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Received from the End-of-life Forum of The Brazilian Critical Care Association - AMIB – An agenda for the survey carried out on August 22<sup>th</sup> and 23<sup>th</sup> in São Paulo (SP), Brazil.

Submitted on October 20 2008 Accepted on December 12, 2008

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## End of life and palliative care in intensive care unit

Terminalidade e cuidados paliativos na unidade de terapia intensiva

#### **ABSTRACT**

The objective of this review was to evaluate current knowledge regarding terminal illness and palliative care in the intensive care unit, to identify the major challenges involved and propose a research agenda on these issues The Brazilian Critical Care Association organized a specific forum on terminally ill patients, to which were invited experienced and skilled professionals on critical care. These professionals were divided in three groups: communication in the intensive care unit, the decision making process when faced with a terminally ill patient and palliative actions and care in the intensive care unit. Data and bibliographic references were stored in a restricted website. During a twelve hour meeting and following a modified Delphi methodology, the groups prepared the final document. Consensual definition regarding terminality was reached. Good communication was considered the cornerstone to define the best treatment for

a terminally ill patient. Accordingly some communication barriers were described that should be avoided as well as some approaches that should be pursued. Criteria for palliative care and palliative action in the intensive care unit were defined. Acceptance of death as a natural event as well as respect for the patient's autonomy and the nonmaleficence principles were stressed. A recommendation was made to withdraw the futile treatment that prolongs the dying process and to elected analgesia and measures that alleviate suffering in terminally ill patients. To deliver palliative care to terminally ill patients and their relatives some principles and guides should be followed, respecting individual necessities and beliefs. The intensive care unit staff involved with the treatment of terminally ill patients is subject to stress and tension. Availability of a continuous education program on palliative care is desirable.

**Keywords**: Hospice care; Terminal ill; Life support care; Intensive care

### **INTRODUCTION**

As from the 20th Century the physician's capacity to intervene has increased enormously, without a concomitant consideration on the impact of this new reality on the quality of life of those critically ill.

Cultural aspects associated to social factors such as difficulty in treatment of a terminal patient at home, led to institutionalized death. In today's world, more than 70% of the deaths occur in hospitals and more specifically in intensive care units (ICU). In these units the technological

armamentarium available is so extensive that it is virtually impossible to die without the intensivist physician's sanction. This is substantiated on a world level by the fact that deaths in the ICU are in 30 to 50% of the cases preceded by the decision to interrupt or refuse treatments considered futile or useless. (1-10)

Members of the multiprofessional team in ICUs become distressed with doubts about the real meaning of life and death. Continue vital support procedures up to what point? When to stop, and, above all, guided by prognostic indices or by models of ethics or morality? Unprepared for this issue, modern medicine begins to underestimate the critically ill patient's comfort imposing a long and suffering agony. To postpone death at the expense of senseless and prolonged suffering. To minimize pain and suffering in the dying process the implementation of palliative care protocols in the ICUs has become mandatory. (11-16)

Taking this into account, professionals experienced in treatment of critically ill patients came together aiming to assess and synthesize the current state of knowledge on the subject of end-of-life and palliative care, seeking to identify the key-issues and recommend a research agenda about these issues.

Professionals, skilled in the treatment of critically ill patients, were invited to the Forum of Brazilian Critical Care Association Fund (Fundo - AMIB). An agenda for the research was carried out on 22 and 23 of August in São Paulo. These professionals were subdivided according to their field of action, into three subgroups to approach these subjects: 1. communication in the ICU, 2. decision making when facing a terminally ill patient and 3. palliative care/actions in the ICU. The subgroups worked together on information and references in the Portuguese and English languages published in the last 10 years. A restricted website was used to store references. According to the modified Delphi method, rounds of discussions among the members of the subgroups and of the entire group were carried out, until a final consensus was reached. Finally, proposals for priorities in the orientation for the research were drawn up.

## **DEFINITIONS**

Before drawing up recommendations and suggestions for the subjects to be researched the commonly used terms were defined. (17-25)

Patients in terminal condition: a patient is con-

sidered in terminal condition when his disease, regardless of adopted therapeutic measures, will inexorably evolve to death.

