ARTÍCULO

The necessity of ethical support for health care professionals in Intensive Care: Role and competencies of the Clinical Ethics Committee

La necesidad de apoyo ético para los profesionales de la salud en Medicina Intensiva: papel y competencias del Comité de Ética Asistencial

La necessitat de suport ètic per a professionals de la salut en Medicina Intensiva: paper i competències del Comitè d'Ètica Assistencial

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Abstract

Promoting measures that aim to mitigate discrepancies in the decision-making process, ensuring adequate training of physicians in the ethical aspect of care, and incrementing the wellbeing of patients and their families are becoming the principal objectives for high-quality care, especially in the Intensive Medicine Unit (ICU). In this paper we’re going to deal with the implementation of a specific ethics support for the ICU health care professionals, and considering the advanced Spanish experience on this matter, it deals with the current potentialities and limits of CEC’ role to improve the quality of health care assistance.

Keywords: decision-making process; ethical support; clinic ethics committee; advanced directive; intensive medicine unit.

Resumen

Promover medidas que tengan como objetivo mitigar las discrepancias en el proceso de toma de decisiones, garantizar la capacitación adecuada de los médicos en el aspecto ético de la atención e incrementar el bienestar de los pacientes y sus familias se están convirtiendo en los objetivos principales para una atención de alta calidad, especialmente en Medicina Intensiva. En este artículo abordaremos la implementación de un apoyo ético específico para los profesionales de la salud de la UCI. Teniendo en cuenta la amplia experiencia española en este tema, nos centraremos en el potencial y los límites actuales del rol del CEA para mejorar la calidad de asistencia sanitaria.

Palabras clave: proceso de toma de decisiones; soporte ético; comité de ética asistencial; documento de voluntades anticipadas; Medicina Intensiva.

Resum

Promoure mesures que tinguin com a objectiu mitigar els discrepàncies en el procés de presa de decisions, garantir la capacitació adequada dels metges respecte a l’aspecte ètic de l’atenció i incrementar el benestar dels pacients i els seves families s’estan convertint en els objectius principals per a una atenció de qualitat, especialment a Medicina Intensiva. En aquest article abordarem la implementació d’un soport ètic específic per a professionals de la salut de l’UCI. Tenint en compte l’àmplia experiència espanyola en aquest tema, ens centrarem en el potencial i els límits actuals del rol del CEA per a millorar la qualitat de l’assistència sanitària.

Paraules clau: procés de presa de decisions; suport ètic; comitè d’ètica assistencial; document de voluntats anticipades; medicina intensiva.
1. Introduction

Over time, the Intensive Care Units (ICUs) advanced therapies and sophisticated technology, such as mechanical ventilators, dialysis, implantable mechanical hearts, artificial nutrition and hydration, have been more and more associated to the image of an invasive aggression on the patient’s personal integrity, which has an inevitable repercussion on his or her moral perception of the self, or, using a more bioethical language, on his or her personal dignity. Consequently, the arising of this ethical aspect in daily clinical practice called the biomedical field for “a change of attitude and a commitment to positioning the person as the central axis of health care”, and for a critical re-consideration of that principles which underlie health care professionals’ understanding of their approach to critically ill patients.

Up to date, is widely acknowledged, and approved by international legislations as well, that no patient should receive health care treatment that can so profoundly undermine their personal overarching philosophy, especially when they are unable to communicate their preference of care, as usually the situation in the ICU setting. However, knowing and respecting patients’ preferences and values is not a common practice in the ICU, and considerable ethical conflicts and moral distress in both patients, their relatives, and health care professionals commonly affect the ICU’s clinical practice, with a negative repercussion on the health care assistance provided and, inevitably, on the patient’s quality of life.

In order to reduce the negative impact of ethical conflicts, a clinical ethics support has progressively been strongly required and widely implemented in health care institutions. In this paper we’re going to describe role, nature an goals of an ethical support for the clinical practice, disclosing not only the well known potentialities of this intervention in ICU, but also the persisting current limits and uncertainties, such as the the sindrome de retard en el creixement that is

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3 Please, take into consideration the article number 5 of the Universal Declaration of Human Rights, which explicitly states that "no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment". This understanding of a person’s basic rights has been instrumental for the development of the notion of human dignity in international law, providing also a legal and moral grounding for improved standards of health care assistance.
actually affecting the activity of the Spanish Comités de Ética Asistencial. Taking into consideration this jarring situation, we will finally suggest that, despite the theoretical advocacy for a wider CEC’s implementation, lot of uncertainties and questions still need to be identified, discussed and evaluated, in order to develop CEC as a concrete and measurable objectives for the improvement of health care assistenance.

