

ETHICAL DILEMMAS EXPERIENCED BY THE HEALTH TEAM IN THE CARE OF THE PERSON IN CANCER TREATMENT

DILEMAS ÉTICOS VIVENCIADOS PELA EQUIPE DE SAÚDE NO CUIDADO DA PESSOA EM TRATAMENTO ONCOLÓGICO

DILEMAS ÉTICOS EXPERIMENTADOS POR EL EQUIPO DE SALUD EN EL CUIDADO DE LA PERSONA EN TRATAMIENTO ONCOLÓGICO

Maryana Carneiro de Queiroz Ferreira¹
Marluce Alves Nunes Oliveira²
Thamara Arianny Ventin Amorim Oliveira de Assis³
Elaine Guedes Fontoura⁴
Manuela Bezerra Pina Oliveira⁵
Keccya dos Santos Nunes Gonçalves⁶
Joselice Almeida Gois⁷

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Objective: to know the ethical dilemmas experienced in the practice of the health team in the care of the person in cancer treatment. Method: exploratory and descriptive study of qualitative approach conducted in a unit of high complexity assistance in oncology in a municipality in the countryside of Bahia, Brazil. A semi-structured interview was conducted, with the participation of eleven health professionals. Data analysis occurred using the Content Analysis technique proposed by Bardin. Results: the study pointed out that health professionals working in cancer care experience ethical dilemmas in practice, before interventions in palliative care, such as not revealing the diagnosis to the person with cancer and doubt as to the maneuvers to revive or not. Conclusion: health professionals daily experience ethical dilemmas and most have knowledge about them, although ambiguity has been found between the terms ethical conflict and ethical dilemma.

Descriptors: Ethics. Oncology. Patient Assistance Team.

Objetivo: conhecer os dilemas éticos vivenciados na prática da equipe de saúde no cuidado da pessoa em tratamento oncológico. Método: estudo exploratório e descritivo de abordagem qualitativa realizado em uma unidade de

¹ Nursing Student. Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. <http://orcid.org/0000-0002-5711-4485>.

² Nurse. PhD in Nursing. Professor at the Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. milialves@yahoo.com.br. <http://orcid.org/0000-0002-9109-0106>.

³ Nurse. Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. <http://orcid.org/0000-00023356-8044>.

⁴ Nurse. PhD in Nursing. Professor at the Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. <http://orcid.org/0000-0002-3434-2215>.

⁵ Nurse. Coordinator at the Hospital Infection Control Commission of Hospital Dom Pedro de Alcântara. Feira de Santana, Bahia, Brazil. <http://orcid.org/0000-0002-8407-0553>.

⁶ Nurse. Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. <http://orcid.org/0000-0002-3122-9313>.

⁷ Nurse. MSc in Nursing. Professor at the Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil. <http://orcid.org/0000-0001-8870-3509>.

assistência de alta complexidade em oncologia em um município do interior da Bahia, Brasil. Foi realizada entrevista semiestruturada, que contou com a participação de onze profissionais da área da saúde. A análise dos dados ocorreu utilizando-se a técnica de Análise de Conteúdo proposta por Bardin. Resultados: o estudo apontou que os profissionais de saúde que atuam em cuidados oncológicos vivenciam dilemas éticos na prática, frente às intervenções nos cuidados paliativos, tais como não revelar o diagnóstico à pessoa com câncer e dúvida quanto às manobras para reanimar ou não. Conclusão: os profissionais de saúde vivenciam dilemas éticos cotidianamente e, em sua maioria, possuem conhecimento sobre eles, embora tenha sido encontrada ambigüidade entre os termos conflito ético e dilema ético.

Descritores: Ética. Oncologia. Equipe de Assistência ao Paciente.

