

## The process of death in the intensive care unit (ICU). From a medical, thanatological and legislative point of view

Francisco de J. Takao Kaneko-Wada<sup>1\*</sup>, Guillermo Domínguez-Cherit<sup>1</sup>, Ariadna Marcela Colmenares-Vásquez<sup>1</sup>, Paola Santana-Martínez<sup>1</sup>, Juan Gutiérrez-Mejía<sup>1</sup> and Alejandro C. Arroliga<sup>2</sup>

<sup>1</sup>Subdirección de Critical Medicine, Instituto Nacional de Ciencias Médicas y Nutrición Salvador Zubirán, México, D.F., México; <sup>2</sup>Medicine Professor, University of Texas, A&M HSC College of Medicine and Baylor Scott and White Health Science Center, USA

### Abstract

*Traditional goals in the intensive care unit are to reduce morbidity and mortality. Despite medical and technological advances, death in the intensive care unit remains commonplace and the modern critical care team should be familiar with palliative care and legislation in Mexico. Preserving the dignity of patients, avoiding harm, and maintaining communication with the relatives is fundamental. There is no unique, universally accepted technical approach in the management of the terminal critical care patient, so it is important to individualize each case and define objectives together under the legal framework in Mexico. (Gac Med Mex. 2015;151:586-91)*

**Corresponding author:** Francisco de J. Takao Kaneko-Wada, franciscotakaokaneko@gmail.com

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### Introduction

The main purpose of the healthcare team in the intensive care unit (ICU) is to restore health (save the life) of patients in critical state with conditions with possibility of recovery and requiring multi-organ support specialized measures administered by specialized professionals<sup>1,2</sup>. In spite of the implemented measures, from 5 to 40% of patients in the ICU are expected not to survive<sup>1,2</sup>. Survival of the patient does not only depend on the quality of healthcare or the patient's response to procedures and medications, but also on the seriousness of the disease or injury and

previous conditions of the patient. When the possibility of survival is non-existent, another important goal of the ICU arises, which is to alleviate the suffering.

It is a reality that in the current professional training of the healthcare team few teach how to address the patient or the family during the process of dying, which, together with sociocultural and religious differences, as well as international and national controversy, can turn out to create a debate in the field of action and intervention. In the present article, we make a review of the physiological and psychological changes occurring during the process of dying, the bioethical principles in the ICU, as well as current legislation in Mexico with regard to the care of patients with end-stage conditions.

#### Correspondence:

\*Francisco de J. Takao Kaneko-Wada  
Instituto Nacional de Ciencias Médicas  
y Nutrición Salvador Zubirán  
Subdirección de Medicina Crítica  
Vasco de Quiroga, 15  
Col. Sección XVI, Del. Tlalpan, C.P. 14000, México, D.F., México  
E-mail: franciscotakaokaneko@gmail.com

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## ICU admission and discharge criteria

Ideally, 10% of total beds of a hospital should correspond to ICU beds; however, in Mexico, the great majority, especially institutional hospitals are far from this number<sup>4</sup>. Another problem is the cost of the patients' care in the ICUs, which in the USA accounts for 15-20% of the national annual budget for healthcare, and in community-based hospitals, up to 17% of their total resources is used for the care of patients in critical condition<sup>3</sup>. Considering that not all patients benefit from admission in the ICU and that an inadequate selection of patients may deprive recoverable patients of the benefit, the different admission criteria models shown in table 1 have been proposed, which should be adjusted to each hospital or institution's needs<sup>5</sup>. In the Categorization model (Section C, table 1) within Priority 4, patients considered inappropriate for care in the ICU are those who are very stable for such a large benefit or those patients who are very ill, sometimes in terminal conditions, and in whom there is nothing else to offer. ICU discharge is decided once the problem that puts the patient's life at risk has been controlled, when the patient remains stable and doesn't require specialized care or surveillance. However, when clinical conditions of the patient have deteriorated and no specialized intervention is contemplated, moving the patient together with his/her family to some hospital area where he/she can spend more time with his/her loved ones can be considered<sup>5</sup>. Unfortunately, neither the cost-benefit of care in the ICU, nor the futility of invasive procedures in terminal patients or the importance for the patient of dying with dignity is always considered. The General Statute of Health in its article 345 contemplates that when the patient is not able to make the decision and there is no document available where the patient expressed his/her wishes, either the spouse, concubinage partner, descendents, living forebears, siblings, adopted child or adopter parent, in the expressed order, are the ones that, in situations such as brain death, can decide to disregard life-support artificial means<sup>6</sup>.

