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EXPERIENCES IN CLINICAL ETHICS: A PROJECT FOR MEETINGS ON CLINICAL ETHICS IN PALLIATIVE MEDICINE

*EXPERIENCIAS EN ÉTICA CLÍNICA: EL PROYECTO DE "ENCUENTROS
SOBRE ÉTICA CLÍNICA EN LA MEDICINA PALIATIVA"*

*EXPERIÊNCIAS NA ÉTICA CLÍNICA: O PROJETO DE "ENCONTROS SOBRE
ÉTICA CLÍNICA NA MEDICINA PALIATIVA"*

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ABSTRACT

"Meetings on Clinical Ethics in Palliative Medicine," as outlined in this article, is a project on ethical and clinical training in the area of palliative care. The project is part of a clinical program and broader research pertaining to recovery of the anthropological and ethical roots in the clinical practice of palliative care. It is aimed at professionals and researchers in palliative care and consists of informal meetings where the human and professional values involved in actual clinical cases are analyzed. Anthropology, general ethics, medical epistemology and philosophy of medicine are considered essential in this program of ethical and clinical training, as are the valuable insights provided by the humanities. The specific objective is not only to provide a list of ethical principles, but also to promote an ethical disposition on the part of the person who acts.

KEYWORDS: casuistic; ethical-clinical training; palliative care (Source: DeCS, Bireme).

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RESUMEN

“Encuentros sobre ética clínica en la medicina paliativa” es un proyecto de formación ética y clínica en el ámbito de los cuidados paliativos. Hace parte de un programa clínico y de investigación más amplio que pertenece a la línea de recuperación de las raíces antropológicas y éticas en la práctica clínica de los cuidados paliativos. Está dirigido a profesionales e investigadores en cuidados paliativos, y contempla el desarrollo de reuniones informales, donde se analizan los valores humanos y profesionales involucrados en casos clínicos reales. En este programa de formación ética y clínica, se consideran esenciales la antropología, la ética general, la epistemología médica y la filosofía de la medicina, además es valiosa la información proporcionada por las humanidades. El objetivo específico no es solo proporcionar una lista de principios éticos, sino también promover una disposición ética de parte de la persona que actúa.

PALABRAS CLAVE: casuística; formación ética-clínica; cuidados paliativos (Fuente: DeCS, Bireme).

RESUMO

“Encontros sobre ética clínica na medicina paliativa”, apresentado neste artigo, é um projeto de formação ética e clínica no âmbito dos cuidados paliativos. O projeto faz parte de um programa clínico e de pesquisa mais amplo que pertence à linha de recuperação das raízes antropológicas e éticas na prática clínica dos cuidados paliativos. Está dirigido a profissionais e pesquisadores em cuidados paliativos e leva em consideração o desenvolvimento de reuniões informais, em que se analisam os valores humanos e profissionais envolvidos em casos clínicos reais. Nesse programa de formação ética e clínica, consideram-se essenciais a antropologia, a ética geral, a epistemologia médica e a filosofia da medicina, além da valiosa informação proporcionada pelas humanas. O objetivo específico não é só oferecer uma lista de princípios éticos, mas também promover uma disposição ética de parte da pessoa que atua.

PALAVRAS-CHAVE: casuística; formação ética-clínica; cuidados paliativos (Fonte: DeCS, Bireme).