Objetivo: conocer los dilemas éticos experimentados en la práctica del equipo de salud en el cuidado de la persona en tratamiento oncológico. Método: estudio exploratorio y descriptivo de abordaje cualitativo realizado en una unidad de asistencia de alta complejidad en oncología en un municipio del interior de Bahía, Brasil. Se realizó una entrevista semiestruturada, con la participación de once profesionales de la salud. El análisis de los datos se produjo mediante la técnica de Análisis de Contenido propuesta por Bardin. Resultados: el estudio señaló que los profesionales de la salud que trabajan en la atención oncológica experimentan dilemas éticos en la práctica, frente a las intervenciones en cuidados paliativos, como no revelar el diagnóstico a la persona con cáncer y tener dudas sobre las maniobras para revivir o no. Conclusión: los profesionales de la salud experimentan dilemas éticos a diario y, en su mayor parte, tienen conocimiento sobre ellos, aunque se ha encontrado ambigüedad entre los términos conflicto ético y dilema ético.

Descriptorios: Ética. Oncología. Equipo de Asistencia al Paciente.

Introduction

Ethics, over time, has been improved according to the evolution of society. Such evolution promoted the freedom of action of the professional who cares, as well as respect for the autonomy of the sick person and his/her family members. Thus, the care of the health team incorporates, in daily life, personal, theoretical and practical, ethical, moral and legal perspectives and promotes reflection about the attention and respect for the dignity of the sick person.

Ethical dilemmas emerge in people's both personal and professional lives. These may be administrative or related to ethical and moral problems. Therefore, as ethics is necessary in professional practice, when approaching people with cancer, it is necessary to have a constant reflection on ethical problems, in order to design coping strategies⁽¹⁾.

Cancer is considered a public health problem of great epidemiological relevance worldwide, concerning the incidence and morbidity and mortality⁽¹⁾. People diagnosed with cancer experience both physical and psychological changes that may begin in the disclosure of the

diagnosis, treatment and post-recovery. At this moment, the person experiences side effects of medications, comorbidities and deterioration of the body's functionality, in addition to experiencing anxiety, fear, sadness and other feelings at all stages of the disease. Such feelings are also experienced by family members, who face a heavy mental burden along with their loved one, because this disease requires a multidisciplinary team in cancer care that assists all involved and promotes quality of life⁽²⁾.

The multidisciplinary team, when providing cancer care, may experience ethical dilemmas that are difficult to solve, which require knowledge and ethical-professional action, in addition to being familiar with interpersonal relationships, so that the values of people in cancer treatment, family members and professionals are respected and the care provided is ethical and dignified⁽³⁾.

This study was motivated by the practical experience as members of the health team that cares for people in cancer treatment and by realizing that ethical dilemmas occur and are often not identified. Then, the question of investigation arose: How does the health team

experience ethical dilemmas in the care of the person in cancer treatment?

This study is considered of great relevance, because it allows knowing the ethical dilemmas experienced by the health team in the care of the person in cancer treatment in the hospital context, as well as to promote reflection, so that, before them, the people who make up the team have the ability to make decisions.

This study aims to know the ethical dilemmas experienced in the practice of the health team in the care of the person in cancer treatment.

Method

It consists of an exploratory and descriptive study of qualitative approach, which had as object of study the “ethical dilemmas experienced in the care of the person in cancer treatment”. It is part of the Research Project entitled “Conflicts and Ethical Dilemmas Experienced in the Care of the Health Team in the Hospital Context”, with Resolution n. 016/2018 of the Higher Council of Teaching, Research and Extension (CONSEPE).

The study was carried out in a reference High Complexity Oncology Care Unit located in a large city in the countryside of the state of Bahia, Brazil. The oncology unit was inaugurated in September 2009 and has an outpatient clinic where consultations are performed with the clinical, surgical and radiotherapy teams, in addition to outpatient chemotherapy, immunotherapy, hormone therapy and radiotherapy treatments.

It consists of a multidisciplinary team composed of nurses, doctors, nutritionists, psychologists, pharmacists, speech therapists, social workers, physiotherapists, receptionists, radiology nursing technicians and medical physicists.

The participants investigated were 11 health professionals: eight nurses, a doctor, a nutritionist and a physiotherapist. The following inclusion criteria were: to develop care activity for over one year. The exclusion criterion was to be absent for vacation or leave.

