

# Ethics and palliative care: what do physicians know about it?

Izabela Dias Brugugnolli <sup>1</sup>, Ricardo Alessandro Teixeira Gonsaga <sup>2</sup>, Eduardo Marques da Silva <sup>3</sup>

## Abstract

According to the new Code of Medical Ethics (2010) in Brazil it was established that physicians should employ palliative care when the cure is not possible. The aim of the study was to know the current state of this discussion. To this end, we have conducted a transversal quantitative epidemiological study with physicians from the clinical staff of a complex of Hospitals Schools regarding ethics in Palliative Care. When questioning physicians about their goals in the care of a patient, according to medical ethics, most of them gave us incomplete responses. Only 28.9% answered straight away that they would use palliative care. Most physicians (59.2%) only consider palliative care for pain relief and quality of life, and 38.2% regard age as an important factor for this indication. Therefore, the knowledge of practicing physicians on this topic is precarious and medical education measures are necessary.

**Key words:** Palliative care. Medical ethics.

## Resumo

### Ética e cuidados paliativos: o que os médicos sabem sobre o assunto?

A partir do novo Código de Ética Médica brasileiro ficou estabelecido que o médico deve empregar cuidados paliativos na impossibilidade de cura. O objetivo do estudo foi conhecer o estado atual dessa prática. Para tal, conduzimos um estudo epidemiológico transversal quantitativo com os médicos do corpo clínico de um complexo de hospitais-escola quanto aos preceitos éticos implicados no exercício dos cuidados paliativos. Ao se questionar o médico sobre os seus objetivos no cuidado de um paciente, segundo os preceitos da ética médica, a maioria constrói respostas incompletas, apenas 28,9% responderam diretamente que empregariam os cuidados paliativos. A maioria dos médicos (59,2%) ligam os cuidados paliativos somente ao alívio do sofrimento e qualidade de vida e para 38,2% deles a idade ainda é fator de influência importante na indicação. Logo, o conhecimento dos médicos em atividade sobre o tema é precário e medidas de educação médica se fazem necessárias.

**Palavras-chave:** Cuidados paliativos. Ética médica.

## Resumen

### Ética y cuidados paliativos: ¿qué saben los médicos al respecto?

A partir del nuevo Código de Ética Médica en Brasil (2010) se establece que el médico debe emplear cuidados paliativos en la imposibilidad de cura. El objetivo del estudio fue conocer el estado actual de esa práctica. Por esta razón, llevamos a cabo un estudio epidemiológico transversal, cuantitativo, con los médicos de un complejo de hospitales-escuelas en cuanto a preceptos éticos relacionados con el ejercicio de los cuidados paliativos. Al cuestionarse al médico acerca de sus objetivos en el cuidado de un paciente, de acuerdo a los preceptos de la ética médica, la mayoría construye respuestas incompletas, sólo el 28,9% respondieron directamente que emplearían los cuidados paliativos. La mayoría de los médicos (59,2%) se refieren los cuidados paliativos solamente al alivio del sufrimiento y la calidad de vida y, para 38,2% de ellos, el factor edad es todavía una importante influencia en la indicación. Luego, el conocimiento de los médicos sobre el tema es precario y las medidas de la educación médica se hacen necesarias.

**Palabras-clave:** Cuidados paliativos. Ética médica.

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1. Graduate izabrug@hotmai.com 2. Master novo02@uol.com.br 3. Expert dumarques@gmail.com – Integrated College Padre Albino, Catanduva/SP, Brazil.

## Correspondence

Izabela Dias Brugugnolli – Praça Nove de Julho, 131 apt 150, Centro ZIP 15800-225. Catanduva/SP, Brazil.

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From the new Brazilian Code of Medical Ethics (CME), in force since April 2010, it was established, in a regimental way, that the doctor, if not providing the cure for a disease, shall employ all available palliative care provided by medical science, as well as to dispose of all his knowledge and experience to care for the patient<sup>1</sup>. Death is invariably a component part of the health professionals' everyday.

