Ethical conflicts in communicating bad news in oncology

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Abstract

Identifying difficulties and ethical conflicts experienced by oncologists in communicating cancer diagnostics, by analyzing ethical problems caused by bad news communication. A qualitative approach was chosen, by conducting semi-structured interviews, which were analyzed based on the hermeneutic-dialectic method. Fifteen oncologists, surgeons and physicians took part of this research. Diagnostic communication of cancer was assessed as a difficult task to be performed due to the lack of investments for the development of communication skills in medical schools; the symbolism of cancer, the presence of unreality related to the knowledge of the diagnosis and the difficulties in dealing with death. The main ethical conflicts cited are related to moral suitability of using truth in the communication to be established with the patient, if this action is a benefit for him and the medical management of the relationship with the patient's relatives. The ethical problems trigged are the predominance of paternalistic relationship and the interference in the autonomy of the patient.

Key words: Neoplasms. Physician patient relationship. Truth disclosure. Ethics. Paternalism. Personal autonomy.

Resumo

Conflitos éticos na comunicação de más notícias em oncologia

Partindo de abordagem qualitativa, com entrevistas semiestruturadas, analisadas pelo método hermenêutico-dialético, busca-se identificar os conflitos éticos vividos por oncologistas na comunicação de diagnósticos de câncer, analisando os problemas desencadeados pelas más notícias. Da pesquisa participaram quinze oncologistas clínicos e cirurgiões, que relataram que a comunicação do diagnóstico de câncer é considerada difícil tarefa devido à ausência de investimentos para o desenvolvimento das habilidades de comunicação na graduação médica; ao simbolismo do câncer; à presença de fantasias relacionadas ao conhecimento do diagnóstico e a dificuldades na abordagem da morte. Os principais conflitos éticos citados estão relacionados à justa adequação moral do emprego da verdade na comunicação, se esta é uma ação beneficente para o paciente, e ao manejo com a família na relação médico-paciente. A conclusão observou que os problemas éticos desencadeados decorrem, predominantemente, em relações paternalistas com interferência na autonomia do paciente.

Palavras-chave: Neoplasias. Relações médico-paciente. Revelação da verdade. Ética. Paternalismo. Autonomia pessoal.

Resumen

Conflictos éticos en la comunicación de malas noticias en oncología

Desde un enfoque cualitativo con entrevistas semiestructuradas, analizadas por el método hermenéutico dialéctico, se busca identificar los conflictos éticos vividos por oncólogos en la comunicación de diagnósticos de cáncer, analizando los problemas éticos provocados por las malas noticias. Participaron de la investigación quince oncólogos clínicos y cirujanos que reportaron que la comunicación del diagnóstico de cáncer como una tarea difícil de realizar debido a la falta de inversiones para el desarrollo de habilidades de comunicación en el pregrado de medicina; al simbolismo del cáncer; a la presencia de fantasías relacionadas con el conocimiento del diagnóstico y ; a las dificultades en el planteamiento de la muerte. Los principales conflictos éticos citados están relacionados con la justa adecuación moral del empleo de la verdad en la comunicación, si dicha acción es beneficiosa al paciente y al manejo con los familiares en relación médico-paciente. Se concluye que los problemas éticos que se desencadenan derivan, predominantemente, en relaciones paternalistas con interferencia en la autonomía del paciente.

Palabras-clave: Neoplasias. La relación médico-paciente. La revelación de la verdad. Ética. Paternalismo. La autonomía personal.

Approval CEP/ENSP 36/10

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The authors declare no conflict of interrest.

Research article

Cancer is considered a public health problem today showing a significant increase in both the developed and the developing countries. Remaining as the most important cause of death worldwide, part of its growth can be attributed to the growing aging population; it would also be associated with behavioral changes of life and consumption, as well as the rapid urbanization [1].

Statistical data indicate the severity of cancer, reaffirming the symbolic and imaginary contents assigned to the illness. It is commonly related to a loss of integrity of its bearer, physical mutilation and, finally, the finitude of life. Therefore, the symbolic universe used to refer to cancer is usually permeated with significant contents that evoke negative slant, with treatment is commonly associated to war or military language, thereby revealing the state of war which marks the period of treatment and the attempt to remission of the disease [2].

It is considered pertinent to assume, therefore, that in oncology difficult news are constantly transmitted, both in the initial and in the terminal stage of the disease, demanding that oncologists develop skills focused on the communication of difficult diagnostics and prognostics [3]. According to Baile et al [4], it is considered bad news any information that affects radically and definitely the future perspective of the recipient.

