

**Life-sustaining interventions and terminal patients: the integration of palliative and intensive care medicine**

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## Introduction

This paper is a reflection on the role palliative care medicine (PCM) can legitimately play in the field of critical or intensive care medicine (ICM). In principle, given the marked differences in clinical context, purposes and means generally assigned to PCM and ICM, it could be thought that only on very rare occasions could these two specialties justifiably meet together to help one and the same patient.

Until recently, the border between ICM and PCM was crossed rather infrequently. The number of patients in an advanced stage of their terminal disease who were in need of a life-sustaining intervention was small. To offer them the doubtful benefits of ICM posed, beside well known problems of justice and equity in the use of human and financial medical resources, the thorny bioethical quandaries surrounding futility, overtreatment, or the limits of medical intervention. Some historical cases of therapeutic obstinacy set a precedent on why, when and how to decide the withdrawal of life-sustaining interventions. A substantial proportion of the work of ethics committees in hospitals over the years was devoted both to counselling doctors on these problematic situations or to avoiding their occurrence.

For some time now, however, things have apparently been changing for the better. In the immediate past the idea has been gaining acceptance that the transfer of certain mental habits of PCM to the field of ICM could make it easier to solve some of the troubling perplexities that doctors and nurses meet rather frequently in the intensive care unit (ICU) once their efforts meet with failure. In fact, we are now superseding the generally accepted concept that the ethos of ICM and the palliative ethos are so distant in their character, motivations and purposes that it is almost impossible to blend them in a common purpose. An interesting aspect of this change is that it will have an important and enriching impact on the ICM's ethical decision making process, and also lead to a substantive reduction of the current debate on ordinary and extraordinary means, proportionality of measures, therapeutic obstinacy or neglect.

To understand the change in the relations between PCM and ICM from divergence to concordance<sup>1</sup>, in the first part of this article, the nature, means, and goals of these two (intensive and palliative) modalities of medical care will be briefly reviewed, with the intention of offering a tentative characterization of the peculiar ethos of each specialty.

In the second part, the progress to a close interdisciplinary collaboration and communication between ICM and PCM is described, followed by some thoughts on the ethical effects the new situation will have on the prevention of conflicts of overuse of life-sustaining interventions in terminal patients. Although thorough integration of PCM and its distinctive ethos into the IC is desirable, it is necessary to evaluate this according to the demanding criteria of evidence based medicine.

Finally, in the third section of the article, some open questions on the border between ICM and PCM are referred to: their respective role in the hospital emergency department in the care of terminal patients brought to it in an acute crisis; the help that tele-

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<sup>1</sup> The expression from divergence to concordance is taken from BYOCK I., Improving palliative care in intensive care units: Identifying strategies and interventions that work, *Crit Care Med* 2006; 34:S302–S305.

medicine can lend when terminal patients are affected by unexpected complications; and, finally, the role of biomedical research in the intersection of PCM and ICM.

## **I. Intensive care and palliative care: their different ethos**

PCM and ICM are commonly seen by both public and professionals as markedly dissimilar, even as polar opposites, as a result of their disparate origin, development, technological support, financial strength and professional lustre<sup>2</sup>. They have, however, some features in common, since they care for patients at a high risk of losing their lives or who come very close to this, patients with an immediate perception of extreme vulnerability. In no other clinical circumstances is the connexion of human dignity and weakness more relevant than in ICM and PCM. In no other place does the condition of man as a puzzling intertwining of dignity and misery, as a *res sacra miser*<sup>3</sup>, show itself more clearly. Probably in no other specialty does the patient's centrality appear to doctors and nurses more meaningful, and at some moments more obscure.

In the course of their historical development, ICM and PCM have followed divergent paths. In consequence, their respective characters have matured continuously and independently, leading to the forging of each respective and distinctive *ethos*. PCM seeks primarily the alleviation of pain and other symptoms, but simultaneously intends to create a human and peaceful, personalized and patient centred environment, capable of giving sense to the suffering of patients and their relatives and friends. The emphasis is on a holistic outlook. On the contrary, ICM is a discipline for biological crises, forced in some measure to cancel what is more deeply personal in the patient and to focus all its powers on stabilizing the deranged physiology of an out-of-order organism. The emphasis is on the quantitative data of physiological monitoring and on aggressive instrumental and pharmacological interventions to correct abnormal parameters and so overcome organ failure. That does not mean ICM is lacking in humaneness, since it is about "medicine, compassion and organization"<sup>4</sup>.

In fact, ICM and PCM cannot live neatly separated one from another. Not infrequently, a patient in the intensive care unit (ICU) takes a downhill course and becomes refractory to aggressive therapies; then, a decision must be made to shift the patient to palliative treatment once aggressive and expensive therapies, already deemed futile, are discontinued. In this way, in the ICU or outside of it, the intensivist must turn to palliative care. The reverse is also true: PCM does not renounce the occasional use of invasive or aggressive interventions (chemotherapy, radiotherapy, surgery) directed, not towards a curing the underlying disease, which is already deemed impossible, but towards the palliative purpose of alleviating symptoms.

