Bioethics and humanization in the final stage of life: physicians' view

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Abstract Aiming to identify physicians' stand in face of life terminality, a survey carried out through a questionnaire, with closed and open questions, applied to physicians whose activity would involve terminally ill patients. The study was conducted in two hospitals institutions in Bauru/SP, Brazil. The results indicated that 70% of participating physicians informed the true diagnosis to the terminal patient, however, 80% did not clarify their life expectancy. Most physicians (90%) state adopting the emotional support on their patients, and 70% believe that palliative care improves quality of life of these patients, but only half (50%) reported to follow these caring. We conclude that physicians' stand in relation to palliative care is fragmented, involving some difficulties with regard to the end of life, especially with respect to clarification and patients' options, denoting the need to broaden the debate concerning the relationship between bioethics and life terminality.

Keywords: Bioethics. Humanization of assistance. Terminally ill. Palliative care.

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The process of humanization of health seeks to recover respect for life, including the bio-psychosocial, spiritual and educational circumstances[1], considering the respect for individuality and professional differences, and the necessity for building a concrete space in the health institutions that legitimizes the human aspect of all those involved in care. This process, being more than a humanitarian act, requires the implementation of an interdisciplinary and reflective system about the principles and values that govern the practice of different health professionals in search of its ethical dimension [2].

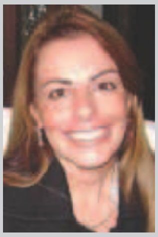
The patient, excluded of expectation for cure, i.e., in terminal stage, appears fragile and with psychosocial, spiritual and physical limitations. In this circumstance, from what legislation, studies and medical research prescribe, there are several palliative responses for him.

It opens, then, a wide range of behaviors that can be offered to patients and their families, aiming now at pain relief and reduction of discomfort, but most importantly the possibility to confront the time at end of life accompanied by someone who can listen and give them support. Acknowledging, wherever possible, their active place, autonomy and choice allows them not to anticipate the time of death by neglect and isolation. One establishes, under this view, a new perspective on multidisciplinary work, called humanization [3].

One understands that, by analyzing the need to adapt the treatment of the terminally ill, this process depends on the ability to speak and listen, that goes through dialogue. Enabling relationships and interactions between people, dialogue conforms not only in verbal communication skill, with predetermined goal, but as another way to discover and understand it, facilitating the establishment of joint goals to provide reciprocal welfare[4].

Thus, communication in the patient-professional relationship demonstrates to be a basic tool in building strategies that aim at humanized care. A care that is premised to preserve the dignity of the patient, realizing him holistically, characterizing the therapeutic encounter from which the caregiver must take into account the weaknesses that affect the patient [5].

Assuming that there are flaws in the implementation of these strategies, we set as objective to identify some physicians' stand at the terminality of life. Thus, the present study, understanding death as an integral part of life, points out aspects of health promotion in relation to humanized care for terminal patients, with families and health professionals involved.



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Method

Initially, the research project was submitted and reviewed by the research committee of each hospital, as well as by the UNESP/Bauru Campus Ethics Committee, following the standards established by Resolution 196/96 of the National Health Council (CNS). The study was conducted in the following hospitals in the city of Bauru, Brazil: Bauru State Hospital and the Portuguese Beneficence Hospital.

Configured as a quantitative and qualitative study, cross-sectional data were collected by questionnaire with open and closed questions on physicians' stand about terminal patients. The inclusion criterion was to be a physician working with terminally ill patients in intensive care sector. Data were collected between September-October 2008. By prior contact, it was found that there were 16 physicians in the mentioned institutions: 10 from the Portuguese Beneficence Hospital and 6 from the State Hospital. From this universe, only 10 completed the questionnaire, the others refused, saying it was too controversial topic, and for not believing in humanization and palliative care.

We performed an explanation about the research objectives, justifications and methods, and applied the term of informed consent (IC) to those who agreed to cooperate, according to the guidelines of Resolution 196/96. The data extracted from the objective questions (closed) were tabulated and analyzed using descriptive statistics, using the program Excel for Windows 2007. The subjective information gathered by open questions were evaluated using *content analysis*, which involves close reading of each of the responses (report by report), bringing out a list of key ideas. The discussion section of the article cites some excerpts from these reports.

Results

Regarding physicians' stand in situations involving humanization of health, it is noted in Table 1 that almost all respondents (90%) embrace the emotional support of their patients, and 70% said they talk about the disease, informing the true diagnosis to those in the final stage. Although the majority (70%) agrees that open discussion about matters of life and death does not hurt patients in this situation and, in fact, they like that honesty, 80% preferred not to clarify the estimated survival time.

