Meanings of termination of life and palliative care for physicians

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Abstract

This paper aimed to know the meaning of termination of life for physicians working at the Samuel Libanio University Hospital (HCSL) regarding oncologic patients. Through a qualitative and exploratory research, as well as methodological guidelines of the collective subject speech, 20 physicians who took care of oncologic patients were interviewed. It was observed that pain relief and life quality are extremely important in palliative care. These professionals understand that termination of life is just the physical death of a person, since there is something beyond the human living – the metaphysics of dying.
Key words: Termination of life. Palliative care. Physicians.

Resumo

Significado, para os médicos, da terminalidade da vida e dos cuidados paliativos

Objetivou-se conhecer o significado da terminalidade da vida de pacientes oncológicos para médicos do Hospital das Clínicas Samuel Libânio (HCSL). Por metodologia tipo qualitativa exploratória e diretriz metodológica do discurso do sujeito coletivo, entrevistaram-se 20 médicos que cuidaram ou cuidam de pacientes oncológicos. Notou-se que o alívio da dor e a qualidade de vida são de suma importância para os cuidados paliativos. A terminalidade da vida é compreendida por esses profissionais apenas como a morte física do individuo e que existe algo além do viver humano - a metafísica do morrer.
Palavras-chave: Terminalidade da vida. Cuidados paliativos. Médicos.

Resumen

Significado para los médicos del carácter terminal de la vida y de los cuidados paliativos

El objetivo fue conocer el significado del carácter terminal de la vida de pacientes oncológicos para médicos que trabajan en el Hospital das Clínicas Samuel Libânio (HCSL). Por metodología de tipo cualitativo de exploración y directriz metodológica del discurso del sujeto colectivo, fueron entrevistados 20 médicos que cuidaron o cuidan a pacientes oncológicos. Se señaló que el alivio del dolor y la calidad de vida son de suma importancia en los cuidados paliativos. Y que el carácter terminal de la vida es comprendida por esos profesionales sólo como la muerte física del individuo y que hay algo más allá de la vida humana - la metafísica de la muerte.
Palabras-clave: La vida de los enfermos terminales. Cuidados paliativos. Médicos.

Research article

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Death is a phenomenon that is subject to multiple interpretations, which varies among societies, cultures and historical moments. It can be seen as part of human life or as hideous circumstance that unavoidably and definitely ends this very existence, i.e. death can be noted from physical and metaphysical perspectives; as the end or the restart.

Oliver Holme's maximum says medicine aims at *sometimes curing, very often relieving and always comforting* [1]. As such, death is a constant, to which the reason of existence of medicine can be attributed. It falls upon physicians the duty to work with an event that defines knowledge and that becomes inherent to the profession. Medical teaching is still centered on cure, which not only is perceived as victory over the illness, but also over death [2]. As time goes by, death has come to be seen as malpractice and not as part of life [3].

The word death is often associated to feeling pain. As to physicians, who are graduated to save and cure, there is also an association to the feeling of failure or error [4]. Laymen see it as resulting of one of the most fearful disease: cancer [5]. The power of such association is reinforced by its highlights on mortality rates of the national sanitary scenario [6]. As a consequence, the word cancer has in itself the meaning of death [7].

Dealing only with the disease and vividly searching for the cure are two potentially problematic factors in Oncology. In the specialty, the word *cure* is replaced by expressions like *quality of life, no evidence of the disease, non-active disease* etc. In face of such precaution, which changes the ontological conception of medicine, an important question is prompted: what drives somebody who was trained to cure to go into an area where the cure is ranked if not as impossible, at least as unlikely? There could have been formulated some answers, such as the will to care for the patient or, still, to improve the patient's quality of life [3].

Researches have indicated more profound reasons for choosing medicine, which comprise: *denial of dependence, search for omnipotence, defense against disease, suffering and death. These unconscious reasons drive physicians, without their knowledge, to seek what they fear most* [8]. Many professionals cannot understand despite experiencing the phenomenon for various times throughout their practice that the death of a patient is mostly not a direct result of a physicians fault; but the natural progress of the disease [2].