The border between ICM and PCM, not always clearly discernible and necessarily open to two-directional traffic, has been, and continues to be a fertile place for ethical conflict. It is to be hoped that free circulation of persons and ideas between ICM and PCM will help to reduce the number and the intensity of such disagreements. A glimpse at the

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<sup>2</sup> BYOCK I., Improving palliative care in intensive care units: Identifying strategies and interventions that work, *Crit Care Med* 2006, 34:S302–S305.

<sup>3</sup> VOGELSANGER P., *Die Würde des Patienten*, *Bull Schweiz Akad med Wiss* 1980, 36: 249-58.

<sup>4</sup> NELIGAN P., *Critical Care Medicine* Tutorials, 2006. (Available at: <http://www.ccmtutorials.com/>)

nature of ICM and PCM will help us to understand the need for replacing divergence with concordance.

### A. The *ethos* of intensive care

The purpose of ICM is to treat patients who are critically ill with the intention of reducing avoidable mortality and morbidity<sup>5</sup>. ICM was born from the medical advances prompted by the World War II. In those postwar years, physicians thought that they had a moral duty to save life at all costs<sup>6</sup>. Until today persists the view of ICM as a discipline dominated by an ideal of preserving life at all costs, by means of instrumental monitoring, aggressive intervention and pathophysiological data evaluation. According to Byock this technological perception corresponds to the popular view of ICM as the pinnacle of mainstream medicine, the epitome of scientific and technical prowess, the well paid specialty served by the most highly trained and technically sophisticated doctors and nurses, the one that uses prehospital air or ground mobile ICUs<sup>7</sup>.

The message sent by the media to society includes the ICUs among the triumphant fighters of medicine against death, inflating its achievements and aligning it among the pursuers of human immortality.

But doubtless what most properly characterizes ICM is not the intensity of action or the concentration of effort in a small amount of time, as its usual name of “intensive care” suggests: its crucial feature is the ability to discern the critical, but recoverable, nature of the physiological derangement afflicting patients who are admitted to, and cared for, in an ICU. In this sense, the term “critical care medicine” would be more apt than “ICM”, because it shows more clearly that its defining peculiarity is the potential reversibility of the clinical processes treated, not the application of invasive monitoring or strenuous interventions.

When ICM is competently applied to patients fulfilling the criteria for admission to the UCI, the great majority of them recover after a brief sojourn in it, while a few die; a small number neither die nor recover. Others linger many days in an unsteady situation, until at last they drift into extreme weakness and death. Death in the ICU is not a professional failure, but the natural conclusion of overwhelming disease and complex comorbidity<sup>8</sup>. The wise acceptance of the finitude of human life and also of the limits of medicine should be an inescapable condition to provide end-of-life care in the ICU and a basic element of the intensivist *ethos*.

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<sup>5</sup> JENNET B., *The inappropriate use of intensive care*, Br Med J 1984, 289: 1709-1711.

<sup>6</sup> Callahan has described the emergence in the 1970s of what he qualifies as a schism in medicine, the silent confrontation of palliative care, seeking to bring back into clinical practice the relief of pain and suffering, with the then expansive medical research drive, implacable enemy of bodily miseries and death, (CALLAHAN D., *Death: “The Distinguished Thing”*, in JENNINGS B., KAEBNICK G.E, MURRAY T.H., (eds), *Improving End of Life Care. Why Has Been It So Difficult?*, Hastings Cent Rep Special Report 2005, no. 6: S5-S8. That situation shows some similarities with that opposed in the early years of the XIX century interventionist heroic medicine to therapeutic scepticism. See: PERNICK M.S., *A Calculus of Suffering: Pain, Professionalism and Anesthesia in Nineteenth Century America*. New York: Columbia University Press, 1985.

<sup>7</sup> BYOCK I., *Improving palliative care...*, Crit Care Med 2006, 34: S302–S305.

<sup>8</sup> NELSON J.E., *Identifying and overcoming the barriers to high-quality palliative care in the intensive care unit*, Crit Care Med 2006, 34: S324-S331.

Clinically and ethically, the intensivist's most valuable skill is to be a competent selector of patients to be admitted into the ICU, a knowledgeable evaluator of their physiopathological course and a sound prognosticator of their outcome.

The mark of a good intensivist is his or her capability for a realistic and circumspect evaluation of patients' potential for recovery<sup>9</sup>. To admit a patient to the ICU is a responsible decision, not be made lightly under the influence either of unreasonable compassion or prognostic pessimism<sup>10</sup>. The primary goal of ICM is to recover life, not merely to prolong it. Such is the purpose for which critical patients, or their proxies, decide to enter the ICU and accept its hardships and burdens. They are determined to fight for life not because they are vitalists, but in the hope of survival. The consent to intensive care includes a determination to suffer in exchange for outliving the crisis of overwhelming disease, not to receive non-beneficial aggressive therapy or to participate in a trial measuring human endurance. The consent of the patient to ICM is the answer to a serious and considered offer of help to overcome the critical situation. In any case, information on alternative palliative treatment must be given<sup>11</sup>.