With the significant advancement of technologies in medicine, today life can be prolonged artificially<sup>2</sup>. Specialties increasingly specialized allow a complete focus on the disease and not on the individual as a whole. Treating an individual whose death cannot be avoided was not part of medical education and is often seen as a failure by the health professional himself and others<sup>3</sup>.

Against this process, palliative care arise as an area of healthcare whose principles is the idea that death is a natural human process, as well as the consequent adequate healthcare practice in the context of orthothanasia, which implies in neither committing euthanasia nor inducing dysthanasia to patients at the end of their lives<sup>4</sup>. A study including 901 physicians showed a reduction of symptoms with a palliative care approach in 78.1% of cases<sup>5</sup>, besides evidences in favor of cost<sup>6</sup> and gain in survival<sup>7</sup>.

Palliative care is something fairly recent in Brazil. In order to know the current status of this practice we have conducted a study with physicians from the medical staff of a teaching hospitals complex concerning the ethical principles involved in proving palliative care.

## Materials and methods

This is a cross-sectional, quantitative and epidemiological study, including qualified and registered physicians at the Regional Medical Council of the State of São Paulo (Cremesp). The study has covered preceptors, residents and autonomous of the medical staff of the Teaching Schools Complexes "Padre Albino" and "Emilio Carlos", who were linked to the Integrated College Padre Albino – medical school of the city of Catanduva-SP, the most important city of a micro region with nineteen cities and about 200 thousand inhabitants, located in the northwest of the state of São Paulo. Until the completion of this study, at the end of the third quarter of 2011, the college did not provided specific lectures or practicals in palliative care. This subject, created in early

2012 aiming to correct this deficiency, consisted of ten hours of lectures to students at the fourth year of course and twenty four hours of nursing practicals for students at the sixth year of course.

The assessment instrument was an interview based on a semi-structured questionnaire consisting of two parts: the first with sociodemographic questions and the second with essay questions. It was only possible to see one question on each page, without the possibility of going back and changing the answers. It was an inclusion criterion in the study to be a member of the medical staff of teaching hospitals by signing the term of informed consent (TIC).

Socio-demographic questions were included, such as: name, age, medical specialty, gender, year of graduation and area of expertise (clinical medicine, clinical surgery, orthopedics, pediatrics, obstetrics and gynecology). The qualitative questions involved issues about medical ethics related to the end of life and palliative care (Appendix). The responses of physicians were analyzed based on the proposal of the Collective Subject Discourse (CSD), technique of dual representation<sup>8</sup>. The CSD is an explicit proposal for reconstitution of a being or a collective empirical entity, which opines as the subject of a speech made in the first person singular. By having as foundation the theory of social representation and its sociological aspects, it promotes a technique for computation of qualitative data through procedures that aim to add testimonials in order to express the idea.

This technique enables the analysis of verbal material collected in the interviews and extract from them each of the central ideas or anchors and their corresponding key expressions. Thus, the central ideas emerge with anchors and key expressions similar in one or more synthetic discourses, which are the CSD – which improves dimension of research, without losing the qualitative character.

## Results

Based on a list provided by the teaching hospitals' clinical directors, 103 blank questionnaires were sent, of which 76 (73.8%) were returned to the researchers as completed questionnaires, as well as completed TICs.

The median age of study participants was 33 years old, with a minimum of 25 and maximum of

68 years old. The median year of graduation was 2002; 1968 was the minimum and 2002 the maximum. Grouping by the time of graduation, 34.5% of respondents graduated less than five years ago, 19.7% between five to ten years ago, 36.8% 10-20 years ago, and 9.2% graduated over 35 years ago. Regarding gender, the majority are men (65.8%). About the area of expertise, 30.3% are clinicians, 25% surgeons, 14.5%, gynecologists and obstetricians, 5.3% orthopedists, 9.2% pediatricians and 15.8% comprise other specialties.