INTRODUCTION

In recent decades, the profound changes in medicine - not only in scientific techniques but also those of an economic, social and cultural nature - have created new ethical dilemmas that primarily affect decision-making in clinical activity. Numerous training initiatives have developed alongside models for an ethical analysis of clinical cases and decision-making. These initiatives are aimed at providing the tools for moral reflection that are necessary in the context of clinical medicine and to form "human" attitudes in health professionals. While models for an ethical analysis of clinical cases have been established quickly (especially in the form of principlism and casuistry) (1), ethics training for health professionals continues to find different proposals, among which two approaches stand out: 1) analysis and solution of clinical cases with ethical dilemmas, possibly through the application of the principlist method or casuistry; and 2) the formation of human attitudes in professionals by means of through history, art, literature, music, etc. (2). Although today's medical and nursing schools have programs to teach medical ethics or clinical ethics, there is still no uniformity as to when these subjects are taught, the methodology used, the course content, the number of hours of training provided, teacher training, etc. (3). Also, the interdisciplinary approach that seeks to promote teaching does not always achieve a single body of knowledge or true integration of the content being imparted, with the end result being various possible perspectives on the same subject. Finding the right training or the essential elements of ethical training in clinical medicine is still an open question.

In this paper, we present an ethical-clinical training activity that still has the characteristics of a pilot pro-

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ject. However, after a year of work, we want to present the proposed model, together with some thoughts on its implementation and its impact on those who participated in the activity. The program is interdisciplinary in nature, given the way its projects are articulated, as well as the make-up of the research team. The team includes palliative care professionals, along with other researchers who have different profiles in the humanities and social sciences. This aspect favors the development of joint initiatives between researchers and palliative care professionals. One such initiative is the Project for Meetings on Clinical Ethics in Palliative Medicine, which is presented as follows.

JUSTIFICATION FOR THE PROJECT

Palliative medicine is found continuously in clinical situations that pose ethical dilemmas related to the most appropriate action for the patient. Many times, the doubts that exist depend on a lack of clarity at the anthropological and ethical level, because clinical action

is rooted not only in scientific knowledge and technical possibilities, but also in the very “being” of the human person and in his “well-being” (4).

That trait of humanity, which has been decisive since the beginning of medicine and for ever so long, is now in the shadows and only scientific knowledge and technical possibilities seem to have value. An important transformation is occurring within the medical culture itself and is echoed in and strengthened by the overall cultural landscape: in every field of human endeavor, physical science has made conquests and determined changes in cultural paradigm (anthropological, epistemological and ethical). In light of this shift in paradigm and the challenges (cultural, social and ethical) it entails, it has become increasingly urgent to recover explicit, methodologically rigorous thinking on the anthropological and ethical foundations of the medical profession. Moreover, palliative medicine constantly raises issues that require a clarification of anthropological and ethical aspects, either because of its proximity to the end of life, or its inspiring principles that are rooted especially in the humanity of the patient and oriented towards a holistic view of care. As an example of this transformation in medical culture, it is common in clinical practice that informed consent has become a bureaucratic routine, one that does not really involve the patient in the respective decision-making process. However, in its ethical and clinical sense, informed consent is legitimate only if it coincides with a free and responsible decision on the part of the patient. This, in turn, is possible (and necessary) because freedom is an essential element of human nature and human dignity. The problem of genuinely free will (in its deepest anthropological sense) is posed nowadays in the case of living wills and advance directives. Likewise,

both the prohibition of euthanasia and the need for proportionality in medical interventions are explained because there is, at the ethical level, the right / duty to heal (and also the physician’s duty to cure). These rights / duties (and also their limits) arise from the particular forced interpretation of the quality of life, as an element of the human person, and also from the ultimate purpose of medical practice.

Another example is the clinical debate on artificial nutrition and hydration in patients with a severe or advanced illness, which is clarified when we consider that, from an ethical point of view, there is a duty to care for the human being in every /her aspect and also in terms of the person’s basic vital functions. This duty arises because the anthropological interpretation of human beings teaches us that the body invariably represents the dignity of the person (because it is a substantial spiritual-corporeal unit). Also, man’s spiritual nature fits with the manner and timing of patient care within hospital management: time, attention and effort must be dedicated to relational, spiritual and existential aspects. This implies a certain vision of man.