2. Nature, role and aim of ethical consultation and Clinical Ethics Committees

Defined as a “service provided by an individual consultant, team, or committee to address the ethical issues involved in a specific clinical case”, the central purpose of any ethical intervention is to “improve the process and outcomes of patients’ care by helping to identify, analyze, and resolve ethical problems”. Clinical ethics consultation represents, indeed, the main activity of an ethical intervention, assuring that the process of decision making is “inclusive, educational, respectful of cultural values, and supportive of institutional efforts at quality improvement and appropriate resource use”. An ethics intervention can be performed in different ways and with different methodologies, depending on the amount of person who perform the consultation. The development of ethics consultation in the USA and Europe is paradigmatic of this difference: while in the USA ethics consultation is mainly performed by a single specialized ethics consultant and is mainly focused on the consultation’s outcome (which is, indeed, the resolution of the ethical conflict), among European countries pluralism and multidisciplinary discussion between different actors of the health care path represents the principal features of an efficient ethical consultation, with a deeper interest in the full development of the global deliberative process. For that reason, while in the USA consultation represents the target construct of a clinical ethics support, Europe has developed a "broader interest in clinical ethics supports, which includes both consultation as well as clinical ethics committees”.

This is also in line with the Universal Declaration on Bioethics and Human Rights, which specifically claims for a "multidisciplinary and pluralistic dialogue about bioethical issues between all stakeholders and within society as a whole" through the establishment of an "independent, multidisciplinary and pluralist Ethics Committees (EC)". Following the Declaration, the goals and responsibilities of an EC are to protect the rights, safety and well-being of the patient both in the health care and health care research-related setting, to assess the relevant ethical, legal, scientific and social issues, to provide advices on ethical problems in clinical settings through the formulation of recommendations and guidelines on complex ethical issues and, finally, to foster debate, education and public awareness of, and engagement in, bioethics. However, nature, scope an function of ECs have been deeply modified due to the recent regulation 536/2014 of the European Parliament and the Council of Europe, which specified the crucial role of ECs in the evaluation of trials and biomedical research, but giving them "little time for other issues such as clinical ethics, in particular". Consequently, the regulation created a normative vacuum for cases like urgency and critical care, where the immediacy and imponderability of the events require the necessity to entrust these issues to a specific support, able to help health care professionals in the decision making process, in the most rapid and effective way.

Due to the lack of legal support and guidance for this kind of institutional supports for health care professionals, many european countries have already opted for a spontaneous creation of a specific institutional body, called Clinical Ethics Committee (CECs). Currently considered as a "forum which can help bridge the gap between clinicians and health care management by increasing understanding for each other's perspectives", an increasing collection of studies has already illustratred the CECs' potential benefits in critical situation and its positive impact in the health care assistance for a more "appropriate" transition from "cure" to "comfort" modes of care. Addressing the ethical issues related to ongoing and retrospective patient cases (i.e. ethics consultation), identifying the ethical needs within clinical settings, writing or reviewing policy

14 Pope Tm, "Legal Briefing: Healthcare Ethics Committees," The Journal of Clinical Ethics 22, no. 1 (Spring 2011): 74-93. CECs are now legally mandated in only a few nations, among which Israel, Taiwan, the Spanish state of Andalucia, Norway, Alberta, and Singapore.
and, finally, supporting health care professionals, patients and their relatives to find agreements and make decisions, especially at the end of life, CEC has been widely implemented in the ICU ward, where the lack of advance directive and the loss of decision-making capacity in many ICU patients may contribute to conflicts at the end of life.16

3. Is the Clinical Ethics Committee really suitable for an ICU?

As said, CEC service can be particularly relevant for the management of critical situation, especially for those dealing with end of life-related, promoting the overall satisfaction with care and the reduction in unnecessary or unwanted treatments, diagnostic interventions and related costs. In fact, in the ICU ward, clinicians are usually reluctant to engage in end of life discussion, especially when early phase clinical trials are available. Moreover, as noted in the recent review by Visser and colleagues, physicians’ lack of communication training and skills, their attitudes towards death, their focus on clinical parameters and their lack of confidence in their own judgment of their patient’s true condition deeply hinder an adequate communication and shared decision-making in ICU, incrementing the feeling that the care given to a patient may be inconsistent with health care professionals’ knowledge or beliefs17. Furthermore, advance directives specifying limitations in care are often ignored in the critically ill population, giving rise to “disagreement among the family or health care providers as their applicability and relevance”.18