The response to each question was rated to create a scaling related to a certain score level. We have divided the score based on keywords from the definition of patient healthcare, according to the Brazilian Code of Medical Ethics (CME), which were: to provide maintenance or quality of life, to inform the patient about the disease and treatment options and to respect the patient's decision<sup>9</sup>. The score was obtained according to the number of words and/or ideas mentioned in the response. When the doctor was questioned about his objectives when providing healthcare for a patient, according to the precepts of medical ethics, most of them presented incomplete responses (Table 1).

**Table 1.** Medical knowledge about what is it to provide healthcare to a patient through the medical ethics

Score*	Percentage
Inadequate	
No point	5,3%
Incomplete response	
One point	64,5%
Two points	28,9%
Completely correct	
Three points	1,3%

\*Rating as defined by the Brazilian Code of Medical Ethics (CME).

Similarly, we have divided the score based on keywords from the definition of palliative care, according to the World Health Organization (WHO)<sup>10</sup>. The score was obtained according to the number of words and/or ideas mentioned in the response. By asking the doctor about his ethical conduct faced with the patient without any possibility of cure we have received responses which, in 30.3% of the times, were related to refocusing the goals for the patient's care, concerning about his symptoms and/or pain; 28.9% answered directly the words palliative care (Table 2).

**Table 2.** Medical knowledge about what it is to propose to the patient without any possibility of cure

Response*	Percentage
Palliative care	28,9%
Quality of life	25,0%
Taking care of the symptoms and/or pain	30,3%
Inadequate response	13,2%
Not answered	2,6%

\* Rating as defined by the World Health Organization (WHO).

When addressing issues of finiteness of life, 78.9% of doctors think that the patient would like to die at home; 15.8% did not answer and only 5.3% thought that patients would like to die in the hospital. The majority (98.6%) stated that patients wish to die with family close by, the rest (1.4%) added friends to the response. When the doctor is directly asked about his/her desire, responses are not different ( $p = 29.5$ ), since 75% of them would like to die at home. However, 19.7% were unable to respond and 5.3% said they would like to die in the hospital. The majority (97.3%) would like the family around and 2.7% said they would like to be alone at this time.

Regarding the fact that today, in Brazil, many people die in an intensive care unit (ICU) or inside infirmaries, doctors participating in the study think that in 42.1% of times this situation stems from the operation of the Brazilian health system; 10.5% think that the medical staff attitude is wrong; and 27.6% think that the patient and his family do not clearly express their will. Only 7.9% of respondents states that the error lies in the three sides (health system, medical staff and patient); 5.3% think they are both wrong, either the health care system and the medical staff; 3.9% blame the health system and the patient; and 1.3%, the medical staff and the patient's attitude. Only 1.3% did not answer.

Even so, 85.5% believe to be of great importance in Brazil to address systematically the patient and his family as to the priority location for death, the order not to perform cardiopulmonary resuscitation and the authorization to perform invasive procedures. However, 9.2% do not consider this to be valid, and 5.3% were unable to respond. In a direct approach to self-knowledge in palliative care, 47.4% admitted having good and sufficient knowledge under the theme; 44.7% regular and 7.9%, insufficient. However, only 2.6% were able to correctly answer the question: what do you mean by palliative care? (Table 3). Most respondents

linked the palliative care concept only to the relief of physical suffering (pain) and quality of life (59.2%).

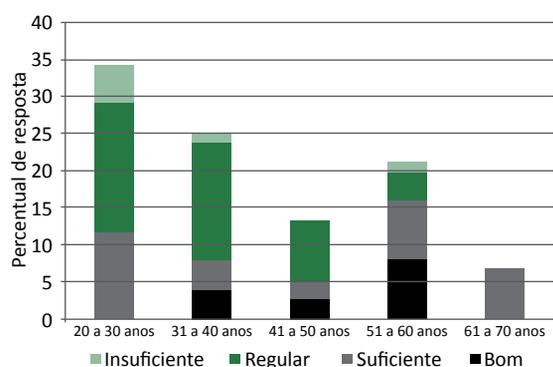
When analyzing the age of the respondents in relation to their own judgment as to self-knowledge

in palliative care, younger doctors admit to not having enough knowledge about the subject. The most experienced ones, in turn, think themselves, for the most part, as competent to take care of a patient with an indication for palliative care (Graph 1).