With reference to the influence of technology in the humanization process, it was found that 60% of participating physicians believe that advanced technologies to sustain life become a complicating factor in the process of humanization of the assistance to the terminally ill patient. Thus, 50% claim to use devices to extend the life of their patients.

About palliative care, still according to the data in Table 1, all physicians participating in the research (100%) agree that palliative care improve the quality of life for terminal patients. However, only half (50%) of them say they take such care with their patients.

Table 1 - Positioning of doctors before the humanization of health care and palliative care for terminally ill patients

Questions	Answers		
	Yes	No	No answer
Do you adopt emotional support for terminal patients?	9	1	-
Do you talk to terminal patients about the illness?	7	2	1
Do you tell terminal patients how long they will live?	2	8	-
In the case of a terminal illness, do you tell patients about their true diagnosis?	7	2	1
Do you agree that open discussion on matters of life and death does not hurt the patients in this situation and that, in fact, they like this honesty?	7	3	-
Do you use devices to prolong your patients' life?	5	3	1
Do you think that high technology becomes a complicating factor in the humanization of terminally ill patients?	6	3	1
Do you agree that palliative care improves the quality of life of patients?	10	-	-
Do you adopt palliative care with your patients?	5	5	-

Total interviewed: n=10

Still with relevance to palliative care, among consulted physicians 70% reported they observed pain relief in patients receiving such care; 60% noted an improvement in self-esteem and 50% found improvement in depression and acceptance of terminal illness (Figure 1).

In Table 2, related to emotional support, it was found that 70% of participating physicians state they support and establish a relationship of trust with the families of terminal patients. Only half of them (50%) talk openly with family members about the disease.

Figure 1 - Percentage of physicians' responses when asked which improvements they observed with palliative care

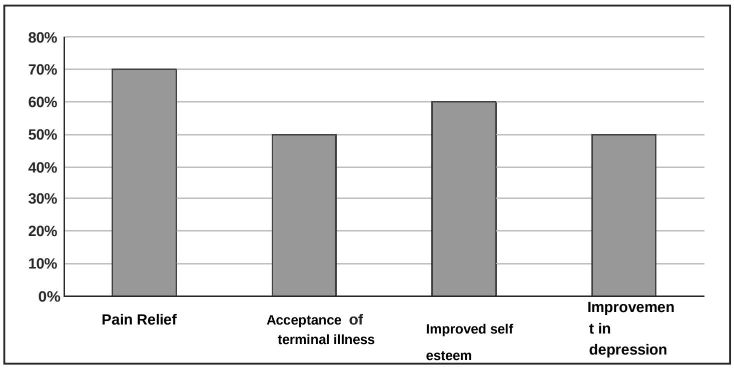

Table 2. Physicians' stand on emotional support for families of terminal patients

Questions	Answers		
	Yes	No	No answer
Do you talk openly with the family about the disease?	5	3	2
Do you establish a trust relationship with the family?	7	-	3
At each visit, do you try to answer family's doubts?	8	1	1
Do you try to give support to family members?	7	3	-

Total interviewed: n=10

Discussion

The humanization of health care requires a process of reflection on bioethical principles and values that guide professional practice. In addition to decent, supportive and welcoming treatment by health professionals to their main object of work - the patient/fragile being humanization requires a new ethical posture that permeates all professional activities and institutional work processes. In this perspective, several professionals, when confronted with the arising ethical dilemmas show to be increasingly looking for answers which ensure the human dimension of work relations, especially those related to autonomy, justice and the need to respect the dignity of the person[6].

These questions and relationship problems on health professionals exacerbate when the patient is excluded of expectation of a cure, or terminally ill. This research, conducted with physicians who deal with terminally ill patients in the intensive care sector, expresses this reality. Although the majority of consulted physicians (90%) state that they seek to provide emotional support to their patients, 20% did not talk to patients about the disease, nor communicate the true diagnosis to terminal stage patients. Although the majority (70%) agrees that open discussion about matters of life and death does not hurt the patients in this situation and that, in reality, they like that frankness, 80% of respondents preferred do not explain the estimated survival time to their patients.

According to Castro[7], for the principle of autonomy to exist in the patient-professional relationship it is necessary that the patient has the independence of will and action, which means control of their ethical capacity. This principle depends on the careful revelation of the truth about the diagnosis, health status, management options, planning and treatment - and about future expectations also. In parallel, to the author, this *revelation* of truth to the patient is directly related to the ability to communicate honestly and compassionately by the involved professionals – including, the very importance to *listen* to what the patient has to say.