Advance directives (AD) consists in a written document where an adult and competent person manifests his or her will regarding specific preferences about his or her future care and treatment and/or indicates a trustee who will be responsible to enforce the patients’ will in the case that they are unable to do so themselves19. AD are preposred to ease the decision making process in critical situation, respecting patient’s self determination and health care professionals’ autonomy, and their application is particularly advocated in the ICUs setting. However, the recent study by Dr. Nadja Leder and collaborators on the doctors’ and relatives’ perceptions of AD’s validity in acute situations in that ICU states that: “in an acute situation, the patient’s wishes often

cannot be clearly deduced from the written content of an Advance Directive\textsuperscript{20}, reflecting an increasing trend in the bioethical community for which not everyone agree on the opinion that AD can offer a realistic solution to the complex problem that called them into existence. The inability to predict every possible clinical circumstance, linguistic vagueness and the fact that some patients may not know a suitable person to appoint as a trustee have limited the usefulness of an AD\textsuperscript{21}. In addition, questions regarding the timing of an AD preparation, the content and its form can be also obstacles to its correct implementation, especially when the AD presents a request not yet legally regulated by the national law (e.g., euthanasia and assisted suicide), or a topic not in line with good clinical practices such as extension of life with futile treatments\textsuperscript{22}. Moreover, citizens who desire to complete an AD desire also to be briefly prepared and counseled by competent clinicians, who are able to deal with the value leaden aspects implied in such choices of care. Dealing with patient’s AD, however, requires clinicians to deal with ethical and relational aspect of care which, to a greater or lesser degree, are not yet characterizing the current curriculum of health care professionals.\textsuperscript{23}

It is not difficult to suppose that preserving dignity in the patient dying process and respecting moral value as implied by an AD are even more difficult for inadequately trained health care professionals. Again, this is particular evident in ICU setting, where active listening, empathy and compassion, as well as critical and ethical analysis - which are widely considered essential qualities of a basic toolkit to promote and improve the humanization of critical care - are currently underestimated in ICU setting\textsuperscript{24}. Hence, the promotion of ethical discussions by the CEC’s activity in their teams “may be pivotal to improving moral distress and the quality of patient care”.\textsuperscript{25}

As confirmed by the recent systematic reviews conducted by Shildman and colleagues, the number and the quality of empirical studies aiming to evaluate the CEC’s activity in ICU are still quite low, and just few of them has partially shown the benefit of ethics consultation in resolving disputes in ICU, showing an impact in decreasing the use of life-sustaining therapies, and reducing


\textsuperscript{23} See the study of Velasco-Sanz and Rayón-Valpuesta, on the Health professionals’ competences about ADs in intensive care and Ruth, D., Azoulay, E., Ricou, B., Dekeyser Ganz, F., Max, A., Michalsen A., and then ‘…’ Appropriate Study Group of the Ethics Section of the European Society of Intensive Care Medicine: “Inappropriate Care in European ICUs Confronting Views From Nurses and Junior and Senior Physicians”, Chest., 2014 Aug; 146(2), pp. 267-275.

\textsuperscript{24} Ibidem.

ICU length of stay\textsuperscript{26}. However, as we said at the very beginning, CEC aims not only to the solution of ethical conflicts but to a broader development of ethical attitude among all the actors implied in a discussed case. However, patients and health care professionals’ engagement in the decision making process and the management of moral distress are not empirically evaluated in the existing literature, questioning the assumption that a CEC can really improve the quality of health care professionals’ attitude and practice toward patients’ values in the critical situation.

Hence, we can suppose that the lack of an high-quality evaluation on the ethical outcomes dealing with the development of the decision making process among the actors involved in critical situation would have a broader repercussion on the quality of clinical practice, especially as regard ICU’s helath care professionals attitude towards patient’s involvement in a good an efficient advance care planning and the attitude towards patients’ AD.