The intensivist *ethos* is not free of dangers, among which are the risks of recommending potentially ineffective therapy associated with the risks of heavy side-effects, or of therapeutic escalation induced by irrationality, fear of failure, or by a vicious circle in which each further treatment is justified by the huge investment already entered into<sup>12</sup>.

Certainly, the science of medical prognosis, despite very considerable efforts, is still in an early stage of development<sup>13</sup>. This imposes on the doctor the duty of balancing, for each candidate to receive critical care and in each stage of the patient's clinical evolution, the risks and benefits of initiating or maintaining aggressive interventions. Although patients affected by a wide variety of diseases are admitted to the ICU, they are subjected to a relatively limited number of possible aggressive interventions and with some defined purpose in view<sup>14</sup>.

## **B. The ethos of palliative care**

Today, PCM is becoming more than an acceptable alternative to the shortcomings of the curative health model. Thanks to the experience gathered over the four decades of its history, PCM is the most adequate and humane response that it is possible to offer at present to incurable patients in the terminal phase of their disease<sup>15</sup>. It is now a true

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<sup>9</sup> CHEVROLET J.C., JOLLIET P., *An ethical look at intensive care for patients with malignancies*, Eur J Cancer 1991, 27:210-212.)

<sup>10</sup> FAN E., NEEDHAM D.M., *Deciding who to admit to a critical care unit. Scarce resources may cause doctors to be pessimistic about prognosis and refuse critical care admissions*, Br Med J 2007, 335:1103-1104.

<sup>11</sup> RADY M.Y., JOHNSON D.J., *Admission to intensive care unit at end-of-life: is it an informed decision?* Pal Med 2004,18: 705-711.

<sup>12</sup> CHEVROLET J.C., JOLLIET P., *An ethical look ...*, Eur J Cancer 1991;27:210-212.

<sup>13</sup> THE SUPPORT PRINCIPAL INVESTIGATORS. *A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT)*. JAMA 1995, 274: 1591-1598.

<sup>14</sup> In this respect, ICM has spawned some subspecialties, as for example, coronary units for intensive monitoring after myocardial infarction, post-operative monitoring for recovery after high risk surgery, Neligan P., *Critical Care Medicine Tutorials*, 2006. (Available at: <http://www.ccm-tutorials.com/>)

<sup>15</sup> CLARK D., *From margins to centre: a review of the history of palliative care in cancer*. Lancet Oncol 2007, 8; 430-438.

medical specialty intended to achieve, through the relief of suffering and the control of symptoms, the best possible quality of life of terminally ill patients<sup>16</sup>.

PCM is intentionally holistic and comprehensive. It has been defined as “the active holistic care of patients with advanced progressive illness”<sup>17</sup>. Cecily Saunders, 25 years ago, described 4 broad domains (physical, psychological, social, and spiritual) of palliative care<sup>18</sup>. This openness of purpose forces PCM to act through closely linked interdisciplinary teams serving the physical, psychological, social, and spiritual demands of patients and their families. In the practice, PCM is provided at different levels of complexity, from the primary and basic skills of the general practitioner; to the secondary care and consultation provided by specialist clinicians and organizations; and the tertiary care given in academic medical centres for the most complex cases together with research and teaching<sup>19</sup>.

The *ethos* of PCM sees inseparably the patient and his or her family as a unit of care. Therefore, the intrinsic value of each patient and family is recognized and respected in its dignity and integrity. Palliative care physicians maintain frequent dialogue for communication on the clinical, human, ethical and spiritual needs of patients, and to make shared decisions with them and their families. Palliative care, patient-centred and family-focused, is sensitive to their personal and cultural values, and their religious beliefs and practices; is assured to everyone without discrimination; and respects with due sensitivity their legitimate autonomy and freedom in the clinical context.

The recognition of death as a natural event, a part of life, is a distinctive feature of the palliative *ethos*: in consequence, life is affirmed, but the process of dying is neither hastened nor prolonged. Although dying can be difficult at times, the purpose of PCM is the search for quality of life, taking into account the spiritual distress of patient and family to help them to spiritual well-being. Although, in palliative care, the routine assessment and management of symptoms is the first concern, due attention is paid to the functioning of doctors, nurses, social workers, therapists as a well integrated interdisciplinary team to coordinate care and ensure its continuity. Despite that, palliative care can be successfully implemented even if resources are limited<sup>20</sup>.

It must be pointed out that the palliative *ethos* is not one of passivity towards death, as could be inferred from the basic commitment of PCM of neither hastening nor prolonging the process of dying. In contrast with the frequent reference to the probable shortening of life induced by vigorous treatment of pain or other symptoms, justified by the ethics of double effect, rarely is it mentioned that life can be extended as a collateral effect of palliative care. Some palliative interventions interfere directly with the occurrence of some complications. Moreover, supporting patients physically and emotionally

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<sup>16</sup> AMERICAN BOARD OF HOSPICE AND PALLIATIVE MEDICINE, *Definition of Palliative Medicine*. (Available at: <http://64.85.16.230/educate/content/elements/abhpmdefinition.html>).