Irreversibility of disease is defined consensually by the medical team, based upon objective and subjective data. Once diagnosis is established, palliative care is the main objective of the support to the patient.

Palliative care: according to the World Health Organization, palliative cares are active and comprehensive actions for patients with progressive and irreversible diseases and to relatives. In these cares control of pain and other symptoms by means of prevention and relief of physical and psychological, social and spiritual suffering are fundamental.

**Palliative actions:** defined as therapeutic measures, without curative intention aimed to reduce negative impacts of the disease on the patient's well-being.

**End of life care:** those given to the family and to patients at the acute and intense suffering stage, in the final evolution of terminal disease, in the hours or days prior to the moment of demise.

**Futile treatment:** is every intervention that does not meet or is incoherent with proposed objectives for treatment of a given patient.

Palliative care in the ICU: Care given to the critically ill patient in terminal stage, when cure is unattainable and therefore is no longer the focal point of assistance. In this situation, the primary objective is the patient's well-being, warranting a dignified and peaceful death. Priority is given to palliative care and identification of the futile measures must be reached in a consensual way by the multiprofessional team by agreement with the patient (if capable) the relatives, or legal representative. Once defined, palliative actions must be clearly recorded on the patient's medical chart.

During treatment of a terminal patient, many of the curative/restorative measures might configure futile treatment, such as parenteral or enteral nutrition, administration of vasoactive drugs, renal replacement therapy, institution or maintenance of invasive mechanical ventilation, admission or stay of the patient in the ICU.

Should a conflict arise when deciding for palliative treatment, it is suggested that heads of the ICU make the fact known to the institution's board for support by its legal instruments (Ethics, Bioethics Committees etc.) to pursue the required intermediations.

Adequate communication among actors involved in the process, must exist because poor communica-

tion is one of the principal barriers, generating conflicts in the management of a terminal patient in the ICU.

## COMMUNICATION IN THE INTENSIVE CARE UNIT

Communication refers to a process related to thoughts, opinions and information. (19-23) It is the transmission of continued information from one person to another, then shared by both. Communication requires that the recipient of this information receives and understands it. Information merely transmitted but not received was not communicated, it requires that transmitter and receiver actively participate in the same process.

In the ICU, communication is a process involving perception of the environment and of the work climate, including non-verbal communication by the multiprofessional team, even the interaction physician/patient and relatives. The communication process in the ICU involves the patient, relatives or any person with affective nearness, physicians, nurses, psychologists, clergies and other members of the multiprofessional team. Assessment of the process' channels, the main barriers of communications, elements and strategies of good communication must be identified, acknowledged and fought against as required, or followed for success.

Channels of the critical communication process are:

- noise it is an interference alien to the message rendering communication less efficient. It means any and all undesirable disturbance or noise. Noise of loud conversation, telephone ringing, equipment, etc.
- omission may take place when the recipient is unable to seize the entire content of the message and only receives or passes on what he/she was able to seize.
- distortion may be caused by the so-called "selective perception" of people: each person consciously or unconsciously selects stimuli and information that are of interest and begins to perceive them selectively, omitting the remaining information.
- overload takes place when communication channels carry a volume of information greater than the processing capacity. Overload causes omission and greatly contributes to distortion.

Barriers for communication in the ICU are described in Chart 1. Charts 2 and 3 specify elements and strategies of good communication.

Chart 1 – Communication barriers in intensive care units

ļ	Communication barriers
	Body posture
	Preconceived ideas
	Perceptions and interpretations
	Schooling
	Personal meanings
	Motivation and interest
	Inability for communication
	Emotions and state of mind
	Other barriers: organizational climate, language, tracheostomy

## Chart 2 – Elements for good communication in the intensive care unit

intubation, sedation, cognitive disorders

Elements for good communication		
Humility		
Patience		
Transparency		
Assurance		
Teaching skill		

