Role of Clinical Ethics Support Services in End-of-Life Care and Organ Transplantation

Mario Picozzi, Sara Roggi, and Alessandra Gasparetto*

Center for Clinical Ethics, Department of Biotechnologies and Life Sciences, Insubria University, Varese, Italy

ABSTRACT

At times, clinical expertise may not be sufficient to find a way out of a moral impasse, especially in the context of end-of-life and organ transplantation decisions. Advances in medical knowledge and technology, and highly pluralistic and multicultural societies, have led to the emergence of new ethical problems in daily clinical practice along with the need to manage them in a prompt and effective manner. Clinical ethics developed in the late 1970s and early 1980s in North American health care contexts with the aim of identifying, analyzing, and attempting to resolve ethical conflicts and dilemmas at the patient's bedside. At present, only a few regions in Italy have established clinical ethics committees, and Italy may count on a very small number of clinical ethics services fully devoted to ethics case consultation, guidelines development, and the education of health care providers and citizens. Despite this situation, one has to acknowledge both the increasing request for ethics support coming from health care providers who experience an "ethical vacuum" in the Italian health care system and the cultural change that is affecting Italy nowadays. By highlighting clinical examples and sharing experiences, we show and encourage the potential benefits of establishing clinical ethics services in Italian health care contexts.

ADDRESSING ETHICAL QUANDARIES AND DISAGREEMENT IN CLINICAL PRACTICE

CONSIDER a Jehovah's Witness who, before losing his decisional capacity, states his refusal of a life-saving blood transfusion even at the cost of his own life. Such an intervention would be, no doubt, effective in restoring his health and let him get out of hospital. Again, consider a person who documented her treatment wishes 10 years before getting sick or a patient completing an advance directive with no adequate information about his clinical condition and treatment options. Likewise, consider a patient who appointed a proxy to make end-of-life decisions on her behalf without providing any directions as to her treatment preferences. Another example, maybe even more common, consider how to manage disagreement (among the health care team or between clinicians and the patient's relatives) over treatment withdrawal in end-of-life care when the patient is unable to speak for him- or herself and did not leave anything in writing.

The Jehovah's Witness example shows a contrast between 2 fundamental tenets of bioethics: the patient's refusal of therapy, as an expression of moral autonomy, conflicts with the medical indication for blood transfusion to save the patient's life in honor of the Hippocratic principle of beneficence. The other examples prove how the availability of advance care directives does not release health care professionals from complex and careful interpretation of what was the patient's intent. Here too, a difficult balance between different principles needs to be made, for example, between autonomy and "proportionality" [1]. The last case illustrates how each clinical intervention, instead of being a mere technical act, needs to be carried out against the background of an accurate reflection over the patient's best interest, including even a "hermeneutic work" of the patient's life story [2]. Ethics as a discipline never provides

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*Address correspondence to Alessandra Gasparetto, PhD, Center for Clinical Ethics, Department of Biotechnologies and Life Sciences, Insubria University, Pad. Antonini, Via O. Rossi 9, 21100, Varese, Italy. Tel: (+39) 0332217500. E-mail: alessandra.gasparetto.1@gmail.com

230 Park Avenue, New York, NY 10169

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ready answers since it deals with what is heterogeneous, irreducible, and unpredictable, namely with human life and experience. However, this does not prevent ethical reflection from being exercised, albeit with difficulty, for the purpose of defining and regularly revisiting common criteria to inform decision makers. In all the above clinical circumstances, conflict of values or moral uncertainties make it impossible to refer to the "good" of the patient as an unambiguous notion [3]. At times, clinical expertise may not be sufficient to find a way out of the impasse. On the contrary, the emergence of ethical conflicts and dilemmas in the clinical field urges the adoption of an approach that discusses and compares moral values and positions through ethical arguments.

THE SPREAD OF ETHICS SUPPORT SERVICES IN HEALTH CARE CONTEXTS

Clinical ethics is a branch of bioethics that developed in the late 1970s and early 1980s in North American health care contexts with the aim of identifying, analyzing, and attempting to resolve ethical conflicts and dilemmas at the patient's bedside [4]. Differently from the more general bioethics, clinical ethics is problem and decision-oriented and is aimed at improving patient care [5–7]. Advances in medical knowledge and technology, and highly pluralistic and multicultural societies, have led to the emergence of new ethical problems in daily clinical practice along with the need to manage them in a prompt and effective manner. Moreover, in the last decades, the increase of chronicity has brought into play the need of an ethical perspective in order to give an answer to several questions about end of life and the boundaries of medicine [8]. Therefore, clinical ethics is structured around 3 main activities aimed at managing such issues: clinical ethics consultation, ethics education of health care professionals, and policy development [4].