Data collection was performed by one of the authors and member of the Interdisciplinary

Center for Health Research and Studies (NIPES), from June to October 2018.

At first, the nursing coordination was contacted to clarify the research theme, objective and justification of the study. Then, the professionals were invited to participate in the research. Those who accepted received the Informed Consent Form (ICF), with the guidance that it should be read and signed in two copies.

Data collection was performed through semi-structured, audio-recorded interviews, with an average of 3.23 minutes for the guiding questions and 1.0 minute for the characterization, according to the participants' availability, on a day and place determined by them. The largest number of nurses interviewed was because they performed daily care and had the possibility of experiencing ethical dilemmas. It is noteworthy that the interruption of data collection, as well as the definition of the number of participants, occurred with theoretical saturation at the eleventh interview.

The data collection instrument was divided into two parts: the first contemplated the characterization of the participants – age, gender, time since graduation, time of work in an oncology unit, weekly workload, other employments, other sectors of activity, degree and post-graduation; the second was composed of guiding questions: What do you mean by ethical dilemmas? Tell me about ethical dilemmas experienced by you while caring for people in cancer treatment.

For organization and subsequent data analysis, the Content Analysis technique proposed by Bardin⁽⁴⁾ was used, which is divided into three stages: the first, pre-analysis, in which the materials that would be useful for the research were organized, with a systematized analysis, in order to conduct a precise scheme for developing successive operations; the next step, exploration of the material, consisted of an analytical data description; in the last stage, inferences and interpretations were made based on the proposed objective⁽⁴⁾.

To ensure anonymity, the participants were identified by the initial letter of their profession

followed by the number corresponding to the order of the interview: N1, N2... (Nurse); NU1 (Nutritionist); P1 (Physiotherapist); and D1 (Doctor).

The project was submitted to the Research Ethics Committee (REC) of the Universidade Estadual de Feira de Santana (UEFS) and approved by the Certificate of Presentation of Ethical Appreciation (CAAE) n. 2865214.9.0000.0053.

Results and Discussion

The interviewees were 11 health professionals working in cancer treatment units. Eight were female and three were male, aged between 27 and 36 years. Regarding training, eight were nurses, one nutritionist, one physiotherapist and one physician. Training time from one year and since months to 10 years, which corresponded to the time of operation in oncological units of the researched institution.

The reading of the reports allowed identifying three categories: How the health team understands the ethical dilemma, Ethical dilemmas before the person in palliative care and Ethics.

How the health team understands the ethical dilemma

In this category, the team professionals expressed that they understood ethical dilemmas as a need to make a decision that went against their values and became a barrier to their ethical doing and acting.

In the statements of N1 and N2 show that, in situations with two options, the professional has to make a decision. Then, from the moment the decision affects his/her ethical and moral principles, doubts arise and the ethical dilemma is established.

Situation in which you, as a professional, have to take an attitude [...] [which] often can somehow affect your, your morals, yours, your customs. (N1).

You have two paths to follow and you... have to choose one of the paths, and you cannot identify what is going to be best for that moment. (N2).

For N3, N4 and N6, the health professional experiences the ethical dilemma at a time

when, even knowing that he/she goes against professional ethics, he/she must decide on a situation in which a barrier prevents him/her from making the most appropriate decision.

Some situations in which, sometimes, we face during the profession, referring to ethical conduct that, in most cases, you unable to know, in fact, how to get out in some situations. (N3).

You know what something is, the right thing to do and have a barrier that prevents you from doing it, because you get in the middle of a certain situation, right? On one side and the other, but never running away from what is right, but you cannot change that. (N4).

Well... what a difficult question! For me, I do not know if I am going to say it right, but for me, we experience much dilemmas here. We actually have... when we study, right? We have a dilemma to follow that is ethical, and usually we end up not following what, for us, would be ethical. So, it is a dilemma for us. It is something, not that we do it wrong, but are things outside of what we can do about ethics. (N6).