## Chart 3 - Strategies for good communication

Charty Strategies for good communication			
Strategies and techniques of communication			
Verbal	Non-verbal		
Promote empathy	Maintain physical		
Promote an interactive environnent	contact- touch		
Repeat information whenever	(Places suggested for		
necessary	touch hands, arms,		
Assure that communication was	shoulders))		
understood			
Know how to listen/foster	Facial expression		
communication of the other			
Use adequate tone of voice, be sincere	Body language		
and transparent			
Make time available and be available	Proper physical		
Mantain a consistent discourse	appearance		
Offer the best ( personal/technical)			
Stay alert mainly to your reactions			
and not those of others			
Suggest that the family put			
themselves in the patient's place (bring			
the patients opinions and feelings into			
the con versation)			
Use colloquial language and avoid			
euphemisms (simple and precise words)			

For communication related to treatment of patients in critical, terminal conditions it is recommended that:

- ICU must have an adequate place for interchange

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with the relatives:

- the physician does not assign to other professionals his/her role in communication;
- the same physician gives information to the family representative;
- the person who may serve as spokesmen in the patient's family, when needed, must be identified;
- unnecessary information or that not requested should not be anticipated;
- the largest possible number of meetings between patient/family/health staff must be assured;
- at least one exclusive time schedule should be set up for supply of information;
- information, after consensus among all involved physician, must be uniform.

The importance of developing continued/permanent educational activities about communication and terminality must also be considered. These activities may be lectures, training groups, courses etc. and collaborative information among the different professionals acting in the ICU, must be enhanced.

# PALLIATIVE CARES/ACTIONS IN THE INTENSIVE CARE UNIT

Interaction of all those involved in the process is important in palliative practice that is to say, the patient, relatives and health team. Such care necessarily includes a multidisciplinary perspective and institutional dimension, furthermore directed towards health teams. An ample approach encompasses this practice in the health systems and in society. (26)

Palliative care can and must be offered together with curative/restorative care, because there are not exclusively used for prevention and treatment of the suffering of patients and relatives. (26-28) Fundamental principles of palliative care in the ICU are specified in Chart 4.

To supply palliative care to critically ill patients and their relatives, action areas must be followed: peculiar to the patient, relatives and the multiprofessional team.

Regarding action areas peculiar to the patient, the individual's autonomy must be respected, also the principle of nonmaleficence, privileging decisions by consensus with the maximum assurance of irreversibility. That is why prior to the team's decision, the patient or the legal representative must have given their consent, as registered on the medical chart. (26.30)

For the purpose of nonmaleficence, the physician

## Chart 4 - Fundamental principles of palliative care in intensive care units

Palliative care in intensive care units Fundamental principles

Accept death as a natural end-of-life process Always give priority to the patient's best interest Reject futility: diagnostic and therapeutic

Do not shorten life nor prolong the process of dying

Warrant the quality of life and of death

Relieve pain and other associated symptoms

Heed the clinical, psychological, social, spiritual aspects of patients and relatives

Respect the patient's autonomy and of the legal representatives Assess the cost-benefit of each medical attitude taken Encourage interdisciplinarity as an assistential practice

will be authorized to interrupt futile interventions that only put off the act of dying, without benefit to the patient. Thus professional cannot avoid the responsibility of this final decision. All actors of the process must shun any conflict of interest in the face of this decision making. (26)

For full attention to relatives of a patient critically ill at terminal stage, any person showing an affective lien with the patient must be acknowledged as a relative when sharing in this end-of-life moment. Managers must guarantee privacy in the physical space and in the relations between those dying and their relatives. Cultural values and beliefs of each patient must also be recognized and respected. Support to relatives after the patient's death should be included in palliative care. (31,32)

It should be emphasized, in the interviews, the listening to relatives, the obtaining and sharing of the maximum information available, a compassionate attitude by the interlocutor with understandable information. It is mandatory that the time of understanding and family decision be respected because death involves numerous feelings that cannot be viewed entirely from a rational point of view. (30-35)

Members of the team that provide treatment to patients in end-of-life condition in the ICU endure enormous emotional stress. Therefore this team must be viewed not only as supplier but also the subject of care. As such, it is suggested that training and continued education be offered to qualify professionals for palliative care. The institution managing the process cannot exempt itself from its participation in the palliative care to the patient and relatives in an integral form. (26,28,29) Generally speaking, the palliative actions in the ICU are outlined in Chart 5.