## Vital support measures

Special procedures most commonly used in the ICU include a) cardiopulmonary resuscitation; b) defibrillation; c) mechanical ventilatory support; d) use of vasopressors; f) dialysis; g) cardiac pacemaker, and e) artificial nutrition. The Society of Critical Care Medicine of the USA recommends the distribution among family members and patients of the ICU of a booklet with clear language for the general public, which is available on

**Table 1. ICU admission criteria**

### A. Objective parameters model

Vital signs alteration  
 Pulse < 40, > 150 beats/minute  
 SBP < 80 mmHg  
 MBP < 60 mmHg  
 Respiratory rate > 35 breaths/minute  
 Laboratory tests abnormalities  
 Glucose > 800 mg/dl    Na < 110 or > 170  
 pH < 7.1 or > 7.7    K < 2.2 or > 7  
 Ca > 15    Medications toxic levels

### B. Model according to primary diagnoses

- Cardiopulmonary
- Digestive
- Renal
- Neurological
- Endocrine
- Surgical
- Drug overdose
- Miscellaneous (near drowning, burn patients, cerebral death with organ donation)

### C. Case categorization model

#### Priority 1

Critical patients, requiring mechanical ventilation, vasopressor amines

#### Priority 2

Unstable patients requiring intensive monitoring with possibility of emergency interventions.

#### Priority 3

Unstable with little possibility to survive, may require specialized support, but limits for support have to be defined.

#### Priority 4

Not appropriate for care in ICU:

- a) Too stable for so much benefit.
- b) Too ill, terminal stages, nothing else to offer.

Radiologic, electrocardiographic abnormalities.

Physical alterations (serious burns, multiple fractures, etc.).

SBP: systolic blood pressure; MBP: mean blood pressure.

the internet, where the indicated procedures are explained in detail, with the purpose of serving as a support for decision making with regard to specific forms of life support<sup>7</sup>. Additionally, the authors recommend for a validly informed consent document to be available in each ICU for each indicated procedure.

## Mortality in ICU patients

The most critically ill patients of a hospital are found in the ICU. In spite of all efforts by the healthcare team and the use of the most advanced technological resources, mortality in the ICUs is 5-40%<sup>1,2</sup>. There are conditions, such as serious pneumonia, that may cause death in up to 40% by itself, but if organic failures are added (e.g., renal failure, serious coagulation disorders, etc.) for each organ or system in failure,

mortality increases from 20 to up to 80% when more than 4 organ systems fail<sup>8</sup>. Furthermore, mortality can increase if the patient has a chronic underlying condition before being admitted at the ICU, for example, disseminated cancer by up to 40%. In a study in France, elderly patients with medical conditions that prompted their emergency admission were shown to die more frequently outside the ICUs, with this probably being related to the wish of each patient and his/her families<sup>9</sup>.

## The process of agony and death

According to the American Association of Critical Care Nurses, “agony” is defined as the psycho-physiological process that produces considerable stress and concludes with death for the dying person and suffering for the close persons who survive him/her<sup>10</sup>. Dr. Rebolledo Mota defines terminal status as a progressive and generalized dissociation of the biopsychosocial order that determines a human being, the ultimate end of which is the termination of the person's life. It comprises progressive and generalized organic deterioration and the decease can occur within the following 4-6 months. In contrast, in the agonic state, the decease will occur within the next 21-48 h<sup>11</sup>. The General Statute of Health defines as patient in terminal situation to that person who has an incurable and irreversible disease and has a life prognosis of less than 6 months<sup>12</sup>.