**Table 3.** What do doctors mean by palliative care?

Responses		Percentage
Relief of physical suffering (pain) and quality of life	Incomplete responses	59,2%
Relief of physical symptoms and others (social, psychological, spiritual)		3,9%
Pain relief and quality of life, besides relief of physical symptoms and others (social, psychological, spiritual)		10,5%
Pain relief and quality of life for the patient and his Family		7,9%
Palliative care is the approach that promotes quality of life of patients and their families faced with diseases that threaten the continuity of life through the prevention and relief of suffering <sup>10</sup>	Complete responses	2,6%
Not answered or inadequate responses		15,8%

**Graph 1.** Impression on the self-knowledge in palliative care and age



Teste  $\chi^2$  ( $p=0,003$ )

To actually evaluate the knowledge of the respondents, we have proposed them the citation of some clinical situation in which they would indicate palliative care: 61.8% answered correctly, 73% were situations related to neoplasms, 21% to other diseases and 6% of respondents promoted mixed situations. Then, we formulated neoplastic and non-neoplastic clinical situations that would all be considered indications of palliative care: a patient aged 40, with inoperable CA, low functional performance (KPS <50 – Karnofsky Performance Status, index used to assess functional performance) and that is not in radio or chemotherapy; 50% of physicians would indicate palliative care in this situation. Second situation: a patient aged 80, totally dependent, bedridden with a chronic kidney disease and malnourished, 73.7%. Third situation: a young man of 35 years old with liver disease Child-Pugh C (index used to assess the degree of chronic liver di-

sease), but not constant on the transplant waiting list, 34.2% of respondents considered the indication.

Next situation: a 51-year-old patient, grade 5 renal dysfunction, unable to perform dialysis and without transplant indication, 77.6%. We observe, therefore, a major resistance to providing palliative care to younger patients. According to 38.2% of respondents, age is an influencing factor in the indication of palliative care. Although these percentages, 53.9% stated they would not be influenced by age and 7.9% had no opinion.

When analyzing other aspects of palliative care, except for pain control and to propose a better quality of life, only 34.2% of respondents answered that if they would watch a patient in palliative care they would propose taking care of non-physical symptoms, i.e., social, spiritual and psychological. Only 6.6% would propose a palliative care approach to the patient’s family. When it is excluded the physical care side from the question, the majority (55.3%) showed to be not attentive to the points of attention related to the social, psychological and spiritual sides. As for end of life decisions, 31.6% answered that they would handle the subject, and only 5.3% would do an extensive analysis on the two topics. We have paid attention to the fact that 18.4% of respondents did not answer or answered incorrectly.

The final moments of the patient’s life were investigated by analyzing the proposition of medical measures: 58.7% of survey participants would propose measures such as catheters, surgeries, medication, if they would bring relief to suffering; 20% would talk

with the patient in order to protect their autonomy or the responsible interlocutor's autonomy; 21.3% did not answer or answered improperly.

## Discussion

This paper presents data on the palliative care knowledge of physicians of a Brazilian clinical medical staff, for the first time. The limitation here is represented by the difficulty of preparing an assessment questionnaire with objective questions, i.e., multiple choices, and also the fact that these questions encompass ethical concepts and palliative care. In addition, there was the possibility of influencing the study participants with "common sense" alternatives and, thus, create a false impression of actual knowledge of the subject.

Another limitation was the individual interpretation of responses based on keywords, which is susceptible of an interpretation bias. We tried to minimize this effect grounding the responses on reliable sources such as the Brazilian CME, making use of objective questions and two different examiners in order to analyze the responses – in case of discrepancy there was the opinion of a third examiner.

