzed using the chi-square test, with a 95% confidence interval and *p-value* less than 0.05. The research project was registered on Plataforma Brasil and approved by the Ethics Committee.

Results

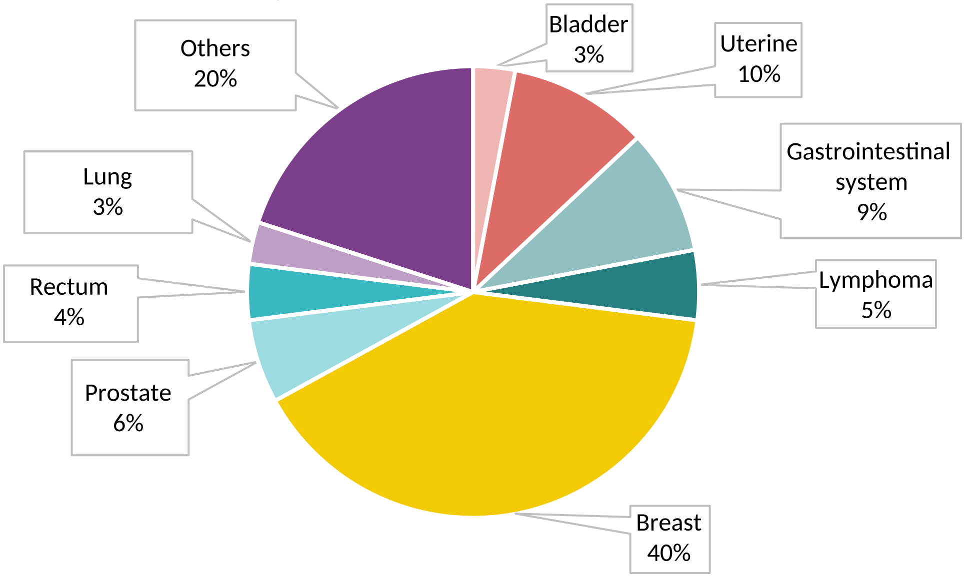
Knowledge of patients

Most of the sample was composed of female patients (74%), with 55.19 years as the mean age (minimum of 22 years and maximum of 76 years), married (40%) and with incomplete elementary education (48%). The most representative professions were: housewife (14%), retiree (12%) and farmer (9%). Regarding religion, 62% were Catholic and 24% Evangelical. The most common cancer was breast (40%), as shown in Figure 1.

Of those interviewed, 78% say they have no metastases or are unaware of the term; 87% report having received medical support at the time of diagnosis and report that good communication and attention between the physician and family members was maintained; and 94% say they have not received a lifespan forecast. Regarding knowledge about palliative care, 78% of participants are unaware of the term "palliative care," 85% are unaware of the term "do not resuscitate order" and 96% are unaware of the living will. After explaining this last term, 60% said they were interested in the document. In 63% of cases, patients report never having thought of a scenario in which a cure is no longer possible.

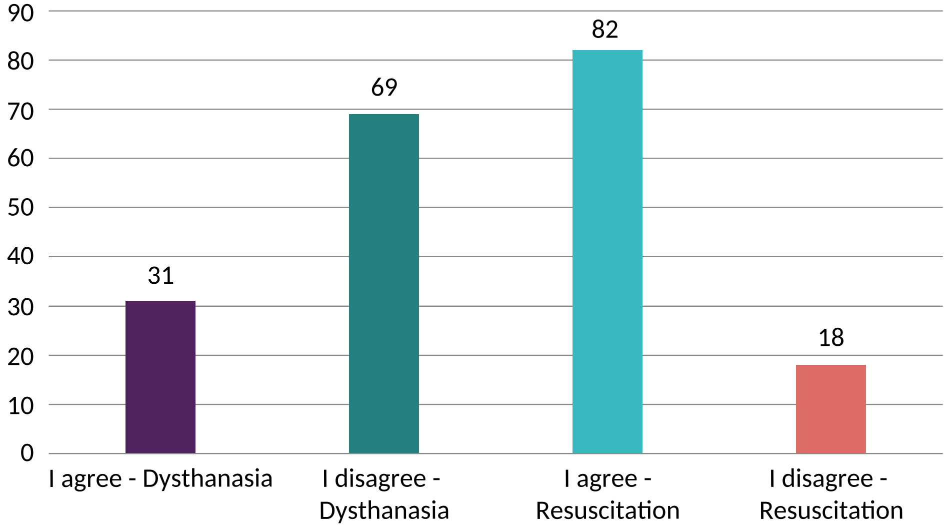
Asked about the place of care, 61% said they would like to receive care at home and 35% at the hospital. About deliberation, 52% prefer the decision on treatments to be taken together, between the physician, family and the patient. Of the total sample, 82% of patients wish to be resuscitated in any medical circumstance; and 69% disagree with dysthanasia, whereas 31% agree (Figure 2). As for the score attributed by patients to their own quality of life after cancer diagnosis, the mean was 7.89.