The process of dying is usually not exclusive to the patients' families, but it also produces strong emotions and diseases in the entire healthcare team, which vary between sadness, depression, frustration and anger. In occasions, medical personnel can have the desire to “avoid” patients in process of agony and their families, while others experience a “displacement” or indifference reaction in order “not to die” together with the patient. The burnout syndrome, typified in the DSM-IV and the international code of diseases, considers this syndrome within the relational problems in the management of life<sup>13</sup>. Some symptoms include physical depletion with feelings of helplessness, abandonment and despair, emotional exhaustion, development of negative attitudes towards work, life and even other people, sensations of anguish and of having failed to ideals. Frequently, it is not considered by the patients' family members or hospital managements<sup>14</sup>.

## Clinical evolution of the process of dying

In a study in Canada, the behavior of patients in agony process is described over the previous 3 months

**Table 2. Clinical evolution of the dying process (Barbara Karnes)**

### 1-3 months before

- Isolation from people
- Decreased food intake
- Introspection
- Increased sleeping

### 1-2 weeks before

- Decreased fluid intake
- Decreased blood pressure, paleness, diaphoresis, irregular breathing, hypothermia, variable heart rate
- Disorientation/agitation. Hallucinations

### Days-hours before

- Increased energy
- Blood pressure variation
- Glassy, half-opened eyes
- Irregular breathing
- Oliguria, sphincter incontinence

### Minutes before

- Agonal respiration
- Deep stupor

until the last minutes prior to death (Table 2). Regardless of the patients' psychological behavior, the investigators noticed that after weeks of variation in their vital signs and mental status, before death, patients can show an energy increase to subsequently die<sup>15</sup>.

## Physiopathology of death. A theory

According to the inflammatory response theory, homeostasis depends on the balance between pro-inflammatory and anti-inflammatory cytokines<sup>16</sup>. An acute lesion or disease releases pro-inflammatory cytokines, causing systemic inflammatory response syndrome manifestations (increased heart and respiratory rate and fever) in a sustained form until the body starts failing or until anti-inflammatory cytokines release is generated, which may help to stabilize the patient but, if the initial lesion or disease is not controlled, the release of these cytokines may lead to multi-organ failure and death. Clinically, this is translated into alternating stability and progressive instability episodes until the patients' deterioration, who even hours before their death may be able to talk to and say goodbye to their loved ones.

The study of the dying process from the physiopathological point of view is not enough. Dr. Roger C. Bond, a North American military physician with 3 specialties (anesthesiologist, pneumologist and intensiv-ist), was a world-wide pioneer of intensive therapy. He described the inflammatory response theory based on his own life; at 56 years of age he died from a cancer. He highlighted the importance of communication with

the family members and the end-stage patients themselves, since he suffered it himself<sup>17</sup>. Dr. Gutiérrez-Samperio pointed out that the care of critically ill patients from a physiological point of view is not enough, but it requires an analysis from the bioethical point of view<sup>18</sup>.

## **Phases of the process of dying**

In 1969, Dr. Elisabeth Kübler-Ross described the stages of the dying process, currently known as the Kübler-Ross model, which later we will briefly describe and that can occur not only in the end-stage patient, but in his/her family members and loved ones<sup>19</sup>. It is important to note that in clinical practice there is not an order for the stages to appear and that we found different family members and the patient to be “out-of-phase” or in different stages, which results from insufficient communication between family members, either because they don’t want to worry the rest of the family or because some become aware of the existence of the disease at advanced phases.

### **Denial**

It’s a way to express disagreement and rejection in the face of the idea that the moment of death is near. Frequently, the patient or his/her loved ones express it as: “This cannot be happening to me (him/her)”. “This not true, doctor! You must have mixed up the studies...”. Frequently they need a second opinion or for the symptoms and evolution of the disease to become more evident to overcome this phase.

### **Bargaining**

It can be simultaneous with denial. A religious “manipulation” can be attempted, by expressing: “God, if you really exist, why is this happening to me?” “If I (he/she) get(s) cured, I swear that...”. Emotions fluctuate between hope and despair and there can be isolation or “false oblivion” by thinking “If I don’t speak about it maybe it won’t be true or go away”, “if I don’t go for information at the ICU tomorrow I will receive better news”.