<sup>17</sup> THE NATIONAL COUNCIL FOR PALLIATIVE CARE, *Palliative Care Explained*. (Available at: [http://www.npc.org.uk/palliative\\_care.html](http://www.npc.org.uk/palliative_care.html)).

<sup>18</sup> SAUNDERS D.C., *Principles of symptoms control in terminal care*, *Med Clin North Am* 1982, 66: 1169-1188.

<sup>19</sup> VON GUNTEN C.F., *Secondary and Tertiary Palliative Care in US Hospitals*, *JAMA* 2002, 287: 875-881.

<sup>20</sup> The preceding description of the palliative *ethos* is based on: CENTER FOR ADVANCED PALLIATIVE CARE, *Values that Guide Palliative Care Practice*, 2001; and on WORLD HEALTH ORGANIZATION *Definition of Palliative Care*, 1990. (Available at: <http://www.who.int/cancer/palliative/definition/en/>, and <http://64.85.16.230/educate/content/elements/values.html>, respectively).

makes them able to tolerate some rigorous treatments that contribute to give quality and more days to life<sup>21</sup>.

PCM *ethos* is intrinsically connected with respect for life. It excludes any deliberate shortening of the dying process. The unusual claims that hastening of death can be included as an aspect of palliative care<sup>22</sup> are simply rejected.

## 2. When intensive-care and palliative-care meet

As previously stated, ICM and PCM are converging, not to fuse together in a new entity, but to open themselves reciprocally to a higher level of cooperation<sup>23</sup>. According to Nelson, the traditional *dichotomous* model, in which palliative care was usually deferred until any hope of cure was abandoned, must give way to a new *integrated* model in which the intensivist's efforts to combat and defeat disease coexist with the palliativist's measures to optimize wellbeing as death approaches. In this way, palliation plays an increasing role as death draws near; or both intensive care and palliative care walk side by side until the patient survives or dies<sup>24</sup>.

Convergence of PCM and ICM is not an easy task for the general public, the patients and their families, and doctors. Advanced societies have inherited from the immediate past the notion that a good death involves a courageous fight against disease with the help of biomedical technology. This is a very popular concept, reinforced by the hope engendered almost daily by the news on stem cell research and genomic medicine. Death is considered by the many as an event that can be more or less postponed in anticipation of successful remedies.

For many patients and families, the background noise of scientific progress and immortalist illusions make inaudible the message of the benefits PCM can bring to the dying process. The number of those who consider a good death as one that includes acceptance and intimacy, most often at home or at the hospice, grows steadily, as the hundreds of thousands of patients show who are now served at home, hospices and hospitals by palliative care programs. As time passes, the help of palliative care at the bedside of terminal patients is increasingly viewed as something desirable and even indispensable. Moreover, it has been recognized that as far as the ranking of ethical values and care attributes in face of terminal disease and dying is concerned, there is, besides understandable differences, a marked harmony between the views of patients and pallia-

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<sup>21</sup> BYOCK I., Improving palliative care ..., *Crit Care Med* 2006; 34:S302–S305

<sup>22</sup> Billings J.A., Recent Advances. Palliative care. *Br Med J* 2000, 321: 555-558.

<sup>23</sup> For the description of the changes leading to the integration of PCM in ICM, I will follow the pioneering articles of Nelson and Meier (NELSON J.E., MEIER D.E., *Palliative Care in the Intensive Care Unit: Part I*, *J Intensive Care Med* 1999, 14:130-139, as well as the papers presented at the conference "Improving the Quality of End-of-Life Care in the ICU: Interventions That Work", funded by the Robert Wood Johnson Foundation and hosted by the Society of Critical Care Medicine on February 17–19, 2006, in Miami, Florida. The proceedings of the conference were published in November 2006 in a Supplement of the *Journal Critical Care Medicine*, and introduced by: LEVY M.M., CURTIS .R., *Improving end-of-life care in the intensive care unit*, *Crit Care Med* 2006, 34:S301.

<sup>24</sup> NELSON J.E., MEIER D.E., *Palliative Care in ... : Part I*, *J Intensive Care Med* 1999, 14:130-139

tive care providers, particularly on those issues considered most important for end-of-life care<sup>25</sup>.

Among physicians there are visible signs of acceptance of convergence of PCM and ICM. The perception of what constitutes inappropriate or excessive care has reached a critical mass among intensivists, as well as the adoption of strict clinical criteria to reduce the impact of futile therapies in the ICU. They are also resolved to limit by education and kind persuasion the unrealistic expectations of the patients and families<sup>26</sup>.