In social settings, including medical class, people refuse treating the phenomenon of death as natural. Seeing it as strange, forgetting it and not giving it a name and just accept it as inevitable are some of the few strategies used to *avoid* death. Medicine is dedicated to a fist fight against death. When the latter is defeated, medical omnipotence is reproduced and confirms its essential objective. Thus, professional, patients and the society in general attribute to physicians nearly divine power, hierarchically below God only [9].

The prevention and refusal of death in our century are undeniable phenomenon. The technological advances of this day and age have been posing difficulty upon detection of the exact time it happens, turning the decease into a too painfully and lonely long a process [9, 10]. Many times, the fact that everybody is entitled to the option of death with dignity or good death is forgotten [11-13].

The single paragraph of Article 41 of the new Code of Medical Ethics (CEM) indicates such right: *in cases of incurable and terminal disease, the physician shall provide all palliative care without employing useless or obstinate diagnostic or therapeutic action, taking always into account the express wish of the patient or, in the disability of whom, their legal proxy* [14]. According to this perspective, the goals of a treatment for an incurable or terminal disease change from bandages to palliative [15, 16].

Poles et al value the respect for the patient, indicating there is a growing concern for the maintenance of dignity at the end of life, a premise based on the moral principle preached by human rights [11, 12]*. There is, then, the possibility to humanize dying again, bearing in mind that treatments should target the quality of this life that ends and one's well-being, even when cure is not feasible* [17, 18].

A study carried out by Moritz showed that physicians and professors have more often than not experienced death of terminal patients. However, most of them report not to have discussed the subject with the patients, adding they would have great difficulty dealing with the subject with somebody who carries a terminal disease [19]. Klafke suggests this difficulty is a result of the lack of prepare by such professionals, besides the behavior presented by patients during the progression of a terminal disease [20].

Death is an integrating part of life and it is fit to medicine dealing with these extremes – life and

death. Therefore, a rescue of values of medicine should be implemented, founded on the patient-physician relationship, as well as a broad discussion involving society as a whole on the concept of death and the care that medicine has to offer terminal patients. The discussion of such values must commence still in Medical School and should concern all occupations that assist the craft of medicine [2].

Laymen understand death as associated to cancer, whose multiple typologies render it as one of the most predominant diseases in the current epidemiological scenario [5]. For experts of the field, cancer is considered a metaphorical illness, once it conveys various meanings such as disorder, catastrophe, punishment, being, in last analysis, related to fatality [21, 22]. The word itself is surrounded by baneful feelings that potentialize its meaning – which can be sensed at the strength in which it is pronounced [6].

Nevertheless, with the continuity of life and work, professionals of medicine, as well as other areas and expertise of health, gradually lose fear of ghosts, even willing to have laymen to follow and help [23]: *I fear ghosts no more, I summon them all, I want them all to come at once, to fill my day, to haunt my nights, among the many insane and free, there is one, who is sweet – who I miss* [24]. These professionals should then reflect and propose the deepening of debates around meanings of death and dying in our society.

In light of this, this paper aims to know the meaning of termination of life for physicians who work at the Samuel Libanio University Hospital concerning patients of oncology. The goal is, thus, for the results of this study to assist the professionals of the institution to deal with death, as well as stimulating the implementation of teaching practices, since Medical School, towards preparing them for this situation.

Method

Bearing in mind this paper's nature, an exploratory and intentional qualitative research approach was chosen. Then, we performed the semi-structured individual interview, after signing the free and clarified consent term (TCLE), as per Resolution 196/96 of the Brazilian National Health Council.

Data collection was performed in the course of 2011, having as subjects physicians who have/had taken care of patients of oncology in the various clinic and surgical departments of the Samuel Libanio University Hospital (HCSL), sampling 20 physicians (including oncologists, proctologists, hematologists, gynecologists, gastroenterologists, urologists, pneumologists). Admission criteria were: being a physician of HCSL with at least one year of experience in treating patients of oncology and; having already treated and have constant contact with patients of oncology who are heading towards termination of life. Exclusion criteria were: being a physician at the HCSL, but having neither treated nor had constant contact with patients of oncology who are heading towards life termination.