PROJECT OBJECTIVES

“Meetings on Clinical Ethics in Palliative Medicine” is a project designed to familiarize the research team and the clinical palliative care team with concepts and forms of ethical and clinical reasoning. The ethical-clinical reflection being done is intended to provide the anthropological roots and the proper form of ethical reasoning in relation to clinical action in palliative care. In addition to this general objective, the project has two other aims: 1) to develop the capacity to manage the ethical

CORRECTLY IDENTIFYING THE SPIRITUAL NEEDS (TRUTH, FREEDOM, RESPECT, HOPE)
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(FAMILY, PROFESSIONALS, ETC.) IS URGENT IN PALLIATIVE CARE.

dilemmas in a clinical situation (for the palliative care team); and 2) to research investigative clues involving the ethical dimension of palliative care (for the program's researchers). The objective of the activity is not to find the "solution" to the clinical case that has been presented, but to provide professionals with basic notions to help them make decisions in clinical practice.

PROJECT METHODOLOGY

The project develops ethical and clinical reflection through informal conversations based on real clinical cases. The clinical ethics developed in this project considers each decision, and the specific clinical action has its justification in the ethical and anthropological structure of the human being. Consequently, a clinical act is "appropriate" only if it is consistent with this ethical-anthropological foundation. Therefore, in the development of clinical-ethical reflection, what is most important is to see what the elements are and how to proceed with ethical reasoning, and how these elements, in turn, have their roots in anthropological reflection. Accordingly, the key to this method is not in analyzing and finding a solution to the case (although useful ideas can arise in practice), but to achieve reflection centered on the person and his or her being, and to provide conceptual elements to form a prudent judgment in different situations.

Clinical Ethical Reflection

The foundation necessary for practical judgment and clinical-ethical decision-making, as analyzed in the project, is based primarily on four areas:

1. Anthropology (philosophical). Anthropology teaches us the importance of considering the "nature" of the human being (what he is/ who he is) (5). As to "what constitutes a human being," people make us understand their needs and their potential. Therefore, this is the first criterion that clinical action should take into consideration. Anthropological reflection is broad and although every question has its own relevance, recovering some of them now seems more urgent. For example, correctly identifying the spiritual needs (truth, freedom, respect, hope) of the patient and those who are involved in the caregiving relationship (family, professionals, etc.) is urgent in palliative care. It is a priority that those needs be recognized as anthropological structures, as fundamental requirements found in every patient, in every person, even if not expressed: accordingly, these needs are not only those of the religious person, or the educated, or the existentially profound individual. They always have to be met and explored. Another relevant anthropological theme to explain in an ethical-clinical project on palliative

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DEDUCTIVE, APPROACHES TO THE SITUATION,
PROCEDURALIS, ETC.

care is human dignity and its characteristics. There is a broad debate on this issue, but what stands out in palliative care is that advanced disease is a challenge to perceived dignity, either for patients or for the people around them. Therefore, in addition to recognizing ontological dignity, it is necessary to help the patient perceive his or her own existential dignity. Other anthropological issues that predominate are the singularity and uniqueness of each human being, and the human person as an intrinsically relational being (e.g., respect for privacy does not mean isolation, freedom is best understood as relational freedom than as self-referential freedom).

2. Ethics. The most pressing problem in contemporary clinical ethics is how to arrive at a correct moral judgment, since there are different ways to address a problem or ethical dilemma: deductive, approaches to the situation, proceduralis, etc. (6). The problem in terms of proper development of moral judgment has arisen not only as a result of secularism and ethical relativism, but also in Catholic moral theology itself (cfr. The Encyclical "Veritatis Splendor", pp. 47-48

on incorrect interpretations of moral conscience and of inadequate models for the development of moral judgment). Therefore, not only North American proceduralism, but also approaches that have their own ethical theory, if they rely too much on logic (on the method), fail to discover all the potential good a human being can do. Virtues are essential to ensuring comprehensive and consistent realization of good (6). The ethics of the "first person" and virtue ethics are the approaches that place the most value on the person in the action undertaken, not only the right action for the patient. Moreover, among the ethical issues that are relevant to ethical clinical action in palliative care, it is necessary to emphasize that the keyword is not only "dignity" but also "natural law": value without essence does not give us clarity as to our duties (7, 8).