The incorporation of the palliative *ethos* in the workings of ICM will probably have a profound impact on the quality of care delivered. It could achieve prudent and efficient prevention of the unfortunate lot that so many patients experience as result of an ill-advised admission to the ICU or overly delayed withdrawal from intensive care. The palliative *ethos* could help significantly to refine the selection criteria for intensive care. Admission of patients with known poor prognosis to the ICU is a frequent error, which becomes an inexcusable levity if it excludes the required informed discussion of palliation as an end-of-life alternative. Such a mistaken decision can disrupt the provision of compassionate care for dying patients and add suffering to their last days<sup>27</sup>. In some hurtful cases, it could be viewed as an instance of professional misconduct and a violation of patients' rights. Moreover, the financial sequels of such levity are considerable, since it diverts a significant amount of limited resources from palliative care and hospice services to wasteful and futile treatments.

In addition, the palliative *ethos* could help to make easier the decisions to withdraw intensive care, when the lack of response of patients to critical care becomes evident. These patients are then entitled to receive as early as possible the best palliative care, together with the most compassionate care for their families<sup>28</sup>. It has been affirmed that in the hospital the palliative care physician can and should exert an impact not only in the ICU but also in the system as a whole, indeed throughout the hospital, using the tools of counselling and education to spread the culture of palliative care<sup>29</sup>.

It is difficult to eliminate non-beneficial aggressive therapy, but recent reports indicate that it is possible to reduce considerably the median length of stay in the ICU among patients. At tertiary care hospitals, medical subspecialists were more likely to recommend or initiate potentially ineffective therapy associated with frequent side-effects and disruption of end-of-life for hospitalized patients with ultimately or rapidly fatal pre-existing chronic diseases.

The close cooperation of PCM with ICM is highly promising. These two areas were considered in detail, together with the barriers to overcome and the questions to be researched, in the course of the February 2006 Conference to which we referred in footnote 23. Probably the most meaningful question for consolidating the alliance between

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<sup>25</sup> STEINHAUSER K.F., CHRISTAKIS N.A., CLIPP E.C., ET AL., *Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*, JAMA 2000, 284: 2476-2482.

<sup>26</sup> SIBBALD R, DOWNAR J, HAWRYLUCK L. *Perceptions of "futile care" among caregivers in intensive care units*. Canad Med Ass J. 2007; 177: 1201-1208

<sup>27</sup> RADY M.Y., JOHNSON D.J., *Admission to intensive ...* Pal Med 2004,18: 705-711Rady

<sup>28</sup> ROCKER GM, CURTIS JR. *Caring for the Dying in the Intensive care Unit. In Search of Clarity*. JAMA 2003, 290:820-821.

<sup>29</sup> ARNOLD R., LIAO S., *The Palliative Specialist in the Intensive Care Unit: Opportunities for Impact*, J Palliat Med 2005, 8: 838-839.

PCM and ICM lies in the need to give evidence based support to the endeavour. As Rubenfeld asserts, although not all processes for excellent end-of-life in the ICU need to be evidence based, because much of end-of-life care can be designed on the basis of ethical and legal principles<sup>30</sup>, it is important that the research targeted at demonstrating the advantages of cooperation between PCM and ICM be objective, strong and convincing<sup>31</sup>.

One last reason for the desirable team work between palliativists and intensivists is the ethical duty to minimize iatrogenic harm inherent in ICM and, in lesser measure, in end-of-life palliative care. The sources of suffering and stress in the ICU are many and varied. Critical interventions inevitably cause pain, given their intensity and invasive nature: intubation, ventilation, placement of central catheters, respiratory exercises, finger sticks, urinary catheters, suctioning, immobilization, besides the stressing environment of the ICU, with its noise, light, disruption of sleep and lack of privacy. Prevention and alleviation of iatrogenic discomfort will be a fertile area for future collaborative research between the disciplines of palliative and critical care.

### **3. Some pending problems**

In this second part, as stated above, some noteworthy problems on the frontier between ICM and PCM form the object of a short comment. These problems are: the role of palliative care in the emergency department when terminal patients are admitted in an acute crisis; the help telemedicine can provide in the care of terminal patients; and, finally, the role of biomedical research in the development of new forms of active care of terminal patients.

#### **A. The role of palliative care in hospital emergency departments**

Emergency departments of hospitals are places where prompt and competent care can be obtained for unexpected health events thanks to the immediate evaluation of clinical cases and the timely application of treatment. But, inevitably, emergency departments are also the site where many people, due to the severity of their illnesses, live their last moments. It is estimated that, in developed countries, one of every 15 to 20 deaths occurs in the emergency rooms of hospitals or on the way to them. Among those dying there are considerable numbers of terminal patients<sup>32</sup>. Despite these facts, it has been affirmed that very little is known about how people die and the care terminal patients receive in emergency departments and prehospital settings<sup>33</sup>.

That is understandable, because the close relatives of a dying patient, alarmed by a sudden or dramatic worsening of symptoms, bring him or her to the emergency department of a hospital in the hope of obtaining relief without delay. The hectic and overcrowded atmosphere of many emergency stations is not the best place to administer adequate

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<sup>30</sup> RUBENFELD G.D., ELLIOTT M., *Editorial Comment. Evidence-based ethics*. *Curr Opin Crit Care* 2005, 11: 598-599.