Interviews were recorded and transcribed. For analysis and presentation of results the collective subject discourse (DSC) was used, written in first person, from which key-expressions (ECH) were taken. From this, the main idea (IC) was found [25]. Similar ICs were grouped, thus establishing the frequency of the following ideas, by means of tables.

Result

Results obtained by semi-structured research were collected from analyzed, grouped reports of the study subject-doctors as to the answers provided for the following questions: "*For you, what is the meaning of termination of life?*" and "*For you, what is the meaning of palliative care for patients of oncology?*". These questions resulted in the main ideas of tables 1 and 2, which respectively refer to each of these questions. The tables show categories that express what physicians considered to be the essence and meaning of termination of life and palliative care for oncologic patients.

Table 1. Meaning of termination of life

Main ideas	Subject	Frequency
Physical/brain death	1,4,7,9,11,16,17,19	8
Bad prognosis	2,3,8	3
Family awareness	2,3	2
The soul remains	4,7,17,19	4
Indifferent	5,12	2
Shock	10	1
Task completed	6,15,18	3
Reincarnation	13,14,20	3
Total		**26**

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Table 2. Meaning of palliative care for patients of oncology

Main ideas	Subject	Frequency
Quality of life	1,4,5,6,8,10,11,15,16,18,19	11
Comfort	1,9,12,13,17,18	6
Pain/suffering relief	1,2,3,4,6,7,11,12,14,16,20	11
Family presence/ support	3,12,14,20	4
Orthotanasia	6,9,12,13,15	5
Dignity	20	1
Total		**37**

According to Table 1, *meaning of termination of life*, the category "physical/brain death" was the most frequent, showing that the understanding of most doctors falls into the biology branch that establishes termination of life to be the ceasing of biological activities essential for maintaining life in an organism. For most interviewees, death represents ceasing of brain activity; physical death, exactly when the brain fails from functioning. As it can be observed from answers four and eight from Table 1, some professionals do not see physical/brain death as always and necessarily irreversible, whereas others believe in the resurrection of the spirit or the body – as it can be inferred for the second highest frequency, which is "the soul remains".

Following the sequence order, with a minute difference if compared with the second category, there is the key word "reincarnation", described as the capacity of the soul to bond to various bodies successively in for the consecution of a specific reason, as self-improvement or purification of karma. It can be observed that a meaningful part of the interviewees (35%) state having a religious belief and that it helps them morally in their decision making.

Regarding Table 2, the categories "quality of life" and "pain/suffering relief" were the ones with higher frequency, having equal numbers. In accordance to the teaching of medicine since ancient times, when there used to be said: *If you can cure, cure; if you can't cure, alleviate; if you can't alleviate, console"* [26]. This way, physicians consider pain/suffering relief of foremost importance for palliative care of all patients, not only the ones of oncology.

And yet that quality of life is not just a trend, quite the contrary, it is one of the objectives to be achieved by human kind. It can be defined as inner feeling of comfort, well-being or happiness in the execution of its functions, in the reality of family contact, of its work and of community values to which it belongs, it demonstrates how important it is, from a medical point of view, the presence of quality in patients, due to the fact that it includes intellectual, psychic, physical and social aspects. Therefore, coherence was observed in this study, because the second most cited category, key word "comfort", is nothing but general well-being of the patient in their final moments of misfortune in this life.

Finally, physicians still reassert the recent discussion on orthotanasia in detriment of euthanasia: always placing quality of life at prime, in lieu of increased life span, in limited or disabled condition. In the event of natural death, providing dignity to patient in death, without extending life with suffering.

Discussion

Termination of life is an incontestable fact and human beings differ from other beings for their awareness about the finitude of existence [5, 27, 28]. According to Carvalho *et al.* [29], in practical terms, identifying a terminal patient is complex and does not involve only logical thinking, as opposing to brain death, for which there are protocols able to define the diagnosis of a halt in brain activity. By analyzing the speeches of the interviewees, we can infer they are aware of such definition. For most of them, the meaning of termination of life is brain death.