Seeking, within the studied universe, for elements which enables to generalize on the results, we compared the profile of doctors in the study with the profile of those who compose the class in the state of São Paulo. Regarding gender, there are 106,536 doctors in activity within the state of São Paulo, of which 59.1% are men<sup>11</sup>, as in the study sample. The age of participants is below the state average, which is 45.1 years old  $\pm$  14.3<sup>11</sup>, a fact explained by the presence of medical residents and young preceptors in our sample, which also ratifies the lowest average years of graduation compared to physicians in the State of São Paulo (19.9 years  $\pm$  13.6)<sup>11</sup>.

The results show that the knowledge about the ethical duties of a Brazilian physician is very precarious. The vast majority of professionals do not include in their answers anything about respecting the autonomy of the patient and informing him of the disease's diagnosis and prognosis, as defined by the Brazilian CME<sup>9</sup>. It is believed that this information correlates with the fact that many families, according to their beliefs and customs, would prefer to hide from the patient his own diagnosis and the decisions regarding the end of his/her life, such as cardiopulmonary resuscitation. According to a re-

cent study<sup>12</sup>, 69% of Americans prefer that doctors do not disclose the actual diagnosis of their terminal illness to their loved ones, and that the family takes responsibility for decisions at the end of life.

Although 28.9% of respondents answered that in the situation of impossibility of cure it shall be offered palliative care for patients, 55.3% of respondents evidenced just some of the goals of palliative care (providing quality of life, taking care of the symptoms and/or suffering). However, most doctors do not use directly in their responses the words "palliative care", showing how doctors are far from the correct concept. Furthermore, it was found that most of the respondents (13.2%) still respond the question completely inappropriately. These data corroborate the need to improve education in palliative care, as pointed out in 1997, The Lancet<sup>13</sup>.

In Brazil, there are no data on the medical knowledge related to that topic. However, some authors<sup>14</sup> estimate that there is still disability on palliative medicine, since it is not a mandatory subject in the curricula of medical schools as established by the Ministry of Education (MEC)<sup>15</sup>. The same authors point out that in the United States of America (USA) medical education on terminally ill patient's healthcare is mandatory in the curriculum of medical schools since 2000, and it was recognized as a medical specialty in 2006. Even so, the result of this incomplete knowledge becomes clear when one observes that half of the patients die with moderate or severe pain, no analgesic prescription, according to a U.S. multicenter study involving ten thousand terminal patients evaluated (Support)<sup>16</sup>.

Surveyed physicians agree that 78.9% of patients would like to die at home and with their families (98.6%). They also have this same desire themselves (75% and 97.3%, respectively). However, we have observed, according to the 2010 records of Datasus that 90.2% of the inhabitants of Catanduva die in hospitals and 7.3% at home<sup>17</sup>. Only 7.9% of respondents have largely understood why this gap between the patient and clinical staff's intention and the reality of the statistics happens, considering that 42.1% of doctors blame only the functioning of the Unified Health System (SUS in Brazil), 27.6% blame only the patient who does not report their wills and anxieties and 10.5% blame only the medical class and the health care team.

Although 47.4% admit a good and sufficient knowledge in the context of palliative care, only 2.6% were able to correctly answer the specific

question. Most of the physicians relate palliative care only to the relief of physical suffering and quality of life, which despite of being a concept correct, is quite broad and subjective, as they still diffuse behaviors that go against the concepts of palliative medicine. The minority cites spiritual, social and family issues. Worryingly, from the bioethical standpoint, is the fact that a significant portion of physicians (13%) have responded completely inappropriately to that question.

It shall be emphasized that younger doctors do not consider themselves experts on the subject, stressing the imperative need to now implement in the curriculum of medical and nursing schools in Brazil the discipline course of palliative care<sup>18</sup>. The responses in this age group show that it is necessary to occupy this space for continuing medical education, which was opened from the new Brazilian CME.