For participant N3, the dilemma presents itself in the exercise of the profession, when it comes to situations that do not really know how to decide. For N4, the dilemma is defined as a barrier before certain situation, which may result in changes in the conduct, according to the case. According to N6, the ethical dilemma will be characterized as a situation in which something is done, contrary to ethical values.

In this sense, associated with the results exposed is the situation in which the health professional faces the ethical dilemma, by having to choose one of the possible alternatives in a given case, but both have ethical advantages and disadvantages. Thus, the decision can go against the ethical and moral principles that guide their conduct⁽⁵⁾.

[Sighed!] Good question [laughs] Boy, it is all that involves ethics within our profession, within ethical conduct as a nurse. Right... as the dilemmas that the patients themselves bring us, within what they live, in addition to the disease itself... (N8).

N8 reports that the ethical dilemma is related to the professional experiences and problems of the person in cancer treatment. In this perspective, the ethical dilemma does not always refer to ethical aspects directly, but may be linked to the personal sphere, incorporated into the individual life of each professional and the people they care for⁽⁶⁾.

The ethical dilemma, in P1's view, is related to the conflict to continue before a situation, when it is not possible to distinguish the ethical conflict from the ethical dilemma. This impasse evidences the possibility of misunderstandings regarding the understanding of these terms.

I understand that dilemma is conflict, right? A conflict that you live in a certain situation and... An ethical dilemma is, for example, following ethics in such a situation, the ethics of your profession, for example, and you have a conflict in following it there, so, as if it were a difficulty in performing that procedure ethically... (P1).

Ethical dilemmas concern situations of difficult decision, in which there is no linear solution, but a confrontation of values. The solution of the dilemma requires responsible and reflective individual involvement, with questions at the time of the decision⁽⁷⁾, since it is necessary to evaluate all alternatives in order to deliberate more clearly⁽⁵⁾. Ethical conflict is characterized as a divergence and diversity of opinions that encompasses people with different perceptions, causing discussions, and a consensus is needed among the different points of view. In this sense, as they are commonly used to refer to the same domain of reflection, it is clear the ambiguity of these terms to define and differentiate the understanding of dilemma and ethical conflict⁽⁸⁾.

In this study, the results revealed that health professionals mostly understood the meaning of ethical dilemmas. One of them, however, was wrong to expose the concept of dilemma and ethical conflict. Therefore, the understanding of ethical dilemmas can be an important aspect in the professional practice of ethical people, since it enables conscious decision-making.

Ethical dilemmas before the person in palliative care

In this category, the findings of the study demonstrated that ethical dilemmas were associated with palliative care of people with cancer, since, in some cases, they need this type of care, which are not always provided. Another observed situation concerns not recognizing the limits of what they can do for that person and

wanting to save their life, even if it is not always possible.

For N1 and N2, the ethical dilemmas they experienced were related to determining or not palliative care for a person. This was associated with the dilemmas caused in the health team, motivated by the unawareness of the concept, because they generated difficulties and questions to provide care in an ethical and qualified way.

The ethical dilemmas with which I experienced during the time in the ward were the dilemmas in which patients had a prognosis of palliative care. This prognosis of palliative care was not in the medical records, signed by the doctor, and you experience the ethical conflict at the time that this patient suffers an arrest, whether you resuscitate or not. (N1).

The main dilemma today here in the medical clinic [...] the patient is not defined as palliative care, but you see that this patient should be a palliative care patient and the oncologist has this difficulty in making this definition and writing in the medical records, because it is not enough to define [...] you have to write in the medical records that it is a palliative care patient, so that the team is aware and can give, continue the care and treatment of this patient. (N2).

Palliative care is considered an integral care, which aims at the quality of life of the person with a threatening disease, including physical, psychological, social and spiritual aspects. Moreover, it aims to promote the prevention and relief of suffering for both people affected by the disease and their families⁽⁹⁾.

In this context, in the presence of a clinical diagnosis, it is the doctor's duty to define the diagnosis and prognosis, recording them in the medical records and maintaining communication with the team, so that interdisciplinary care is performed and with the best treatment for this, in order to achieve the expected evolution. Moreover, this referral supports professional situations that need to be evaluated^(1,10).