The trend of palliative care has brought a new possibility to humanize death. Death is seen again as part of life and in illness treatments should aim at quality of this life, even when cure is impossible [5, 17, 18]. For Silva and Hortale, palliative care comprises attitudes and procedures of assistance in the end of life, composed by active and integral care offered to a patient in advanced and terminal illness – and to their family –, granting the right to die with dignity [13, 30]. In the field of oncology, the omnipotence is something easy to experience, mainly by the fact that physicians have before them a being on his limit of fragility.

As paradoxical as it may seem, the more reinforced is the belief in the social imagination of cancer as an incurable disease, the more divinized is the one who cannot cure [3], that is, although a disease is not curable, a physician who tries to cure the patient is regarded by their wisdom and their possible "gift of cure" of an illness that is incurable to laymen – even if the attempt is frustrating. For Meleiro, a physician is introduced as somebody who nurtures an

ideal of power and at the same time *reveals fragile greatness* [8], which causes them to be permanently using defenses against that which they cannot escape from: their limited human condition [3].

The focus of palliative care is centered on the possibility of providing the patient with the so called *good death* [13]. The concept of such *good death*, in the context of care at the end of life is used when certain characteristics are present, such as: painless death, death with patients' wishes respected (verbalized or registered in advance); death at home, surrounded by relatives and friends; absence of misfortune and suffering for the patient [13, 31, 32].

According to Franzi and Silva [33], the concern with quality of life refer to a trend in human and biological sciences in the sense of valuing parameters broader than symptom control, mortality decrease and increased life span. The very definition of quality of life is self evident, according to the results obtained in this research.

Final remarks

By termination of life there is the origin of complex issues that places us in a conflict about this critical moment of human existence. Would increased life span be correct on the expense of the suffering of a patient? Would orthotanasia be the best way to conduct a terminal patient? Palliative care stands out in our area, in order to answer such questions, having a rough path ahead towards recognition and effectiveness.

The conclusion, therefore, is that pain relief and quality of life are of pivotal significance in palliative care. And that termination of life is but one's physical death; there is something beyond human living – the metaphysics of dying. It is currently to our knowledge that not only is the cure at stake, but also actions that target protection of a patient, from a decisive process which, whenever possible, meet their autonomous decisions.

References

1. Martal GN, Marta SN, Andrea Filho A, Job JRPP. O estudante de Medicina e o médico recém-formado frente à morte e ao morrer. Rev Bras Educ Med. 2009;33(3):405-16.
2. Oliveira LL. As mortes e a morte em oncologia. Sociedade Brasileira de Psico-oncologia. [Internet]. [acesso dez. 2012]. Disponível: http://sbpo.org.br/_img/trabalhos/21/1.pdf
3. Pazin-Filho A. Morte: considerações para a prática médica. Medicina (Ribeirão Preto). 2005;38(1):20-5.
4. Lefèvre F, Lefrève AMC, Teixeira JJVO. Discurso do sujeito coletivo: uma nova abordagem metodológica em pesquisa qualitativa. Caxias do Sul: Educs; 2000.
5. Borges ADVS, Silva EF, Toniollo PB, Mazer SM, Valle ERM, Santos MA. Percepção da morte pelo paciente oncológico ao longo do desenvolvimento. Psicol Estud. 2006;11(2):361-9.
6. Brasil. Ministério da Saúde. Instituto Nacional do Câncer. Coordenação de Controle de Câncer. Estimativas do câncer no Brasil. Rio de Janeiro: Pro-Onco; 2004.
7. Malta JDS, Schall VT, Modena CM. O momento do diagnóstico e as dificuldades encontradas pelos oncologistas pediátricos no tratamento do câncer em Belo Horizonte. Rev Bras Cancerol. 2009;55(1):33-9.
8. Meleiro AMAS. O médico como paciente. São Paulo: Lemos; 1999.
9. Oliveira H, Minayo MCS. A auto-organização da vida como pressuposto para a compreensão da morte infantil. Ciênc Saúde Coletiva. 2001;6(1):139-49.
10. Elias A. Re-significação da dor simbólica da morte: relaxamento mental, imagens mentais e espiritualidade. Psicol Ciênc Prof. 2003;21(3):92-7.
11. Poles K, Bousso RS. Morte digna da criança: análise de conceito. Rev Esc Enferm USP. 2009;43(1):215-22.
12. Mendes AMC, Bousso RS. Not being able to live like before: the family dynamics during the experience of pediatric liver transplantation. Rev Lat Am Enferm. 2009;17(1):74-80.
13. Floriani CA, Schramm FR. Cuidados paliativos: interfaces, conflitos e necessidades. Ciênc Saúde Coletiva. 2008;13(Suppl 2):2123-32.
14. Conselho Federal de Medicina. Código de Ética Médica: resolução CFM nº 1931/2009. Brasília: CFM; 2010. p. 36.
15. Lima RAG. Experiências de pais e outros familiares de crianças e adolescentes com câncer: bases para os cuidados paliativos [tese]. Ribeirão Preto: Universidade de São Paulo; 2003.
16. Ribeiro AR. Psicologia pediátrica em um hospital-escola. In: Kerbauy RR, organizador. Sobre comportamento e cognição: conceitos, pesquisa e aplicação. A ênfase no ensinar, na emoção e no questionamento clínico. Santo André: Arbytes; 2000. p. 139-47.
17. Kovacks MJ. Bioética nas questões da vida e da morte. Psicol USP. 2003;2(14):115-67.
18. Torres WC. A bioética e a psicologia da saúde: reflexões sobre questões de vida e morte. Psicol Reflex Crít. 2003;3(16):475-82.