Figure 1. Primary location of malignant neoplasm in patients



** Types of cancer with fewer than three patients affected were removed.*

Figure 2. Patients' opinions on dysthanasia and cardiopulmonary resuscitation in any circumstance



Knowledge of caregivers

Most of the sample consisted of female caregivers (75%), married (51%), Catholic (51%) or Evangelical (33%), with complete high school or incomplete primary education (27% in both cases). The most representative professions were housewife (14%), retiree (12%) and farmer (9%).

As for the degree of kinship with the patient, 41% are children, 21% spouses and 15% siblings. With regard to time as caregivers, 70% have followed the patient for less than a year and 30% for more than a year. To exercise this function, 97% do not receive any type of remuneration, and 66% disagree that patient care has disrupted their professional lives.

About stress and overload, 56% say they never feel overwhelmed by the care of cancer patients, 20% "sometimes," 13% "often" and 11% "seldom." In 90% of responses, caregivers say they feel capable of performing this role, 65% say they receive support from the medical team and 73% report that the physician openly talked to them about the patient's health status.

Regarding the prospects for the future, half of the caregivers say they do not feel hopeful about what is to come, while the other half say they do. With regard to knowledge about palliative care, 63% are unaware of palliative care, 81% are unaware of the terms "living will" or "advance directives of will," and 75% are unaware of the do-not-resuscitate order. After explaining the living will, 60% showed interest in this instrument. However, after elucidating the term "do-not-resuscitate order," 62% said they would refuse this possibility in a hypothetical case of advanced chronic progressive disease.

Through the chi-square test, an association was identified between length of care and burden [$\chi 2$ (1)=4.55, *p*=0.033; OR=2.88; 95% CI=1.18, 7.06]. The chances of a caregiver who has performed this function for more than a year to present high burden is 2.8 times greater than for a caregiver who has taken on this task for less than a year. An association between the help of the medical team and the feeling of ability to exercise the role of caregiver was also observed. The chances of a caregiver who received support feeling qualified for their role are 5.9 times greater than that of a caregiver who did not have such support.

Discussion

More than half of the cancer patients who participated in the research were over 55 years old, which was expected, since the prevalence of malignant neoplasms increases with age due to the progressive decline in cell regeneration capacity [19,20]. In addition, of the 625,000 new cases of cancer estimated for each year of the 2020-2022 triennium in Brazil, almost 63% affect the Brazilian population aged over 60 years [21,22].

As for the distribution by sex, 74% of the patients in the sample are women. These data are consistent with cancer incidence rates in other developing countries, in which cancer detection and prevention programs are focused on gynecological and breast cancer[23].

Most patients have incomplete primary education. Low education and other socioeconomic factors, such as low family income, contribute to the increased prevalence of chronic diseases. Socially disadvantaged populations have greater difficulties in accessing health care and information, which results in late diagnosis of diseases such as cancer[20,24].

The predominant religion, both in the group of patients and in the group of caregivers, is Catholic. This data is in line with the results of the latest Census by the Brazilian Institute of Geography and Statistics, which indicates Catholicism as the main religion of the Brazilian population (64.6%), followed by the Evangelical religion (22.2%)[25].

The most frequent type of cancer among patients participating in the research is breast (40%), followed by prostate and cervical cancer (both with 6%). This prevalence is similar to data from the National Cancer Institute, which indicates breast and prostate cancer as the most frequent in 2020 after non-melanoma skin cancer[21].

Regarding the knowledge of cancer patients and their caregivers about palliative care, do-not-resuscitate order and living will, these terms were mostly unknown to them. The lack of knowledge was greater regarding the living will among patients. These findings are probably due, at least in part, to the socioeconomic profile of the individuals, considering that schooling was lower among patients than caregivers[14,26].