Certainly the philosophy of palliative care is solely directed toward the critically ill end-of-life patient's well-being, However there is no legal definition in Brazil regarding changes of the therapeutic focus from curative to palliative. Discussions in the legal ambit on the subject have a bivalent interpretation. In defense of death at its due time the opinion of Diaulas

#### Chart 5 - Palliative actions in the intensive care unit

Palliative actions in the intensive care unit

Planning and action

All prevention and therapeutic actions must be planned with the participation of family, patient and health team.

Privilege adequate communication

Give support to those involved in the process (relatives and caregivers)

Permit flexibility to visits and, if possible, a companion Control symptoms and purveyance of the patient's comfort

Prevention and treatment of pain must be included as routine to intensive care. Relief of pain must be assured even in situations of the medication's double effect.

Recognize and treat the physical and psychological aspects of dyspnea and pain.

Aim the patient's well-being and not maleficence

Interrupt futile treatment that prolong the act of dying (Example: vasoactive agents, dialytic methods, total parenteral nutrition).

Adjustment of non-futile treatments (Example: individual sedoanalgesia, reassessment of ventilation support).

### Chart 6 - Key issues to be addressed on the subject

Key issues

Which are the medical practices and palliative cares offered to end-of-life patients that die in ICU and PICU in Brazil?

Which is the lay individual's expectation when facing endof-life and palliative care?

What is the epidemiology of human terminality in the intensive environments in Brazil?

Which are the conflicts of interest that pervade human terminality in the intensive environment?

How does communication interfere in the decision making process for end-of-life of patients among different members of the team?

How efficient is communication with family and patients in Brazilian ICUs?

How much does the family participate in decisions for the end-of-life of patients in the ICU?

ICU- Intensive care unit; PICU - pediatric intensive care unit

Costa Ribeiro "interruption of the therapeutic effort is supported in the Constitution which recognizes the dignity of the human being as basis of the status. Omission of medical treatments, at the request of the non-suicidal patients, is not a crime. The physician, as long as not a member of the transplant team, may participate in the decision of interrupting therapeutic effort (nutrition, hydration, ventilation), considering it futile". (36)

In view of the above stated, the authors took the initiative to suggest the key-issues to be addressed in the future about the subject of end-of-life in ICU (Chart 6).

#### **RESUMO**

O objetivo da presente revisão foi avaliar o estado atual do conhecimento sobre doença terminal e cuidados paliativos em unidade de terapia intensiva. Identificar as questões-chave e sugerir uma agenda de pesquisa sobre essas questões. A Associação Brasileira de Medicina Intensiva organizou um fórum especifico para o debate de doenças terminais na unidade de terapia intensiva, onde participaram profissionais experientes em medicina intensiva. Esses profissionais foram subdivididos em 3 subgrupos, que discutiram: comunicação em unidade de terapia intensiva, decisões diante de um doente terminal e cuidados/ ações paliativas na unidade de terapia intensiva. As informações e referências bibliográficas foram copiladas e trabalhadas através de um site de acesso restrito. Os trabalhos ocorreram em 12 horas quando foram realizadas discussões sistematizadas seguindo o método Delphi modificado. Foram elaboradas definições sobre a terminalidade. A adequada comunicação foi considerada de primordial importância para a condução do tratamento de um paciente terminal. Foram descritas barreiras de comunicação que devem ser evitadas sendo definidas técnicas para a boa comunicação. Foram também definidos os critérios para cuidados e ações paliativas nas unidades de terapia intensiva, sendo considerada fundamental a aceitação da morte, como um evento natural, e o respeito à autonomia e não maleficência do paciente. Considerou-se aconselhável a suspensão de medicamentos fúteis, que prolonguem o morrer e a adequação dos tratamentos não fúteis privilegiando o controle da dor e dos sintomas para o alívio do sofrimento dos pacientes com doença terminal. Para a prestação de cuidados paliativos a pacientes críticos e seus familiares, devem ser seguidos princípios e metas que visem o respeito às necessidades e anseios individuais. Os profissionais da unidade de terapia intensiva envolvidos com o tratamento desses pacientes são submetidos a grande estresse e tensão sendo desejável que lhes sejam disponíveis programas de educação continuados sobre cuidados paliativos.

**Descritores:** Cuidados paliativos; Doente terminal; Cuidados para prolongar a vida; Cuidados intensivos

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