It is highlighted in this article the difference between informing and communicating diagnosis and prognosis of cancer. It is understood that the act of informing is related to the initial stage of the disease's development, its treatment and prognosis. However, it is considered that all information must be entered into the relational process of communication between the physician, the patient and family, passing through the various stages faced by the patient, from the beginning to the final outcome of the treatment and the disease. Thus, we enlarge the meaning of the term communication linking it to ongoing support to professionals and the idea of sharing among all involved [5-7]. It is understood that communication difficulties can occur in any relational situation, especially in discussions which involves issues of illness and death, and in the specific case of oncology, aggravated not only by the symbolism of the word cancer, but also by the limitations of a personal nature and lack of reflection and preparation of the professional assigned to perform the task [2,8,9].

For a long time, such difficulties have contributed to the concealment of the truth, for the use of lie or even silence in oncology physician-patient relationship, establishing this pattern of behavior as morally correct [10,11]. It is believed that the relational model is still present today; however, changes in society, with the development of new information technologies, and in the biomedical field, with the rapid improvement of medical science and the emergence of bioethics, may be contributing to reformulating paradigms in the field of health, in which are highlighted new moral values and rules associated with autonomy and recovery of the patient in achieving their desires and exercising their rights [3].

Confirming these changes, Beauchamp and Childress [12] call our attention to the fact that, in the context of contemporary medical ethics, the virtues of sincerity and honesty are considered a high value in the character of health professionals. So that patients can actively participate in decision makings regarding their treatment, it is essential to be aware of the disease that affects him, its severity and possible evolution, and the benefits and harms of available treatments.

It is considered that most of the changes arising in the biomedical field, without disregarding the pharmacological advances, are centered on changes in the doctor-patient relationship, especially with regard to the place that holds true in this relationship. The incentive to conceal the truth and the lie, considered mild by the intention of not causing harm to the patient, was present in traditional codes of nineteenth-century medical ethics. A century after this, guidelines are focused on being honesty with the patient, highlighting the patient's right to know about his current clinical status [13]. In the Brazilian Code of Medical Ethics, in force since April 2010, although it is not possible to comply with new guidelines regarding the reporting of diagnoses and prognoses, compared with the code of 1988, we have identified the emphasis on the exercise of patient's autonomy [14].

In this context of major social changes with repercussions in relations between professionals and patients, it is believed that the doctor will be charged the challenge of adopting new behaviors, until then little required by society [3]. Difficulties encountered due to the new place that holds the patient in the doctor-patient relationship and the way doctors were trained to act can trigger ethical conflicts to be faced by the oncologist, especially when it is the moment to reveal information about the cancer and its evolution.

This research focused on identifying difficulties and ethical conflicts faced by oncologists in communicating cancer diagnosis and prognosis, both in the

initial and in the terminal stage of the disease, and also analyze the ethical problems caused due to the quality of communication of bad news and the informed content.

Method

We have opted for a qualitative and exploratory approach, using semi-structured interviews as a research tool. The sample was composed of fifteen oncologists, surgeons and physicians, either sex, resident, specialists, or postgraduate physicians in clinical or surgical oncology, working in the city of Rio de Janeiro during the year of 2010.

The selection of participants was done by indicating professionals in oncology belonging to the respondents and the researcher's circle of trust [15]. Pediatric oncologists were not included in this study due to the specificity of the child audience that did not address the objectives of this study.

Interviews were conducted with senior oncologists graduated in medicine at different times, resulting in the participation of professionals from different generations, and covering 4-47 years of medical education. Among survey participants, ten oncologists act concurrently in the public and private network, nine of them are part of the staff of a major cancer referral center in the city of Rio de Janeiro.

In order to analyze the speeches we have used the hermeneutic-dialectic method, seeking to establish a listening that, in addition to what was said and between the lines of discourse, should reveal contradictions and some content that is not manifested in general, that is a characteristic of this social practice.

Results

This research has revealed several aspects manifested in the scenario of oncology doctor-patient relationships, characterizing the difficulties emerged on in this field, especially when it comes to facing difficult and the impact that medical oncologists suffer through the process of breaking bad news to patients and their families – most notably at the stage of disease progression. Although communication is the central theme of this research, it is worth reporting that, since it is a subject inserted into such a complex scenario, other thematic developments were initiated and emerged during the interviews, demanding the extension of the work of listening, interpretation and analysis of information throughout the preparation of the dissertation.