3. Epistemology. The dominant clinical epistemology at present is the biomedical model, which tries to understand disease through the exact sciences. This approach has been understood, for many years, as a methodological necessity for medicine. Today, the epistemological limits of medicine based only on evidence are recognized fully, and it is clear that good clinical results can be lost when only the biomedical / scientific perspective is applied. Recently, the idea emerged that clinical epistemology must use the patient's narration to ensure that all aspects of the disease are included in its diagnosis and therapy. Narrative medicine is a branch that is making an important contribution to the recovery of a biopsychosocial model of medicine and represents a necessary step to get away from ethical rationalism and physicalists' visions of morality (9).

4. Philosophy of medicine. The most important cultural work nowadays is to build a paradigm that better reflects the true identity of medicine (10), including palliative care, which often rests on strong philosophical roots (e.g., the thinking of Cicely Saunders). The identity of medicine is defined by the purpose of clinical activity (to “care” and not just to “cure”) and the intrinsically relational nature of the discipline as a human activity and as a profession (11). It is, therefore, a priority to recover the dimension of “caring” (which has been faded ever since medical ethics began to ignore the good of the patient and the sacredness of human life) and to properly define the characteristics of the therapeutic relationship (the sick person, confidence-promise). It also is important to stress that anthropological and ethical fundamentals are not joined externally to “humanize” the activity of palliative care, but are constituent elements and particularly those that define its very identity.

The context of “Meetings on Clinical Ethics in Palliative Medicine”

Ethical-clinical reflection in the project for “Meetings on Clinical Ethics in Palliative Medicine” is developed through informal conversations based on real clinical situations. These meetings are introduced and moderated by a researcher who is involved in the area that deals with the ethical and anthropological foundation of the program. Each meeting begins with a look at the clinical status of the patients who are being treated by the palliative care team. Then, a clinical case that is ethically relevant for the team is presented and discussed from an ethical-clinical perspective. An important aspect of the presentation of the topic is that the clinical situation

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is not introduced as a medical case, but as a narrative of a human experience encountered by the palliative care professional who is presenting the case. The narrative structure is inherently moral (12). The “material” on which anthropology and ethics reflect is the human experience rather than the facts or technical data.

For example, the issue of honesty in communication with seriously or terminally ill patients has been discussed. After the clinical situation is presented, the ethical and anthropological fundamentals of the professional principle of honesty in communication with the patient are clarified. There is an attempt to highlight the specifics of ethical reflection on the issue at hand and its anthropological roots, so as not to confuse the ethical-clinical argument with other perspectives (legal, psychological, etc.), which also must be taken into account in the specific act, but are different approaches of practical reasoning. The duty of honest communication with the patient exists because human beings have a natural inclination towards the truth that cannot be ignored or betrayed in a therapeutic relationship. It is clear that going from anthropological principle (truth) to concrete action (telling the truth, to what extent, how, etc.) is not automatic. One must take into account the cultural context, the uniqueness of the patient and the support

from the family. Either way, these elements that enter into ethical-clinical reasoning that leads us to concrete action are part of knowledge based on anthropology.

Another example is the “death wish” expressed by the patient, which sometimes can become a request for help in dying. Based on a clinical situation in which a patient has repeatedly expressed a desire to die, the project has led reflection on this human experience, on the category of the “right to die” that has been debated in ethical-medical literature for some time, and on the cultural determinants that lead to its possible recognition. What stands out is the fact that the “desire to die” and the “right to die” are both rooted in the value of the human being: how this value is perceived by the patient, in the first case, and the way society recognizes this value, in the second. It is important to emphasize the effect the caregiving relationship (among other human relationships) can have on a patient’s perception of his or her own dignity. Other ethical-clinical issues have always been studied in light of the anthropological basis.