The only thing that fits is the palliative patient, you want to invest more. The most complicated thing is this [...] because the family wants you to do more and you know that, even if you do more, you won't get the expected result and, in a way, you are unable to get over it... (P1).

P1 reveals the experience of dilemmas when faced with a person in palliative care and, as a professional, not knowing how much can invest in that person. There is also the aspect of the family wanting more investment and the

professional facing the dilemma between doing or not doing more for the person.

In agreement with the literature, before a person with an advanced disease, in palliative care, health professionals may face an ethical dilemma, having to assess risk and benefit regarding the treatments and care to be performed, with the main focus being the maximization of benefits and that care ensures efficacy and efficiency⁽¹¹⁾.

For D1, one of the ethical dilemmas experienced by professionals who care for the person with cancer problems may be related to the issue of palliative care. The deponent clarifies that it is not a question of saving life or prolonging it, but of giving quality of life to the person who experiences a disease without the possibility of cure, as well as to support the family before the sufferings faced.

So, one of the ethical dilemmas that we work with is exactly this. It is the question of palliation. We deal with it, we approach palliation, because, thus, theory, we learn theory. The maximum principle to be, that you see in the health area, what is it? It is saving lives! You go, everybody and talk, I am going to save lives! You are going to save lives! I am going to prolong lives! And often, it is not exactly prolong life in order to prolong. It is you giving that person quality of life and often that is a fear... (D1).

Health professionals, when caring for the person in palliative care, feel powerless and frustrated about the probability of terminality of the disease, due to the impossibility of cure or the real possibility of death. It is noteworthy that academic training prepares the doctor and other health professionals to save lives⁽¹²⁾.

In this perspective, providing palliative care to the person with a chronic disease requires specific experience and knowledge, since professionals need to meet the complexity of the needs of the sick person and his/her families in an integral way, promoting comfort⁽¹³⁾.

Ethics

In this category, the professionals reported that one of the greatest ethical dilemmas they faced in oncology was professional secrecy. This meant that the person did not know about his/her own diagnosis, most often for family reasons, and the professional had to maintain

and respect the request not to reveal, even knowing that, according to ethical principles, it is the person's right to know about his/her disease and diagnosis. Moreover, non-resuscitation was cited. If the person's condition was severe, with no prospect of life, they could request a non-resuscitation order.

The part of the patient knowing about the disease itself. So, we have a little question, which we always ask. Often, the doctor himself does not really speak what the patient has, not because the patient does not want to know, but sometimes really why?... I do not know... (N6).

One of the questions of the clinical anamnesis concerned the patient's knowledge of his diagnosis. In some cases, the patient was not informed about his/her health status and the professional did not know the reason and the patient has the doctor's decision not to communicate, as reported by N6.

People with cancer have rights guaranteed by Brazilian law. Such rights must guarantee the quality of life and dignity of all. However, few people with oncological diseases are aware of their rights^(11,14). Moreover, many health professionals, faced with the reality of the trajectory of treatment of people with cancer, even knowing that the patients have the right to know their diagnosis, end up not informing.

There comes a time when we have a family that, for example, do not want the patient to know. On a legal level, this, the patient, he has the right, legal obligation, for us to inform the patient. But you have to consider the patient's condition, from patient to patient... (D1).

D1 describes the experience of an ethical dilemma before a situation in which the family does not want the person to know that they have cancer, as a form of protection. However, professionals know that, according to the Charter of the Rights of Users of Health Services, art. 3, item II, the person must receive "[...] information about his/her health status, in a clear, objective, respectful and understandable way regarding: a) possible diagnoses; b) confirmed diagnoses;"^(15:7-8).

In relation to this theme, the Code of Ethics of Nursing Professionals (CEPE), in art. 42, chapter II – of duties, urges nursing professionals to:

Respect the right to exercise the autonomy of the person or his/her legal representative in decision-making, free and enlightened, about his/her health, safety, treatment, comfort, well-being, performing necessary actions, according to ethical and legal principles^(16,6).