For that reason is very important that the ethical service promoted by the institution aims not only to resolve ethical conflict but also improve health care assistance through a pratical and bottom up intervention on health care professional’s competences, promoting their knowledge and traning on the ethical aspect of care. Considering the broader interest of CEC in the promotion of bioethics, among which planning an implementing training corse for residents, CEC represents a very useful tool for the amilioration of the whole health care management, due to its appliacation at multiple, trasversal levels of care and the development of its activity “on the field”.

4. The European Experience of CECs in the promotion of ADs: The Spanish CEA

Persisting questions still affect the role that a CEC can play in the promotion of ethical attidues among health care professionals: the current iplementation of CECs in Spain can be paradigmatic of a paradoxical situation, where the contrast between theory and practice is particularly evident.

Taking into consideration the European landscape, Spain is one of the most advanced European countries in terms of the legislative and administrative development of AD (called Documento de Voluntades Anticipadas – DVA). At the same time, differntly from other european

countries, such as Italy, which haven’t already provided a specific national regulation for CECs, Spain has got a specific National regulation about the Comités de Etica Asistencial (CEA). The first one was the Orden de 14 de diciembre de 1993, de acreditación de los comités de ética asistencial, thank which the presence of an hospital’s CEA being mandatory in certain circumstances, in particular for organ transplantation between living patients. In 2010, the Comitè de Bioètica de Catalunya elaborated a document called “Consideraciones sobre el Documento de Voluntats Anticipades” that specifically suggests that when there is difficulty in interpreting the patient's will expressed by a representative or in the absence of the patients’ AD, a hospital’s CEA can offer effective assistance because a collegiate, multidisciplinary, rational opinion with a common and recognized methodology can enrich the quality of assistance for the cited cases.

Due to its consultative and advisory function before decisions on the limitation of vital support treatments, avoiding misplaced calls for therapeutic effort limitation decisions, CEA has recently been defined as a “forma de hacer bioética necesaria en el contexto clínico y, por consiguiente, también en medicina intensiva”. CEA, indeed, has been recognised as a valid aid both to health care professionals and to patients as well as relatives supporting health care professionals "a sentir que trabaja eficazmente en colaboración con el paciente y la familia", promoting and facilitating their participation in the decision making process. Additionally, due to its formative aim, CEA represents an important tool in the regulation of DVA compliance and its enhancement by health care professionals in the ICU ward, providing them with specific guidelines and training on the ethical aspect of care. This aspect should be stressed to prevent the bureaucratization of the DVA for the health care professionals, promoting a wider and specific discussions between all the individuals involved in the health care path at multiple levels of health care assistance, and it can be particularly important in the light of the current situation affecting the rate of DVA compilation among Spanish citizens.

In fact, a recent survey conducted between 2012 and 2015 by the Health Care Department of the Generalitat de Catalunya on the opinion of people regarding the use of a DVA confirms the persistence of a large discrepancy between citizens and health care professionals on the attitude and practice about ADs, highlighting that there still be many opportunities to ameliorate the health care assistance. According to Dra. Maria Casado and colleagues, this survey confirms that a
cultural change toward patient's centrality in the health care environment is still required in the practical experience, and it will require a greater effort both at the professional and, mostly, at institutional level, through a greater “esforzo educativo de los responsables e de la instituciones sanitarias, y en especial de los comites de etica”.31

However, structural difficulties are still arising regarding the institutional value of a CEA inside the hospital walls and activities, hindering, de facto, the identification of the ethical quality of health care assistance promoted by the CEA’s implementation. The recent document La qualitat en els comités d’etica assistencial developed by the Comitè de Bioetica de Catalunya32, indeed, underlines the presence of a “sindrome de retard en el creixement (SRC)”of spanish CEA whose main features are: the uncertainty of the clinical compliance of the CEA and the little knowledge of its existence by the health care professionals (accountability); the presence of doubts regarding its purpose and utility (effectiveness); the bureaucratization of the advisory function and the almost inexistence of its educational functions and protocols realization33. As noted by Dr. de Lecuona and Dr. Royes concerning CEA’s accountability, the actual confusion of a CEA’s role and activity is one of the biggest problems for the correct use of this committee by the health care professionals, especially as concerns the documento of informed consent and DVA34. However, it is especially important that the role of a CEA does not decrease into a only formal organization, explaining what should and what should not be done from the legislative point of view, because the repercussion on clinical practice can be even worse than the actual situation, additionally weighing on the clinical practice of a bureaucratic, formal system that, in the end, will not improve the quality of assistance, due to the absence of that broader and bottom up discussion on the ethical aspect of care. In fact, considering the cited goals of a CEC (i.e. improve the quality of and satisfaction with ethical decision-making through the resolution and/or reduction of the ethical conflicts and moral distress among patients, relatives and healthcare professionals), the service should aim to increase patients' involvement in decision-making according to their preferences,
through acknowledging their wishes and incrementing health care professionals attitude to respect an approach of care which reflects patients’ priorities.