After each meeting there is an anonymous evaluation of what the activity contributed, which is now part of a qualitative study. Although we do not have the final results, the views expressed by the participants underscore the ability of the meetings on clinical ethics in palliative to stimulate thoughtful reflection; the usefulness of these reflections not only for clinical activity, but also

for “life”; and the informal context of the meetings on clinical ethics as a facilitator of learning.

DISCUSSION

The experience of “Meetings on Clinical Ethics in Palliative Medicine” and the initial results led to several considerations.

Informal conversation has the advantage of using “friendship” between those involved in the conversation to promote

learning from the thoughts that are offered. Friendship, which means sharing the same desire to search for the good, is able to stimulate the emotional dimension of knowledge and is ideal for transmitting and teaching human values. Indeed, personal disposition can, influence, encourage, open or close a knowledge or understanding of reality. Specifically, an attitude of willingness can contribute positively to knowledge by “connaturalizing” the knower with the known reality. Thus, with a positive affective

attitude, knowledge becomes “easy” and one might say “enjoyable”. Knowledge through connaturality; that is, “passionate” knowledge, is the ordinary way in which we know everything that has value for us (13).

One aspect that stands out is the specific contribution of the narrative dimension in presentation of the clinical situation. The narrative, more than the description of the facts, underscores the subject’s perspective and his or her

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understanding of reality. Furthermore, it is the best way for values and intentions to emerge. Hence, a narrative ethical approach offers privileged access to the person's individuality and existential singularity. The narrative approach in "meetings" is aimed precisely at explaining moral action based on the subject's interpretation of the situation in which he or she is involved and is the most adequate way to promote "first person" ethics and virtue ethics (14).

In short, our opinion is that, in formative experiences of this type such as "meetings on clinical ethics in palliative medicine," it is important to start with "simple" clinical cases where human and professional values can be expressed, without the need to address complex ethical dilemmas. This is because the first thing to be developed in palliative care professionals is the person's ethical dispositions. The ability to choose and act in specific clinical cases is a fruit of the virtue of prudence, which cannot be formed unless the other moral dispositions are in order. Therefore, it is first necessary to form an understanding or knowledge of the assets of the profession (life and health, promotion of dignity, support for the patient's existential experience, assessment of the care relationship, etc.) and the ethical dispositions that facilitate this specific knowledge. Only then can we possibly deal with clinical cases that involve complex decision-making (suspension of intervention, artificial nutrition and hydration, etc.) (15).

CONCLUSIONS

The objective of "Meetings on Clinical Ethics in Palliative Medicine" is to stimulate reflection on ethical

issues that affect clinical practice in terms of palliative care and to promote integration between clinical practice and reflection on human goods and human values. Ethical-clinical reflection that is rooted in the anthropological and ethical basis of palliative care is necessary, as palliative care constitutes a human activity: every human being wants to express himself or herself at the highest level (realize the good of the person, promote social life, etc.) and needs an anthropological and ethical foundation (16). But in palliative care, it also is crucial to recover the human dimension as an intrinsic element of medicine. The kind paradigm of medicine we have counts a lot in the individualization of person ethics, either as exact science, based on mathematical models and ethically neutral (which receives purposes and values as a social agreement), or medicine that is seen as natural and human science, and considers both as essential approaches (17).

The objective of training developed through "meetings on clinical ethics in palliative medicine," as with any educational activity, is to allow for an increase in professional freedom or freer professional action. This does not mean an increase in possibilities for making a choice, but a qualitative intensification of the act of choosing (18). Therefore, it is important that the training activity is carried out not only through *training* – exercise of the skill for accomplishing specific objectives, such as *problem-solving* or *decision-making* – but is directed towards education that includes all dimensions of the person, as an agent.

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