<sup>31</sup> RUBENFELD G.D., *Where do we go from here? One intensivist's perspective*. *Crit Care Med* 2006, 34: S412-S415.

<sup>32</sup> MCCAIG L.F., NAWAR E.W., *National Hospital Ambulatory Medical Care Survey: 2004 Emergency Department Summary*, in CENTERS FOR DISEASE CONTROL AND PREVENTION, NATIONAL CENTER FOR HEALTH STATISTICS, *Advance Data from Vital and Health Statistics*. Hyattsville: NCNS, 2006, 372 :27.

<sup>33</sup> CHAN G.K., *End-of-Life and Palliative Care in the Emergency Department: A Call for Research, Education, Policy and Improved Practice in This Frontier Area*, *J Emerg Nurs* 2006, 32:101-103.

end-of-life care to terminal or dying patients. On the one hand, there is the immediate danger of unduly applying the aggressive techniques of ICM to patients - futile treatment that can do more damage than benefit. On the other hand, the triage mentality proper to emergency doctors may lead them, without due consideration, to the decision not to treat, or to undertreat, those patients, thus depriving them of the help of palliative care.

This eventuality was dramatically revealed by the recent occurrence in the emergency department of a Spanish hospital of an abnormally high number of deaths among terminal patients brought to it, who were hastily treated with terminal sedation. The event caused a commotion among the public. The judicial inquiry could not find sufficient evidence of criminal behaviour, but discovered many cases of malpractice in the indication of terminal sedation and in the way it was performed. Medical experts criticized strongly the lack of palliative services in the hospital and blamed this circumstance as the main cause of the injudicious use of terminal sedation as a substitute for palliative care. Moreover, it has been deduced from the analysis of the clinical records by experts that there is widespread ignorance of the principles and practice of light and intermittent forms of palliative sedation. Poor understanding of the nature, indications and types of palliative and terminal sedation is also present among bioethicists without a medical background. The need for education in this area is self-evident.<sup>34</sup>

### **B. Telemedicine, an ordinary means in end-of-life care?**

The needs of end-of-life care vary broadly among different patients and their particular conditions. In general, terminal patients wish to avoid as long as possible staying in hospitals, and prefer to spend their final weeks or days at home. Although a daily visit of a palliative care worker can ordinarily be sufficient to satisfy the demands of the majority of patients and families, in some cases a more frequent communication schedule is required. It is in instances of such greater care requirements or of difficult displacement between hospital or hospice and patient's home that telemedicine can help to solve some distressing situations at end-of-life, and becomes an ordinary component of terminal care.

In many cases, the technology needed can be as simple as a household telephone or readily available common video technologies; with their help, it is easy to send medical information, reassuring messages, or make short calls just to overcome the want of face-to-face communication. On the other end, advanced telehealthcare tools must be used, including those specifically devised for end-of-life patient needs, such as pre-programmed infusion pumps to deliver pain medication, or some forms of cardio-respiratory monitoring<sup>35</sup>.

The potential benefits of telemedicine for the care of terminal patients at home are now actively being explored by organizations devoted to developing, enhancing and disseminating hospice and palliative care for people living in isolated rural communities<sup>36</sup>. Some preliminary results are encouraging, both at the organizational and ethical levels.

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<sup>34</sup> SIMON A., KAR M., HINZ J., ET AL., *Attitudes towards terminal sedation: an empirical survey among experts in the field of medical ethics*, BMC Palliat Care 2007, 6: 4.

<sup>35</sup> KINSELLA A., *Tailoring Telemedicine to End-of-life Needs*, Virtual Mentor 2001;3. (Accessed at: <http://www.ama-assn.org/ama/pub/category/4373.html>).

<sup>36</sup> NATIONAL RURAL HEALTH ASSOCIATION, *Providing Hospice and Palliative Care in Rural and Frontier Areas*, Kansas City, MO: NRHA, 2006: 71-75. (Available at: <http://www.capc.org/Rural-Toolkit-READER.pdf>)

For example, it has been found that, by means of videophones deployed for telenursing visits and social workers' evaluations, almost two thirds of home hospice workers' visits could be efficiently performed by telemedicine<sup>37</sup>. Moreover, it has been concluded that end-of-life telemedicine enhances communication between patients and their families and members of the hospital staff; it improves the way in which all of them are informed; and finally heightens the sense of dignity and the quality of care, thanks to a more timely pain and symptom management, relief of burden, avoidance of inappropriate prolongation of life, and solving of medical and technical problems<sup>38</sup>. The use of telemedicine for end-of-life care is in continuity with the hospice mentality, as is testified by the coining of the new concept of telehospice<sup>39</sup>.

Apparently, no discernible risks are linked to the use of telemedicine as an important adjunct to palliative care. The most important deontological duty, that of not reducing the patient/physician relationship to mere telematic communication that excludes any direct face-to-face encounter,<sup>40</sup> appears a very remote risk in the palliative context, when one takes extreme geographical and weather conditions into account.