### **Anger**

It can appear since the beginning. The main component is the belief that what is happening is unfair and the subject can even direct his feelings against himself or others. They think: “Why is this happening to me? What have I done?” “I am to blame for not listening” or even “Doctor, it is your fault because...” “It’s the nurse’s fault, who didn’t...”.

### **Resignation**

The subjects come to express “There is nothing else to do...”. In some cases they fail to attend. Some patients abandon their treatments, loose interest on their wellbeing and this leads to conflicts with other members of the family, who may be experiencing other stages, or else wanting to use experimental or alternative treatments. They may reject any support “A thanatologist/priest came and I got rid of him...”.

### **Acceptance**

It’s not the same as resignation; the patients accept the disease and some treatments. They accept a reality as one’s own death is. Understanding the need to take a step towards a different reality will “alleviate” the patient’s symptoms of defeat.

## **Ethical principles in the ICU**

Both the medical staff and the healthcare team at the ICU govern their actions based on the following ethical principles<sup>1</sup>:

- Autonomy: Freedom of the individual to decide his behavior towards himself, respecting his own dignity.
- Beneficence. Bioethics principle that postulates always to try to do good to patients.
- Nonmaleficence: Avoid suffering for the patient.
- Justice: Treating persons fairly and equally. Adequate distribution of medical resources.

## **Interventions in the process of dying**

In the current professional training of the healthcare team, few teach on the approach to the process of dying. This, together with sociocultural and religious differences, as well as the international and national legislative controversy, can create a debate in the field of action and intervention<sup>19,20</sup>.

In 1987, the World Health Organization (WHO) recognized that the cure in certain diseases is not possible and that quality of life is as important or more than quantity, giving rise to palliative medicine and increasingly accepting the intervention of thanatology<sup>21</sup>. *Pallium* comes from Latin, attenuate, and the main purpose is quality of life and symptom control, without this meaning prolonging life or hurrying death up. Therefore, when a ICU patient fails to respond to the best and maximum efforts and, in addition, any intervention

ends up being regarded as futile, it is then when intensive care palliative care can be applied<sup>2,21-23</sup>.

## Communication, importance and difficulties

In the medical attention of the patient in critical status, communication is vital not only between the health-care team members, but also with the family of the patient. The authors recommend learning about the prognosis and percentage of death from the diseases of ICU patients in order to be able to offer objective information based on current medical literature. We have observed that among the factors that negatively influence on communication, the following can be considered: 1) teaching hospital; 2) the reports are not always provided by the same physician; 3) the reports are not always received by the same family member; 4) socio-cultural level (although not necessarily); 5) language barrier (dialects and other languages); 6) lack of an adequate physical place to communicate the reports; 7) family members experiencing different stages of grief; for example, some in acceptance in contrast with others in denial and anger, and 8) versions of relatives or friends who ask doctor friends for their opinion of the case with incomplete information. Another important factor is the negative influence of television series about doctors and emergency rooms, where average survival after cardiopulmonary resuscitation (CPR) maneuvers was 70%, whereas in real life is 15-20%<sup>24</sup>. Respect should be promoted and the ABCD approach of care with dignity should be considered: A for attitude, B for behavior, C for compassion and D for dialogue<sup>25</sup>. In addition to establishing continuous, clear and friendly communication, interestingly, Dr. Cook emphasizes that effective communication also includes the power of silence<sup>2</sup>. This is true if in the course of the disease, the recommendation to inform and explain the patient and his/her family all doubts has been respected and when the process of dying arrives, rather than a detailed explanation about laboratory tests, physiological variants, etc., what the family members need more is finding a doctor who listens to them.