Martin [8] states that health professionals appear to be unprepared to conduct with proficiency those suffered moments of life of terminal patients. For the author, medicine uses sophisticated technology and understates the confrontation of the terminally ill, imposing them a long and painful agony. As for scientific advances, Lago, Devictor, Piva, and Bergouniou [9] stressed that the sophisticated medical technologies allow physicians to save the lives of critically ill patients, provided there is some potential for reversibility. However, in patients with no possibility of recovery, the use of remedial measures turns out to be a major complicating factor in palliative care, in addition to being burdensome and without benefits, causing only pain and suffering. Part of interviewed physicians agrees with this assertion. Although 50% claim to use devices to prolong the life of their terminal patients, 60% agreed that advanced technologies for the maintenance of life are a further complicating factor in the process of humanization of care to these patients.

The big challenge is to define which patients will benefit from all the technological support, i.e. to distinguish who has a potentially curable situation and those for which, given the irreversibility of the process, therapeutic measures are useless [8]. The biological knowledge and technological skills have made dying more problematic and difficult to handle, being a source of complicated ethical dilemmas and very difficult choices, generating anxiety, ambivalence and uncertainty [10].

This is clear in a intensivist physician's report who took part in the research: *Brazil lacks specific legislation, judging the cases according to 'common sense' and under the Code of Medical Ethics and Constitution (...) All decisions consider the legal aspect and the issue could be exploited not only in this status but also in future approaches to this same subject*. Agreeing with the statement, Bifulco [11] reflects that there are concerns about legal regulations in the medical class on the subject.

The publication of Resolution 1.805/06 of the Federal Council of Medicine (CFM) [12] attempted to regulate the situation. In view of the integral assistance, allowing the physician to limit or suspend procedures and treatments that prolong patient's life, assuring him the necessary care to alleviate suffering, and respecting their will or that of their legal representative. representative. However, by the injunction of Judge Roberto Luis Luchi Demo, in the records of the Public Civil Suit 2007.34.00.014809-3, at the 14th Federal Court, filed by federal prosecutors, the resolution was suspended. Recently, in December 2010, the same judge issued a ruling that considers unfounded the Public Prosecutor's claim of invalidity of the resolution, ending a dispute that lasted more than three years [13].

This decision conforms to the new Code of Medical Ethics (CEM, 2010), which reinforces the unethical character of dysthanasia, introducing the concept of palliative care. Item XXII of the Preamble notes that *in irreversible and terminal clinical situations, the doctor will avoid the performance of unnecessary diagnostic and therapeutic procedures and will allow the patients under their care all forms of appropriate palliative care* [14]. This corroborates the concept expressed by the World Health Organization (WHO) that in 2002 defined palliative care as *an approach that improves quality of life of patients and families facing problems associated with life-threatening illnesses through prevention and relief of suffering through early identification, proper evaluation and treatment of pain and other physical, psychosocial and spiritual problems* [15].

Physicians who collaborated on the research are unanimous in agreeing that palliative care improve the quality of life of patients, but only half of them said they adopt the procedure. As shown in Figure 1, not all physicians identified improvements provided by palliative care. This demonstrates not only the lack of training for professionals, but according to Simoni and Santos [16], shows an incipient health care in our country, particularly for the lower classes. For the authors, even for the middle classes, who have private health plans, often palliative care is not provided.

One of the physicians interviewed, who said that he institutes palliative care, talks about exactly this: *"Whenever I am responsible for a terminal patient (advanced heart failure, stroke, cancer), and death is imminent, I institute proper palliative care to relieve pain/dyspnia and other discomfort that he may be suffering. I do not submit my patients to therapies that will not solve their clinical situation and will only prolong his life, but not the quality of his life. This theme is not consolidated in the training of health professionals and this creates much unnecessary suffering in patients and unhelpful spending in the health system"*.

Another important issue concerns the family of terminal patients. According to Soares [17], the care of relatives is a major part in the global care for these patients, because in most cases they will not be awake and then there will be the need to communicate with the family. The relatives have specific needs and present with high incidence of stress, mood and anxiety disorders during follow-up - which often persist after the death of a loved one. Perhaps the most effective remedy, in terms of healing, would be the quality of the relationship maintained between the patient and their caregivers, and between the patient and his family.

However, the results of this study demonstrate that not all doctors give the proper value to emotional support for families of terminally ill patients.

Most respondents (80%) would only answer questions from relatives and 30% reported not to support or to talk openly with family members about the disease.

In this regard, Costa [18] states that the needs of family members and patients hospitalized in intensive care units (ICU) are not met. Communication between physicians and families seem inadequate and many physicians are unprepared to promote optimal care for terminal patients. According to the author, families reveal that the inconsistent communication, received from the teams of caregivers, is one of their biggest concerns.

It is difficult to provide humane care for critical patients and their families, while communication and therapeutic relationship are not prioritized as the essence of such care. One cannot deny that we are also human beings with feelings, capable of love, cry, grieving, and seek understanding of the ongoing process of living, get sick and die [19]. However, the model of health care, taught at undergraduate schools of medicine and other professions in the health field in Brazil, based on prevention, diagnosis, effective treatment and cure of diseases. Faced with an incurable situation, this model is ineffective [20].