The lack of knowledge of patients and caregivers about the aforementioned concepts can be seen as one of the reflections of the lack of dialogue between the multidisciplinary health team and the patient and their families. Talking about death in the physician-patient relationship remains a difficult task, mainly for two reasons. The first is the inability to deal with the suffering of others, related to the confrontation with one's own finitude – this incapacity that generates the urgency of treating only the physical aspects of the disease, to the detriment of the patient's emotional dimension[3,7]. The second reason is the technical language used by health professionals, which is most often incomprehensible to the patient. The lack of clarification on the prognosis and the exclusion of the patient from decision-making can reinforce feelings of anguish and impotence, both in the patient and in their families[4].

After the researchers clarified the concept of living will and advance directives of will, most patients (60%) and caregivers (60%) showed interest in making their living will – a result similar to that found by Comin and collaborators[14]. On the other hand, with regard to the order not to resuscitate, only 18% of patients and 38% of caregivers agreed with the possibility of not being resuscitated in case of a serious and incurable disease.

Despite the opinion in favor of resuscitation, 69% of patients said they did not want their lives to be maintained by devices in a situation of serious and incurable disease. These results show that, at first, the majority's preference is for survival at any cost, even in a condition of terminality of life. However, with the change of scenery, few agree with the artificial maintenance of life (dysthanasia). Comin and collaborators[14] argue that such behavior is probably due to the lack of knowledge about the sequelae of unsuccessful resuscitation, such as myocardial dysfunction, stroke and multiple organ dysfunction[27].

Although other studies[14,28] have identified a relationship between disease severity and the patient's confrontation with the possibility that their condition is incurable, there was no significant association, in the present study, between the presence of metastases and the reflection generated by the awareness of being in a situation of terminality of life.

Among the most frequent chronic diseases, cancer is one of the most stigmatizing, and among cancer patients the prevalence of psychiatric disorders is higher than in the general population. Anxiety, common at the beginning of antineoplastic chemotherapy treatment, and depression, which can be present at any stage of the disease, affect the patient's quality of life[29]. In this sense, the role of spirituality and religiosity in accepting the diagnosis and creating a purpose for life has been recognized, helping to overcome the patient's anxiety and suffering[30].

In addition to the spiritual and religious dimension, family and the health team support can also improve the patient's quality of life. In the present study, patients who reported support at the time of diagnosis and good communication with the physician attributed a higher score to their quality of life after discovering the disease. This result reinforces the need for health professionals to be trained to care for cancer patients in a comprehensive manner.

According to data from ANCP[31], in 2019 there were 191 palliative care centers in Brazil, which is equivalent to one service per 1.1 million inhabitants, a number far below what the European Association of Palliative Care recommends (two services per 100 thousand inhabitants). In addition, these centers face several difficulties, such as the absence of their own guidelines for pain management; absence outside the hospital environment (for example, in primary care); inequality in geographic distribution, as most are concentrated in the Southeast and South regions; and lack of ordinances that regulate the inspection and financing of these institutions[31].

The ANCP study also points out that, although it is possible to observe a growing engagement of palliative care centers with medical or multidisciplinary residency programs, less than 20% of these institutions have links with undergraduate and graduate courses[31]. According to Nickel and collaborators[32], the resistance to inserting palliative care in the curricula of medical schools and other areas of health prevents a complete and humanized professional training to deal with the suffering of others. This is reflected in the lack of multidisciplinary teams, observed in the ANCP survey of palliative care centers, which have few professionals specialized in this type of care.

Regarding the profile of caregivers, most are children (41%) and spouses (21%) of the patients, female (75%), and are between 25 and 51 years old (65%). This profile coincides with findings from other studies[16,18,33,34] that reveal a predominance of women as a reflection of the sociocultural pattern that associates the female gender with domestic tasks and care for others. The age profile corresponds to the most prevalent family relationships.

As for the caregiver's quality of life, 66% disagreed that the role of companion/caregiver interfered with their professional life, and 56% did not feel overwhelmed by the care provided to cancer patients. These results are not compatible with what is observed in the literature, which points to recurrent physical and mental exhaustion of family members responsible for caring for patients diagnosed with cancer[16,18,33,34]. In view of the impossibility, in most cases, of maintaining privacy in the application of the questionnaire, with physical separation between caregivers and patients, it is possible that the answers in this study were biased in this regard.

Caregivers of cancer patients are more likely to experience depression, anxiety, insomnia and stress inherent in providing daily care and attending surgery, chemotherapy and radiotherapy sessions. Furthermore, most of the time, the caregiver also needs to deal with domestic activities and provide financial and emotional support to the patient[18].