## Legislation on the rights of the end-stage patient

In the decade of the 70's, the controversy arose worldwide on whether to initiate or not CPR maneuvers in all patients, leading to legislative changes in different countries. In the USA, the patients must sign the

living will with regard to medical interventions, where the refusal to accept resuscitation maneuvers must be respected, otherwise, anyone who doesn't respect it can be penalized<sup>20,22,23</sup>. In Mexico, it was until the year of 2002 when efforts to create a law on the rights of patients in terminal situation were initiated, which led to the emergence of the first *Ley de Voluntad Anticipada* (Advance Directive Law) in the Distrito Federal in 2008<sup>26</sup>. Since the Federal initiative required different modifications due to the rifts and controversies with regard to terminology and legislation, it was until January 5, 2009, when the Decree that reforms the General Statute of Health was issued, adding Chapter Eight Bis on Palliative Care. Articles 13, 27, 59, 112 and 421 were modified and, most important, 166 Bis was created<sup>12</sup>.

The published Decree states that it corresponds to the governments of the states to organize, operate, supervise and assess the provision of public health services involving comprehensive treatment of pain and palliative care. Until the writing of this article, only in the Distrito Federal and 8 states of the Mexican Republic (Aguascalientes, Michoacán, Guanajuato, Hidalgo, San Luis Potosí, Coahuila, Estado de México and Colima) had the Statute of Health been reformed. In the states of Puebla, Chihuahua and Jalisco, the initiatives were in their respective Congresses but, even so, in more than 60% of the national territory there is no estatal Law on advance directive available.

We recommend the readers to review the reforms to the General Statute of Health, since they define basic concepts, actions and sanctions that can be incurred should this Law not be obeyed. In the process of natural decease of a patient in terminal situation, allowing to voluntarily discontinuing any medical treatment that needlessly prolongs the patient's life is contemplated and euthanasia is forbidden, understood as mercy homicide, as well as assisted suicide. The patient's decision to discontinue his/her curative treatment will be stated in a document with characteristics predetermined by official regulations, stating his/her wishes and that can be issued, as well as revoked, anytime. If the patient is a minor or incapable to express his/her wishes, decisions will be assumed by a relative, legal guardian, legal representative, person of trust or judge. In cases of medical emergency where there is incapacity of the patient to express his/her consent and in the absence of relatives, legal representative, legal guardian or person of trust, the decision to apply a medical or surgical procedure or necessary treatment will be made by the treating physician and/or Bioethics Committee.

Treating physicians will be able to provide palliative drugs, even opioids to a patient in terminal situation, even when this results in loss of alertness or shortening of the patient's life, as long as these drugs are administered with the purpose to relieve the patient's pain. In no case will these drugs be administered with the purpose to shorten or terminate the patient's life; in such case, the healthcare professional will be subject to applicable penal regulations. There is no universal approach technique for terminal-stage patients. Admissible strategies in most clinical scenarios include pain-suffering palliation and not escalating therapeutic and medical interventions.

In Mexico City, the advance directive document can be subscribed before a Public Notary, before healthcare personnel of any hospital of the Distrito Federal Ministry of Health, before personnel of any private healthcare institution of the Distrito Federal, or when the patient is impaired to express his/her wishes, the request can be submitted by the relative or person legally responsible, according to the order of preference stated by the law<sup>27</sup>. The document is nullified or revoked when it is made under threat against the patient or subscriber, when it is made trying to obtain any benefit or profit by the patient or subscriber of the program, when the patient or subscriber do not clearly and unequivocally express their wishes and when thus is decided by the patient or subscriber. Due to legal validity situations with regard to local and federal laws promulgation, there has been confusion regarding the validity of the advance direction of the Government of the Distrito Federal in Federal Institutions and Hospitals, where the document is not legally valid. In the light of this situation, the request for the current General Statute of Health application before a public notary is one solution. To date, the number of requests for the legal document does not exceed 1,000 annually; however, year after year these have been increasing, always looking for the wellbeing of the patient even in the process of dying.

## Conclusions

When the healthcare team and the relatives have reached the top of their efforts to save a life and in spite of it these have been unsuccessful and the possibility of death is certain, we should not forget that death is the only thing we can be certain of in life. Recognizing this fragile limit allows for us to keep on acting with the quality, warmth and humanism that patients require during the process of dying, without

losing professionalism, and today, in Mexico, in full compliance with the law.

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