Secondly, the lack of based-evidence on CEA’s effectiveness, especially as regard the outcomes on moral distress and the cited patient’s engagement in decision-making process, hinder the possibility of a minimal standardization of practice, which is essential for the creation of a broader and more structured framework for further implementation of a consistent and efficient ethical consultation service.

In order to overcome this situation, we believe that further research on the effectiveness of CEC’s activity are needed and, that a bigger effort in the educational path on the ethical aspect of health care management, both inside and outside the hospital’s walls, should be considered as a first, necessary step to improve the awareness and relevance of CECs, that are actually widely under estimate. Furthermore, the comparison and the exchange of experiences not only at the national level but also at the international level, rather in an European framework, will be a crucial aspect for the improvement of CECs’ efficacy, its utility for health care professionals and patients, as well as for the improvement of health care assistance provided by the national health care institutions where these aspect of care are widely underestimated.

5. Conclusion

The highly technological nature of ICU is naturally linked to the risk to encourage over-treatment or the application of life-prolonging treatments often resulting into a complex domain where the boundary limit of the health care professionals’ obligation to cure and preserve life is not always clearly defined. In this grey area of uncertainty, is reasonable supposing that patients who find themselves immersed in a plethora of cables, sophisticated monitoring and life-support equipment that they didn’t required are condemned to a very low quality of life, due to the misalignment between the provision of high technological health care devices and their values and moral beliefs, above all when surviving at any cost is not the priority value in their personal axiological order. Recognising when intensive care will not restore a person’s health, and helping patients and families embrace goals of care in term of symptom relief, interpersonal connection, or spiritual fulfillment, are becoming central challenges of critical care practice and

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Rev Bio y Der. 2020; 49: 125-139

health care professionals. However, knowing and respecting patients’ preference and values is not a common practice in the ICU. Urgency, lack of time and, above all, lack of ethical competencies of health care professionals usually affects the decision-making process on delicate issues such as the withholding and withdrawing of potentially life-sustaining therapies or the management of cases of perceived futility. Consequently, ethical conflicts and moral distress among the health care professionals and their patients and/or relatives are quite common aspect of ICU ward, with a negative repercussion on the health care assistance provided and, inevitably, on the patient’s quality of life. In this paper we have seen that the development of specific ethics support for clinical practice is expected in order to promote an ethical dimension which aims to generate possibilities for improvement in care quality. In this regard, CECs will play a central role for the provision of high health care assistance and so, for the improvement of patients’ quality of life, especially regarding the further increasing implementation of AD in ICU ward.

Taking into consideration the Spanish experience, we’ve seen that both the health care professionals and patients’ attitude to patient’s right in the form of a DVA is currently involved in a jarring condition, divided between a great theoretical interest toward the ethical aspect implied in DVA (such as autonomy and the related patient’s self determination right) and a low implementation of their practical use in the daily life. Supporting the individual involved in the decision-making process at the end of life and helping health care professionals and citizens to be more and more familiar with the content of DVA, CEA can play a central role in the promotion of an high quality health care assistance. However, the implementation of CEA is still quite problematic, due to the difficulties in the evaluation of its activities and in the recognition of its value and role inside (and outside) the hospital’s walls. However, this is not an isolate case. On the contrary, CECs are not a spread reality among Europe and many countries (such as Italy) still lack a national, homogeneous implementation of this ethical support for professionals. The presence of an European framework devoted to the exchange of experiences among the already implemented CECs can be crucial for the improvement of CECs’ utility for health care professionals and patients, as well as for the improvement of health care assistance provided by the health care institutions of that countries where the ethical aspect of care is still widely underestimated.

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Fecha de recepción: 5 de septiembre de 2019
Fecha de aceptación: 28 de noviembre de 2019