Physicians are taught that their mission is to fight death; and once exhausted their resources, they leave the arena defeated and powerless. However, their mission is to care for life and death, just as birth is part of it. Health professionals see his seu patient's death as a failure, a great victory of the enemy, personal defeat, and anguish when faced his own death[11]. In this context, it is necessary that, besides the knowledge acquired, i.e., the technical-scientific, they develop the necessary sensitivity, putting the humanitarian grounds of their personal background and training as essential to the perception and the containment of suffering experienced by patients in their terminal stage [20].

Thus, the supremacy in palliative care is due to the application of techniques to maximize quality of life (even in terminal stage), molded together with the principles of bioethics, which strengthens the doctor-patient relationship and family. We highlight the importance that this triad has a full clarification so that together they can decide on the best approach to the due palliative care, without breaching ethical and bioethical principles.

Final considerations

According to what this research could reveal, there seems to be fragments of palliative care provided to patients outside the expectation of healing, indicating mismatch of care, which shows a significant gap in medical professionals' training. The application of the option of not using resources to unproductively postpone death is shy and fractionated, prevailing still a medical practice in the manner perpetuated for a long time: to prolong indefinitely patients' life, even when there is no possibility of cure that ensures them a worthy quality of life.

The technical and scientific knowledge have great weight in the choice, since the professional was trained to heal the patient at any cost - when he is unable to achieve this result, he feels a failure. This constant search for life ends up excluding the humanized practices, omitting the emotional support to terminally ill patients and their families. It is necessary, in order to change this , to consider - always - the autonomy of the patient and family in the decisions of therapies/care, enforcing the principles of bioethics.

Finally, we must be concerned with caring for the sick person and not just their disease. The dignity of the person/terminal patient must become the foundation of our reflection on the palliative care that we provide to our patients.

Resumen

Bioética y humanización en la fase final de la vida: visión de médicos

Con el objetivo de identificar el posicionamiento de los médicos frente al carácter terminal de la vida, se realizó una investigación a través de un cuestionario con preguntas abiertas y cerradas, aplicado a los médicos cuya actividad, involucrase a pacientes terminales. El estudio se realizó en dos hospitales en la ciudad de Bauru, Brasil. Los resultados indicaron que de los médicos participantes, el 70% informan del verdadero diagnóstico al paciente terminal, sin embargo, el 80% no le aclaran cuánto tiempo va a vivir. La mayoría (90%) afirma adoptar el soporte emocional con sus pacientes, y 70% de los médicos creen que los cuidados paliativos mejoran la calidad de vida de estos pacientes, pero sólo la mitad (50%) dicen tener estos cuidados. Concluimos que el posicionamiento de los médicos en relación a los cuidados paliativos es fragmentado, involucrando algunas dificultades con respecto al carácter terminal de la vida, especialmente con respecto a las aclaraciones y a las opciones de los pacientes, lo que demuestra la necesidad de ampliación de los debates referentes a la relación entre la bioética y el carácter terminal de la vida.

Palabras-claves: Bioética. Humanización de la atención. Enfermo terminal. Cuidados paliativos.

Resumo

Bioética e humanização na fase final da vida: visão de médicos

Com o objetivo de identificar o posicionamento dos médicos frente à terminalidade da vida realizou-se uma pesquisa por meio de questionário, com questões abertas e fechadas, aplicada a médicos cuja atividade envolvesse pacientes terminais. O estudo foi realizado em duas instituições hospitalares no município de Bauru/SP. Os resultados indicaram que 70% dos médicos participantes informam o diagnóstico verdadeiro para o paciente terminal, mas 80% não esclarecem quanto tempo viverão. A maioria (90%) afirma adotar o suporte emocional com seus pacientes e 70% acreditam que o cuidado paliativo melhora a qualidade de vida dos mesmos; e apenas 50% relatam seguir esses cuidados. Concluímos que o posicionamento dos médicos com relação aos cuidados paliativos é fragmentado, envolvendo algumas dificuldades no que se refere à terminalidade da vida, principalmente com relação aos esclarecimentos e às opções dos pacientes, denotando a necessidade de ampliação nos debates referentes à relação entre bioética e terminalidade da vida.

Palavras-chave: Bioética. Humanização da assistência. Doente terminal. Cuidados paliativos.

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Authors participation in the study

Fernando Oliveira participated in project design and assembling, guidance during research execution, data evaluation, and article writing. Daniela Flavio and Mariana Marengo participated in project assembling, data collection and article writing. Ricardo Silva participated project design and assembling, and in article writing.