When it comes to communicating a bad prognosis, there is no way to serve everyone. Each case should be evaluated, not least because providing information to those who do not want or are not prepared can generate weakening⁽¹⁷⁾. In some cases, not wanting to reveal the diagnosis of cancer concerns the need for the professional to evaluate each person in a unique and individualized way, and consider the conditions to know the moment and how to reveal the diagnosis, care and treatments.

The ethical dilemma also emerges when family members request that the diagnosis not be revealed. N7, for example, is aware that the person with cancer has the right to know about his diagnosis, but the impossibility of making this communication constitutes an ethical dilemma with which he/she needs to deal.

We should not talk to the patient, that the patient does not know that he has cancer, and we should not tell. Then, there comes an ethical dilemma [...] the family does not want us to tell, but the patient, he has the right to know. (N7).

The health team often faces the ethical dilemma of revealing or not the diagnosis to the person with cancer disease, because they do not know if this will be the best attitude. Moreover, this dilemma is mainly motivated by the desire of family members to prevent the deterioration of the quality of life of the person who is not a sick person, in his/her physical, emotional, social and environmental aspects⁽¹⁸⁾.

The resuscitation of cancer patients in advanced state of the disease can also constitute an ethical dilemma to be faced by the health team. D1, for example, in another part of his statement, addresses the order not to be resurrected. In his assessment as a doctor, in many situations, because of the advanced state of the disease, the family must request an order not to resuscitate.

There are patients who, in the same picture as his, we would resuscitate and try to do something. There are others... there are others that we would not even try to do

anything about, talk to the family and everything. And often, we think not, but there is legal protection, then this ethical issue comes in. You are going to legally protect yourself, then there are others that the family is aware of, that the family is informed, that the family says they cannot suffer anymore... (D1).

The medical order of not resuscitation is always based on ethical-legal knowledge, defending the autonomy of the person and his/her companions, and on some predefined criteria, in addition to discussion with other health professionals, aiming to provide greater comfort and physical and psychic and affective well-being. An example is that the doctor can choose the order not to resuscitate, when he/she assesses a certain person at the end of his/her life, concerning irreversibility, and the improvement depends on heavy physical sacrifices imposed on the sick person⁽¹⁹⁻²⁰⁾.

This study presents as limitations the difficulty of performing data collection, due to the delay in the release of the health institution, as well as the scarcity of studies related to ethical dilemmas in the oncological context. These difficulties reinforce the importance of further studies on this subject.

The study may contribute to the knowledge about the health team's action in the care directed to people in cancer treatment and their families, besides revealing the importance of decision-making based on ethics and morals.

Conclusion

The results of this study showed that most health professionals had knowledge about ethical dilemmas, defining them clearly and recognizing the experiences in which the dilemma was present. It was also possible to perceive the presence of ambiguity between the concepts of ethical dilemma and ethical conflict.

The ethical dilemmas experienced in the practice of health professionals in the care of the person in cancer treatment were related to palliative care. The professionals wondered about the indication for palliative care, besides questioning how far they could intervene in the care of the person in this condition;

non-resuscitation, associated with the lack of communication between the health team and the person to be cared for, in order to respect it and guarantee its autonomy; unawareness of palliative care, in view of the maximum principle of saving lives; and not revealing the diagnosis of cancer to the sick person, at the request of family members, evidenced by the communication deficiency.

Collaborations:

1 – conception, design, analysis and interpretation of data: Maryana Carneiro de Queiroz Ferreira, Marluce Alves Nunes Oliveira and Thamara Arianny Ventin Amorim Oliveira de Assis;

2 – writing of the article and relevant critical review of the intellectual content: Maryana Carneiro de Queiroz Ferreira, Marluce Alves Nunes Oliveira, Elaine Guedes Fontoura and Manuela Bezerra Pina Oliveira;

3 – final approval of the version to be published: Maryana Carneiro de Queiroz Ferreira, Marluce Alves Nunes Oliveira, Keccya dos Santos Nunes Gonçalves and Joselice Almeida Gois.

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