However, to fulfill the purpose of this article, it shall be exclusively presented the data collected relating to the difficulties and ethical conflicts experienced by oncologists at the time of diagnosis and prognosis disclosure, focusing on issues related to the content of the information supplied, the place of truth in communication and the management of doctors in relation to the patient's family.

Communicating the diagnosis and the ethical conflicts

Among interviewed oncologists, there was a major concern in the development of a good doctor-patient relationship, considered fundamental to the conduct of the treatment. Communication of cancer's diagnosis and prognosis was assessed as a difficult task, and its good conduct was determinant for the quality of the relationship established with patients and their families. Among the main factors attributed by participants to be responsible for the difficulties in communicating bad news, it is included: the lack of investments for the development of relational and communication skills medical schools; social representations and symbolism of cancer; the presence of unreality related to the knowledge of the diagnosis and difficulties in dealing with the finiteness of life.

The main ethical conflicts cited by respondents are related to moral suitability of using truth in the communication to be established with the patient and the medical management of the relationship with patient's family members. The issue is establishing whether the act of revealing the diagnostic truth is a benefit for the patient or not. The fear that having knowledge of the disease shall trigger a worsening of the patient's physical and emotional state, together with the other difficulties mentioned above, contributes to the communication of the diagnosis and, more particularly, prognosis of rapid evolution is not made clearly and objective. Then there is a predominance of the speech that does not encompass the whole truth, full of omissions and half-truths – as it was the default behavior observed in the last century [3,10,11].

However, in the opinion of the participating physicians in this research, it has been characterized as a conflict, as in the face of contemporary changes developed in social and medical fields they no longer feel at ease to act in such a way. According to

the analyzed discourse, the doctor can often appreciate that his/her conduct is wrong, but, in contrast, he/she is not yet adequately prepared and in a position to act differently. In this situation, it is still a common practice of oncologists to transmit some enlightening information, with content that does not contemplate the truth of the disease, its treatment and prognosis. Besides these omissions in the speech, it could also be noticed the presence of misleading content, commonly known as "white lie" [16].

Contributing to intensify this conflict, the oncologist also faces difficulties in dealing with the patient's relatives. In cancer, family is especially present, establishing a protection relationship with the patient in an attempt to spare him/her from all kinds of suffering caused by the treatment and the evolution of the disease itself. It is also possible to see the opposite behavior when the family holds off the patient, leaving him in direct contact with the treating physician.

The type of family dynamics affects the relationship between doctor and patient, either by an absence or excess of participation in the context of the disease, which is a fact that makes the oncologists surveyed to suffer its effects in both cases. This is because the patient's family was mentioned as an important channel of communication with the patient's oncologist, as they are the key relatives, also connoisseurs of the patient's personality, coping style, and wishes. In parallel, the absence of the family requires the physician to have more listening skill in order to identify the appropriateness of the content and the best time to communicate to the patient.

When the family develops a seemingly protective attitude towards the patient, another impasse arises in the relationship: the claim that the truth of the diagnosis or prognosis of the disease is not disclosed. This request of the family to the physician is a characteristic of the last century, when there were few alternative to cure cancer, and it is still present nowadays proving to be a relevant issue for physicians, as shown in the interviews. The request, usually staged by the nearest relative, is the prototype of the maintenance of silence and deceit when behind the patient's back they make negative, mime and postural signals directed to the oncologist in order to establish lies or silence. Nowadays, though relying on different communication technology resources that can make the request reaches the doctor even before the beginning of the medical consultation and without the presence of the patient, the content of the request still remains the same, consisting of major conflict for oncologists participating in the research.

On one hand, the family's request can be adjusted to the oncologist option when he, purposely, also prefers to adopt a misleading conduct, consistent with their own difficulties in coping with the situation. On the other hand, when the doctor wants to establish an open and informative communication with all involved, it appears that the situation is characterized as an ethical conflict, demanding special attention in the management of this relationship.

Despite the difficulties revealed in the interviews, there is little adherence to the use protocols for diagnosis and prognosis communication. Among the doctors who said they knew Spikes protocol, the most widespread protocol for communicating bad news in oncology, there is little acceptance for its applicability, with an obvious concern that a possible systematization of procedures come to settle in this field [4] . In this circumstance, the protocol is understood as a parameter, as it cannot cover the whole relational complexity that the act of communicating bad news involves. The main argument against the protocol was that each communication implies a single meeting, which takes place between doctors, patients and families, generating absolutely unique situations and answers, thus constituting a scenario in which previously standardized conducts do not fit.