19. Moritz RD. Os profissionais de saúde diante da morte e do morrer. Bioética. 2005;13(2):51-63.
20. Klafke TE. O médico lidando com a morte: aspectos da relação médico-paciente terminal em cancerologia. In: Cassorla RMS, editor. Da morte: estudos brasileiros. Campinas: Papirus; 1991. p. 25-49.
21. Bielemann VLM. O ser com câncer: uma experiência em família [dissertação]. Florianópolis: Universidade Federal de Santa Catarina; 1997.
22. Fonseca SM. A dialética da representação do tratamento quimioterápico para o doente oncológico: vida versus morte [dissertação]. São Paulo: Universidade de São Paulo; 1999.
23. Kelner G. Começa tudo outra vez... Rio de Janeiro: Ágora; 2003. p. 289-300.
24. Ruiz A. "Que importa o sentido se tudo fibra". In: Siqueira RA [blog da Internet]. [acesso dez. 2012]. Disponível: www.insite.com.br/rodrigo/poet/leminski/aruizp.html
25. Lefèvre F, Lefrève AMC, Teixeira JJVO. Discurso do sujeito coletivo: uma nova abordagem metodológica em pesquisa qualitativa. Caxias do Sul: Educs; 2000.
26. Conselho Regional de Medicina do Estado de São Paulo. Cuidado Paliativo. São Paulo: Cremesp; 2008.
27. Melo LL. "E a luz está se apagando...": vivências de uma criança com câncer em fase terminal. Rev Bras Enferm. 1999; 4(2):566-75.
28. Vendruscolo J. Visão da criança sobre a morte. Medicina (Ribeirão Preto). 2005;38(1): 26-33.
29. Carvalho PRA, Rocha TS, Santo AE, Lago P. Modos de morrer na UTI pediátrica de um hospital terciário. Rev Assoc Méd Brás. (1992). 2001;47(4):325-31.
30. Silva RCF, Hortale VA. Cuidados paliativos oncológicos: elementos para o debate de diretrizes nesta área. Cad Saúde Pública. 2006; 22(10):2055-66.
31. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet. 1998;351(suppl II):21-9.
32. Clark D. Between hope and acceptance: the medicalisation of dying. BMJ. 2002;324:905-7.
33. Franzi SF, Silva PG. Avaliação da qualidade de vida em pacientes submetidos à quimioterapia ambulatorial no Hospital Heliópolis. Rev Bras Cancerol. 2003;49(3):153-58.

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Authors' participation in the paper

Fabiana Fraga and Rafaela Vilas Boas outlined the subject, performed bibliographical research, wrote introduction, methodology and references, as well as selection of students from 1st, 2nd, and 6th years, transcription of interviews, analysis of results, discussion and writing of the paper. Adriana Mendonça was the advisor for this study.