Thus, the patient's demands are prioritized in relation to the caregiver's leisure time, relationships and work. This reallocation of priorities, with consequent psychological and physical suffering and reduced quality of life, is more prevalent in three situations identified in the literature: caregivers who have been exercising this function for a longer time; caregivers of patients with advanced cancer; and in the absence of support from the medical team[16].

In this research, it was impossible to assess the quality of life of caregivers of patients with advanced cancer, since the variable "presence of metastasis" was included only in the patients' questionnaires, and not all patients were accompanied by a caregiver at the time of data collection. Furthermore, many of the patients, even in the presence of the caregiver, were unaware that they had metastases.

On the other hand, there was an association between length of care and self-reported burden, as the chance of a caregiver who has been exercising this role for more than a year to present an overload is higher than that of a caregiver who started performing this task less than a year ago. There was also an association between the help of the medical team and the feeling of ability to exercise the role of caregiver, a result that shows how the support of the multidisciplinary health team is essential to build a relationship of trust with the patient's family and improve the quality of life of the caregiver.

The feeling of incapacity of the relative caregiver is due to the lack of training and preparation. Left unsupported by the medical board, caregivers often feel unprepared to deal with a disease that they are not informed about and that is advertised as extremely fearful [33,34]. Linked to socially established fear, there is the desire not to lose a loved one: as shown in this research, 50% of caregivers feel bad about the prospect of the patient's disease evolution.

The consequences of caregiver burden are relevant and should be addressed. High levels of stress in caregivers are predisposing factors for grief to be more traumatic and prolonged [33]. Valuing the well-being of these individuals, with guaranteed psychological support by the health team, is also thinking about the patient's quality of life.

Final considerations

With the discovery of new types of cancer, health teams needed to adapt to a new scenario in which the terminality of life is increasingly present. In this scenario, ensuring the patient's "quality of death" becomes more important than preserving life at any cost, through therapeutic obstinacy. As a result of this evolution, legal and medical achievements are being consolidated, such as palliative care and documents such as the order not to resuscitate and the living will, or advance directives of will.

Despite these advances, the end of life is a considerably new subject, still in the process of construction and adaptation, both for those who receive the diagnosis of an incurable disease and for the professional team. Caring for people with advanced chronic progressive diseases requires not only technical knowledge, but also emotional control, as these situations raise the confrontation with their own finitude and demand communication skills to maintain an effective dialogue with the patient and their families.

Talking openly about the patient's health status and clarifying doubts are essential actions to ensure that the caregiver feels capable of performing their role, and this feeling of trust is reflected in the quality of care provided to cancer patients. In this sense, the support of health professionals proved to be a significant variable in the quality of life of patients and caregivers, especially those who have been in this condition for more than a year.

Regarding palliative care, do-not-resuscitate order and living will, the results showed a general lack of knowledge, especially with regard to advance directives of will among patients. Such lack of knowledge on the part of patients and caregivers may reflect the lack of training of health professionals to address these issues. However, providing patients and family members with information about their rights and other ethical issues should be part of medical conduct. This action, which leads to the abandonment of paternalism, is the best way to empower patients to exercise their autonomy precisely at a time when it is at its weakest.

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José Humberto Belmino Chaves – PhD – jhbchaves@uol.com.br
0000-0003-2704-6538

Laura Marques Angelo Neto – Undergraduate – lauramarquesangelo@gmail.com
0000-0002-8579-2291

Viviane Maria Cavalcante Tavares – Undergraduate – vivianemct97@gmail.com
0000-0002-0865-3626

Lícia Pereira da Silva Tuller – Undergraduate – pereiratuller@gmail.com
0000-0003-0503-6304

Criselle Tenório Santos – Undergraduate – crisislle.santos@famed.ufall
0000-0001-7163-4148

Jorge Artur Peçanha de Miranda Coelho – PhD – jorgearturcoelho@outlook.com
0000-0002-0021-5963

Correspondence

José Humberto Belmino Chaves – Campus A.C. Simões. Av. Lourival Melo Mota, s/n CEP 57072-900. Maceió/AL, Brasil.

Participation of the authors

Laura Marques Angelo Neto designed the study. Viviane Maria Cavalcante Tavares contributed with data collection and analysis. Lícia Pereira da Silva Tuller collaborated with the design of the methodology and references. Criselle Tenório Santos collaborated with the writing of the article. José Humberto Belmino Chaves was responsible for a critical review of the manuscript. Jorge Artur Peçanha de Mirando Coelho contributed with the data analysis in the SPSS software.

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