Discussion

The difficulties and ethical conflicts revealed in this study are consistent with those described in the literature and reflect a reality still present in our society [7,8,17,18]. Difficulties in the communication of cancer's diagnostic and prognostic has contributed to the spread of "white lies" or "benevolent lies", terms used to sustain deceit in the doctor-patient relationship, despite of its difficult moral justification. Among the major ethical consequences triggered there are the stimulation to paternalistic and protective attitudes towards patients and the consequent interference with the full exercise of patient's autonomy [12.16].

Impasses in this field affect the quality of the doctor-patient relationship and may cause unrealistic expectations in patients and families, also causing suffering to the professional. Furthermore, the physician's personal impediments in approaching and facing death can lead to therapeutic obstinacy

practices, when the doctor insists to perform curative treatments despite of the fact that the disease is terminal, moment in which it would be indicated exclusive palliate care [19].

Faced with those issues, the aspects related to the patient's autonomy and beneficence may be harmed. According to the four principles theory as described by Beauchamp and Childress [12], autonomy and beneficence are part of the four moral principles governing biomedical ethics. The concept of autonomy is directly related to the idea of belonging to the subject, and this should be the driver of behavior. It is also considered important the principle of respect for the patient's autonomy. Principle which is reflected into actions aimed at enabling the patient, providing them conditions for making autonomous decisions. It also implies recognizing the right of the patient to have opinions and make choices based on his/her personal beliefs and values [12].

In monitoring cancer patients, the knowledge of the real state of health is critical so that patients can actively participate in the treatment, sharing with the medical staff the decisions taken at this important time of their lives. In this case, knowledge about the prognosis and possible treatments must be disclosed as soon as possible and discussed so that the patients can make their own decisions and resolve pending matters he/she deems necessary.

Being cancer generally a disease of rapid evolution and progressive physical weakness of the patient, it is considered important to invest in the development of a communication process that is not restricted to the initial moment of diagnosis or prognosis revelation, but accompanies the patient and his family, from the onset of the disease until its outcome, trying to maintain a standard for disclosure and communication which is adequate to the expectations and wishes of the patient. Communication is a skill that can be developed and enhanced in continuing education programs. Therefore, activities in this field should be encouraged in medical schools. It is currently growing the range of possibilities of teaching resources to this purpose, including through dramatization programs, optimizing the teaching practice and the quality of results [20].

Study conducted between 1999 and 2002 in the United States, shows that the information given by the doctor about the proximity of death happens very late, on average, only a month before the concrete fact, and that patients and families, despite the ambivalence of their wishes regarding prognosis information, consider the importance of knowing the truth for the preparation for death [18]. In this context, characterized by a wide range of difficulties and conflicts regarding the form, content and timing of communication, we seek to propose an alternative and complementary analysis to the model of protocol communication.

The use of specific protocols for communicating bad news, as the Spikes protocol shall be used as a basic reference, as reported by respondents, since it does not address all the demands arising during the communication process [21]. Thus, it is important to stimulate the development of studies in the field of bioethics, which, through its theoretical tools, can offer the professional the guiding moral basis for making decision related to communication.

In this regard, special emphasis is given to the importance of knowing the theory of the virtues. There is, today, a growing movement of resumption of interest and applicability of the theory of the virtues to the biomedical field [22]. Part of this interest can be attributed to the emergence of a contemporary ethics that, with the increasing progress of situations that prevail in the field of unpredictability and complexity factors, strives for reflection and probability, thereby justifying the rescue of Aristotelian concepts that may offer consistent theoretical foundation faced with resolving ethical conflicts [23].

Considering that the act of communicating is a medical assignment, which like every task to be performed requires consideration and preparation for their proper execution, we highlight the guidelines of bioethicist Diego Gracia [24-26] who stated the importance of using prudence in medical practice. Prudence becomes important as an intellectual virtue, as Aristotle's theory of the virtues needed in the face of situations in which to reflect on the best means becomes a necessary condition to make better choices [27].

According to Aristotelian thought, the virtues can be defined, as opposed to vices, as the willingness to do good things. They are particularly are divided into two types: intellectual virtue and moral or ethical virtue. The intellectual virtues can be either developed as enhanced by education as well as by time and experience. They are: wisdom, understanding and prudence. Moral or ethical virtues such as generosity and temperance are consequences of habit. Virtue in man is what makes him a good human being allowing them to perform well their duties. The concept of virtue as a willingness that leads to the determination of choices is increased by the idea of averageness, highlighting its opposition in relation to the concept of vices [27].