### **C. Research on new life-sustaining interventions to be applied in the terminal stage of disease**

Despite the many advances the future will bring to the healing of diseases incurable today, there will always be incurable patients threatened by a more or less impending death. That means that always there will be a permanent and pressing need to develop new and effective remedies directed towards the alleviation of symptoms and the improvement of the quality of declining life.

Although forceful life-sustaining interventions are of none or very limited application in terminal patients, there is, in principle, no reason to exclude them from clinical trials that explore innovative palliative procedures, in particular when such research serves the twofold purpose of improving patient care and strengthening the evidence basis of PCM. As vulnerable subjects, they have the same entitlement as any other people to access the benefits of investigational interventions that show promise of therapeutic benefit<sup>41</sup>. Obviously, given the vulnerable condition of the dying and the terminally ill, such research must be directed to treat specifically the health problems characteristic of either the actual subjects or other similarly situated members of the vulnerable class<sup>42</sup>. But

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<sup>37</sup> DOOLITTLE G.C., WHITTEN P., MCCARTNEY M., ET AL., *An Empirical Chart Analysis of the Suitability of Telemedicine for Hospice Visits*, *Telemed e-Health* 2005, 11: 90-97.

<sup>38</sup> VITACCA M., SCALVINI S., SPANEVELLO A., ET AL., *Telemedicine and home care. Controversies and opportunities*, *Breathe* 2006, 3:149-158.

<sup>39</sup> DOOLITTLE G.C., YAEZEL A., OTTO F., et al., *Hospice care using home-based telemedicine system*, *J Telemed Telecare* 1998, 4 (Suppl 1): 58-9.

<sup>40</sup> HERRANZ G., *Aspectos éticos de la Telemedicina*, VII Congreso Nacional de Derecho Sanitario, Madrid, 2000. (Accessed at <http://www.aeds.org/frames/frame2.htm>).

<sup>41</sup> CIOMS (COUNCIL FOR INTERNATIONAL ORGANIZATIONS OF MEDICAL SCIENCES), *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, Geneva: CIOMS, 2002, Commentary to Guideline 12. (Available at [http://www.cioms.ch/frame\\_guidelines\\_nov\\_2002.htm](http://www.cioms.ch/frame_guidelines_nov_2002.htm)).

<sup>42</sup> CIOMS, *International Ethical Guidelines... Commentary to Guideline 13*.

when the purpose and the circumstances of research are ethically correct, patients do not refuse their cooperation<sup>43</sup>.

The difficulties of end-of-life research are not negligible. On the one hand, this type of research lacks appeal for public and private research agencies, which are more interested in cutting-edge projects. Despite repeated efforts by some important committees, it has not attracted the interest of the pharmaceutical industry, nor does it represent a priority for the leaders of medical research institutions, witness the scant effect of some important and well documented reports<sup>44, 45, 46</sup>. On the other hand, it meets with the reluctance of many palliativists and of the members of research ethics committees to change the tradition of minimum interference and intervention characteristic of PBM<sup>47</sup>.

Above all, it suffers under the burden of intrinsic drawbacks adding important difficulties to the planning and completion of experimental studies. Grande and Todd made a lucid analysis of some of the more relevant difficulties found, such as those related to randomization and blinding; to defining the criteria for eligibility, recruiting and retaining subjects in number enough to give sufficient power to the trials; to the choice of practicable outcome measures; and to the ethical issues related to the information delivered for consent to enter in the intervention and control groups<sup>48</sup>.

Consequently, despite the considerable body of literature and the meaningful growth of knowledge and practical applications of end-of-life research in recent years, particularly in the areas of pain and symptom management, and communication with patients and families, there are still many issues awaiting resolution. For example, in a partial analysis of the quality of the research published on the advanced stages of fatal illnesses, after acknowledging the forward strides made, it was stated that at the present time there is no settled definition of “end-of-life”, nor of some other basic concepts<sup>49</sup>. Regretfully, this report excluded the evaluation of clinical trials on palliative chemotherapy, radiotherapy, stents, laser therapy, and other complex technologies (such as implanted cardioverter defibrillators, biventricular pacemakers, or ventricular assistance devices to help patients in very advanced stages of chronic heart failure). Perhaps some of these sophisticated interventions are not only subjected to the law of diminishing returns: they also incur the risk of futility.

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<sup>43</sup> TERRY W., OLSON .G., RAVENSCROFT P., ET AL., *Hospice patients' views on research in palliative care*. Intern Med J 2006, 36: 406-413.

<sup>44</sup> FIELD M.J., CASSEL C.K., (eds). COMMITTEE ON CARE AT THE END-OF-LIFE, INSTITUTE OF MEDICINE., *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academies Press, 1997: 235-258.

<sup>45</sup> FOLEY K.M., GELBAND H., NATIONAL CANCER POLICY BOARD, INSTITUTE OF MEDICINE and NATIONAL RESEARCH COUNCIL, *Improving Palliative Care for Cancer*. Washington, DC: National Academies Press, 2001: 233-276.

<sup>46</sup> FIELD M.J., BEHRMAN R.E. (eds). COMMITTEE ON PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES, *When Children Die. Improving Palliative and End-of-Life Care for Children and Their Families*, Washington, DC: National Academies Press, 2003: 350-391.