When we proposed the doctor to exemplify a case indicating palliative care, large portion failed to properly propose the case (32%) and from those who made it correctly, the majority cites oncologi-

cal situations. According to a survey conducted from 1992 to 2000 in the U.S., 55% of the indications for palliative care were due to malignant neoplasms, 45% for all other diseases, e.g. cardiovascular diseases (7%), dementia (7%), chronic obstructive lung disease (4%), and cerebrovascular disease (5%)<sup>19</sup>. We have still noticed a difficulty in proposing palliative care when the patient is young, which somehow can generate hospitalizations, surgeries and unnecessary procedures, generating costs for the health system and no benefit to the patient and his family.

### Final Consideration

The knowledge of practicing physicians on the topic is precarious and measures of medical education are needed to overcome this deficiency. The short and medium term alternative would be to implement actions in continuing medical education and, in the long term, the definitive implementation of palliative medicine in the curriculum of medical schools.

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#### Participation of the authors

Izabela Dias Brugugnolli participated in the article's study planning, data collection, statistical analysis and final writing. Ricardo Alessandro Teixeira Gonsaga participated in the planning and guidance of the study and its final writing. Eduardo Marques da Silva, took part in the study planning, statistical analysis and its final writing. All have read and approved this article.



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## Appendix

### DATA COLLECTION

#### Palliative care

Name: \_\_\_\_\_

Age: \_\_\_\_

Specialty: \_\_\_\_\_

Gender: F ( ) M ( )

Year of graduation: \_\_\_\_\_

Major Area of expertise:

Clinical ( )

Surgical Clinics ( )

Orthopedics ( )

Pediatrics ( )

Gynecology and Obstetrics ( )

Another ( ) \_\_\_\_\_

Have you lost some close relative? ( ) No

Father ( )

Mother ( )

Brother or Sister ( )

Children ( )

Place of death? \_\_\_\_\_

Number of chronic diseases that the respondent has:

None ( )

One ( )

Two ( )

Three or more ( )

1. Through the medical ethics, what are your goals when caring for a patient?

2. When it is known that the cure is not possible, which is your ethical conduct regarding the patient?

3. In your opinion, where would most of the patients that you serve like to spend their final moments of life and with whom?

4. And you, where would you like to spend your final moments and with whom?

5. Whereas in the light of current medicine the vast majority of patients will die alone in a hospital or ICU (fact), where do you think that the error is?

In the ethical attitude of the medical staff ( )

In the functioning of the health system ( )

In the patient and family who do not clearly express their will ( )

6. In the U.S. and some European countries there is a policy to address systematically in patients with progressive diseases that can lead to death, issues related to the finiteness of life, such as: who will take decisions in case of unconsciousness? What is the primary place for death? Is there any order to no cardiopulmonary resuscitation?, among others. Do you think that this systematic approach would be beneficial in Brazil?

7. Your current knowledge about palliative care is:

Good ( )

Enough ( )

Regular ( )

Low ( )

8. What do you mean by palliative care?

9. Beyond the control of pain, what else should a doctor watching a patient in palliative care provide to him?

10. Besides the physical sphere of suffering, which other issues do you deem to be ethical to be addressed over the process of death of a patient?

11. Thinking about a patient's final days of life, before proposing measures such as medicines, catheters, surgeries, what possible benefits and risks should be taken into account in decision making?

12. How do you see the influence of patient's age on the indication, or not, of palliative care by the medical community?

13. Is there an example of a clinical situation in which you would propose palliative care to the patient?

14. In which cases below would you propose palliative care?

- a. Patient, 40 years old, inoperable CA, with low functional performance (KPS <50), is not in radio or chemotherapy ( )
- b. Patient, 80 years old, totally dependent, bedridden with IRC and malnourished ( )
- c. Patient, 35 years old, with liver disease Child-Pugh C, but is not on the transplant waiting list ( )
- d. Patient, 62 years old, diabetes, hypertension and liver disease, often hospitalized for decompensation (albumin <2.5) ( )