Ethics consultation is defined as "a set of services provided by an individual or group in response to questions from patients, families, surrogates, health care providers, or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care" [9]. Considered as the most challenging activity of clinical ethics, it aims to improve the quality of patient care and to enhance both health care professionals' familiarity with ethical issues and their competence in handling moral problems [9,10].

Since 1992 in the United States, health care organizations have developed mechanisms to manage ethical questions that emerge from daily patient care through the establishment of clinical ethics committees or more general clinical ethics support services [4]. Historically, clinical ethics committees have been the first concrete means by which the above questions and activities have been handled; indeed, they have been established both to prevent judicial litigation among people experiencing value-laden conflicts and uncertainties in clinical decision making and to give full recognition to the inherent ethical dimension of clinical practice [11,12].

However, over the years, bioethicists have become even more present in hospitals at an international level, since it soon became clear that clinical ethics activities, especially clinical ethics consultation, required full-time professionals specifically employed by hospitals to carry out those functions. As is well known, ethics committees usually meet once a month and cannot significantly impact patient care with continuity. Hence, there has been a developing presence of small groups of ethicists or individual professionals acting directly at the patient's bedside within the frame of clinical ethics services to guarantee a stable and dedicated presence on the wards. Such new professionals may either cooperate with an ethics committee to provide clinical ethics activities, or be independent of it [4,13–17]. Today, in the United States, clinical ethics services are present in health care institutions with more than 400 beds, while they are increasingly being implemented in European countries and in the rest of the world [18,19].

THE NEED FOR ESTABLISHMENT AND FORMAL RECOGNITION OF CLINICAL ETHICS SERVICES IN ITALY—THE CASE OF END-OF-LIFE CARE AND ORGAN TRANSPLANTATION

At present, only a few regions in Italy have established clinical ethics committees (eg, the Veneto region from 2004 and the Friuli Venezia Giulia region from 2016), and Italy may count on a very small number of clinical ethics services fully devoted to the education of health care providers, ethics case consultation, and guidelines development [13,20–22]. Indeed, there are national legal requirements only for the establishment of research ethics committees, which may ensure the ethical legitimacy of research protocols that include human subjects. Despite this current situation, one has to acknowledge both the increasing request for ethics support coming from health care providers who experience an "ethical vacuum" in the Italian health care system and the cultural change that is affecting Italy nowadays. For example, the recent Italian law no. 219/2017 "Rules on informed consent and advance treatment directives," which entered into force January 31, 2018, strongly encourages the provision of information and education of patients and clinicians on the contents of the law (art. 1, para. 9) as well as training of health care professionals in relating to and communicating with the patient (art. 1, para. 10) [23]. However, in the absence of a structured network of clinical ethics services, such ethics-sensitive activities may risk remaining uncovered. It is worth recalling that clinical ethics committees are born precisely to reduce judicial litigation and recourse to courts to solve problems that are first and foremost ethical. Moreover, legal channels often exacerbate relationships, leading professionals, patients, and relatives to experience even worse moral distress. Such a message is clear enough: moral problems should be addressed and handled where they raise, that is, at the patient's bedside and in the intimacy of care relationships. It follows that when ethical dilemmas and conflicts occur, the involvement of ethics support services is strongly recommended. That is true regardless of which model a health care institution has adopted for the provision of ethics support: whether a full committee, a small group of ethicists, or a single ethics consultant [22,24–26]. In short, especially after the entry into force of the new Italian law, ethical reflection needs to be formally embedded in health care assistance in order to appropriately implement legal provisions.

In our experience, developed in the bioethics working group of the North Italy Transplant Program [27], we can refer to 2 clinical cases that particularly express the need to have an ethics consultation. First, imagine a father who wants to donate his kidney to his young son. During the clinical assessment to ensure the eligibility for transplant, clinicians find out that he is not the biological father. Is it ethically acceptable to tell the donor the truth? What kind of information should be made available to the willing donor? Again, think about a patient who receives a liver. If clinicians, immediately after the transplant, find out that the donor was affected by prostate cancer, do they have a truth-telling duty toward the recipient considering that the explantation of the received organ, if requested, would not be recommended?

In addition to ethics consultation on specific clinical cases, a clinical ethics service may assist citizens, patients, and health care providers in developing familiarity with ethical issues in clinical practice through targeted educational activities. Such activities can be as diverse as analyzing the impact of draft advance treatment directives on organ donation and/or describing organ allocation processes.

Lastly, a clinical ethics service may elaborate written nonbinding recommendations that specifically address recurring ethical questions in daily patient care. In particular, in the context of organ transplantation, there are at least 2 emergent topics that urge the need for a formal policy: firstly, patient information and consent to organ transplantation from nonstandard–risk deceased donors; secondly, the inclusion in the waiting list of migrant patients who, for any reason, might not guarantee an adequate follow-up.

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