<sup>47</sup> RILEY J., ROSS J.R., *Research into care at the end of life*. Lancet 2005, 365: 735-737.

<sup>48</sup> GRANDE G., TODD C.J., Why are trials in palliative care so difficult? Pal Med 2000,14: 69-74.

<sup>49</sup> LORENZ K., LYNN J., MORTON S.C., ET AL., *End-of-Life Care and Outcomes. Evidence Report/Technology Assessment: Number 110*. Rockville, MD. Agency for Healthcare Research and Quality, 2004. (Available at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf>).

In effect, the search for new and aggressive procedures to rescue terminal patients from imminent death is plagued by ethical difficulties. Over-zealous physicians can come near therapeutic obstinacy, and reproduce the dangers and abuses of old-time heroic medicine. Modern medical ethics accepts the so-called 'compassionate use' of drugs or other therapies that have not been yet licensed for general use because the studies to establish their safety and efficacy are not completed. The Declaration of Helsinki<sup>50</sup> demands, for the compassionate use to be ethically acceptable, not only the inexistence or previous failure of approved therapeutic methods, and the informed consent from the patient, but also the judgement of the physician that the compassionate intervention proposed offers hope of saving life, re-establishing health or alleviating suffering. It seems congruent with the serious scientific background of the Declaration that the physician's judgement be based on sound and defensible reasons, not on fanciful considerations. To avoid potential mistakes or abuses, the CIOMS recommends in its Guidelines that any compassionate use of a non approved treatment must be previously reviewed by an ethical review committee as though it were research<sup>51</sup>.

The ethics of biomedical research views with distrust trials to test last hope remedies. In desperate circumstances it is extremely unlikely that subjects suffering under severe emotional stress can grant a truly free and informed consent; that the institutional review board be able to reach a well founded agreement; and that the investigators can forward a reasoned and objective research proposal. The preconception that "nothing is lost" can never be an excuse to justify the exploitation of extremely vulnerable patients.

This brief consideration on the research needs of end-of-life care could not end without emphasizing the need to investigate two problems. First, the reasons why what is already known about symptom relief for terminal patients is not applied, or is timidly implemented by doctors everywhere. Curiously, among the causes of that reticence, some ethical concerns are paradoxically invoked<sup>52</sup>. Second, a scientific re-examination of the vexed question of the shortening of life effect of palliative treatment of pain and other symptoms, to determine the validity of the widespread, and probably false, notion of "indirect" euthanasia<sup>53</sup>.

#### 4. Epilogue

Spiritual support for patients and families is ordinarily included as one of the essential domains of palliative care quality. Similarly, to value and support the patient's and family's cultural traditions is also one of the measures proposed to improve comfort and communication for critically ill patients in the ICU<sup>54</sup>.

This article on life-sustaining interventions at the end-of-life cannot omit a short reference to the Christian "end-of-life-sustaining-interventions", particularly to the pastoral

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<sup>50</sup> WORLD MEDICAL ASSOCIATION, *Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects* (Available at <http://www.wma.net/e/policy/b3.htm>)

<sup>51</sup> CIOMS, *International Ethical Guidelines... Commentary on Guideline 13.*

<sup>52</sup> AMERICAN GERIATRICS SOCIETY, ETHICS COMMITTEE, *Position Statement. The Care of Dying Patients, 2007.* (Available at <http://www.americangeriatrics.org/products/positionpapers/careofd.shtml>). Position 8.

<sup>53</sup> AMERICAN GERIATRICS SOCIETY, ETHICS COMMITTEE, *Position Statement... Position 3.*

<sup>54</sup> CLARKE E.B., CURTIS J.R., LUCE J.M., ET AL., *Quality indicators for end-of-life care in the intensive care unit.* *Crit Care Med* 2003, 31: 2255–2262.

ministry to terminal patients in the ICU. The role of hospital chaplains is irreplaceable in administering the Sacraments of Penance, Eucharist and the Anointing of the Sick.

Paraphrasing the words of Pius XII, “Life, health, all temporal activities are in fact subordinated to spiritual ends”, it could be said that “end-of-life is subordinated to spiritual ends”. Seen from a Christian perspective, what dying patients need, besides company and palliation of suffering, is the help of sacraments. As has been beautifully expressed,<sup>55</sup> “Christians should approach death with the joyful anticipation of seeing face to face their Blessed Lord whom they loved and diligently served in their lifetime. In order to prepare themselves [...], Catholics should try to confess their sins to a priest before death”. ICU patients, like all other patients, have the right to receive spiritual help: they need it all the more after their hard struggle with disease. Today, fortunately, in contrast to days gone by, the ICUs are open to the comforting visit of the chaplain.

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<sup>55</sup> THE NATIONAL CATHOLIC BIOETHICS CENTER, *A Catholic Guide to End-of-Life Decisions*, Boston: NCBC, 1998. (Available at: <http://www.ncbcenter.org/eol.asp>).