The average state lies between the two extremes, or between two vices, excess and deficiency, that being the point where we situate virtuous actions and the way to understand the idea of the virtue of prudence as the source of all virtues. Aristotle located prudence as a rational quality, wisdom that may apply to practical life [27]. The word prudence comes from Latin *prudentia*, a contraction of *providentia,* which evokes the idea of foresight, effective knowledge [28].

In western cultures, for a long time, the term was associated with pejorative senses, so that the translation in English of the Aristotelian *phronesis* is practical wisdom, being prudence significantly related to cunning and lack of any kind of commitment [23]. In Portuguese prudence is defined as: *the quality of those who act with moderation, restraint, seeking to avoid anything that is believed to be a source of error or damage, or even as caution and precaution* [29]. Prudence is a virtue that refers to changing situations and is associated with the deliberation capacity.

To connote the term however stands out the importance of specificity and uniqueness of each situation, without neglecting the overall view of the whole, which will focus on the particular action. A wise person is one well able to decide on what is good and useful in a specific situation, whether in general or particular context. To deliberate, in turn, is the act of research and calculation that when directed to a particular situation concerns the correctness or accuracy in thinking. Prudence, minding particular situations, aggregates general and particular knowledge in the deliberation process, in order to achieve the most excellent good in a given situation [26,27].

In the field of medicine, certain physician character traits shall be developed. Among them there are: compassion, benevolence, honesty, courage, intellectual humility and faithfulness [22.27]. This can be considered the difference between doing good in medicine and being a good doctor. To be in compliance with the rules, principles and duties can allow the professional to perform his function well, but it is in the exercise of virtuous practices that he becomes a good doctor.

In this exercise, it is reserved for prudence the integrator role of intellectual and moral aspects in each clinical situation, mediating and ordering these factors. Given the demand for moral choices, prudence works as a virtue guide, providing the opening and directing the way to the applicability of other virtues, in such a way to avoid extreme positions and achieve the averageness of actions [22.27].

According to bioethicists authors [12,22,23], faced with the disclosure of hard news it is essential to have an analytical view of the situation, considering all the aspects related to the patient's clinical situation. Loyalty to the patient is considered fundamental to the achievement of trust in the relationship; however, it shall aim at making prudent decisions, since, as each situation is unique, there is no guarantee of consequences triggered by the position taken. In this case, there is a specific justification that within the uniqueness of each situation there is no correct decisions in fact, but prudent decisions related to the content and quality of information and the time of revelation [23].

Final Considerations

To communicate bad news is a difficult task in the field of oncology, triggering moral conflicts and questions about the relationship that is established between the revelation of truth and the principles of beneficence and patient's autonomy. According to the data collected, the major difficulty faced by respondents relates to the uniqueness of each context and the unpredictability of the consequences related to the decisions taken by the oncologist. It is not only unique situations, permeated with exclusive details in each story, but also situations of different reactions and response capabilities of everyone involved, i.e., physician, patient and family.

The relationship between doctor and patient, seen as essential for the smooth conduct of treatment, is anchored in the style and quality of communication developed, and family participation is an important variable to be considered and appropriately managed by the professional throughout the process. In the context of medical communication, a prudent assessment, consistent with virtue ethics, can harmonize moral values, rules and ethical principles in question. This constitutes an important reference, confirming that, in the matters related to communication, just the knowledge of ethical principles and compliance with the rules does not give the doctor enough ingredients for a moral justification and reasoning for their actions [17,18].

The act of communicating the prognostic of an advanced disease to patients and their relatives is primarily a clinical decision, like many others assumed in daily medical practice, requiring the physician reflection, deliberation and consideration of the facts presented. With no answers *a priori*, it is indispensable to individually interpret the signs and

indications of the patients. This is not necessarily a search for the correct option, but for a prudent decision before the situation presented, covering the context of the patient. This idea is consistent with the goal of ethics in general, and in particular with the virtue ethics, which shall be to avoid those decisions are imprudent, thus targeting the greater good of the patient [24,25].

In order to avoid the extremes that can range from a "white lie" to the "blatant truth", the "prudent truth" is recommended, understanding it as the placement of the truth that is possible and appropriate to the individual needs of each patient. Thereunto, it must be prioritized and invested in continuing education programs for the promotion and improvement of communication and interpersonal skills, which should start in medical education, in association with the conceptual study of bioethics. This seems to be the best way to provide the physician the theoretical basis for their decisions and conducts before the ethical conflicts faced.

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Fátima Geovanini wrote the article e Marlene Braz performed its critical review.

Received: Sep 18, 2013
Revised: Oct 24, 2013
Aproved: Nov 18, 2013