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EDITORIAL

Babylon Tower

Torre da Babilónia



... And they say: "Come on, let's build a town and a tower reaching heaven..."

Genesis 11, 1-9

In most Western countries, about 1% of the population dies every year. Advances in medicine have greatly improved possibilities to effectively treat chronically ill patients and to prolong their life. There is increasing recognition that extension of life might not always be an appropriate goal of medicine. End-of-Life decisions can take place anywhere patients are cared, namely in hospitals, nursing homes, hospices and at home.

COPD is the 5th cause of mortality and will rank 2nd in the next few years. More and more patients are placed on mechanical ventilation (MV). Who should decide: when to start Palliative and/or End of Life Care, and when to withdraw or to withhold MV and End of Life Care?

Definitions are important: *Palliative Care* includes any intervention aimed to prevent and relieve suffering by controlling symptoms and providing other support to patients and families in order to maintain and improve their quality of life during all stages of chronic life-threatening (or end stage) illness.

End of Life Care is the care (comfort, supportive or symptom care) provided to a person in his/her final stages of life.

It is difficult to forecast survival time of COPD patients. End stage COPD patients undergoing endo tracheal intubation and MV suffer from bad prognosis and difficult weaning, due, among others to old age, muscle wasting, chronic hypercapnia and hypoxia, nutrition problems, use of systemic steroids and lack of mobility. Half of these patients will die in hospital, most of them in the Intensive Care Unit (ICU); survivors needing prolonged intensive nursing and physiotherapy complain of reduced quality of life as a result of long periods of hospitalization or tenancy in other health residences.

Nevertheless clinical and physiological severity of COPD cannot be the main determinant of End of Life treatment preferences. That is why doctors should not argue that a severe health status may induce them and/or the patient to

refuse invasive life support. Indeed doctors are usually less able than expected, to predict real life expectancy, and have difficulty in identifying low prognosis patients.³

In this issue of the journal Gaspar et al. ⁴ report the results of a national survey in Portugal on the attitude of pulmonologists toward End of Life Care issues in COPD patients. The main message of this survey is that doctors should spend more time to speak with patients and relatives to inform them about the patient's prognosis and real care possibilities. The other main message is the need of greater awareness of properly treating (and how) the symptoms, first of all, dyspnea.

In this regard it is surprising that even at medical level there is unduly concern about hypothetical dangerous side effects of treating symptoms such as dyspnea. Indeed opioids in lower doses are not associated with increased hospital admissions or deaths in patients receiving long term oxygen therapy for COPD.⁵

Present times are facing changes in patient–doctor relationship. Final decisions on care are not only up to doctors anymore, but they are also the result of the sum of different viewpoints. Doctors and other allied health care professionals seldom share the same view on the prognosis. Relatives have different sources of information: general practitioner, Internet, and TV programs (including fictions like *E.R., Doctor House, etc.* which usually have a more optimistic view of medicine possibilities, including somehow immortality). Religious vision and teaching may influence decisions. Legal issues and fears are more and more main determinants in End of Life decisions. Availability of advanced directives is different in different countries. Health system organization and facilities as a result of Governments' financial restraints are becoming more and more important factors in decisions.

As a matter of fact surrogate decision making occurs for nearly half of hospitalised older adults and includes both complete decision making by the surrogate and joint decision making by the patient and surrogate facing a broad range of decisions in the ICU and the hospital ward setting. Nevertheless appropriate decisions need appropriate information, and this is an issue requiring improvement in knowledge of medical and health care allied professionals.

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Indeed technical progress and availability of machines supporting and prolonging life may result in "challenge to God" like in the Babylon Tower Biblical story. The challenge is: God has given a natural history to illness, machines prolong this story. We should remember that the final result of such a challenge was the complete confusion in language. I wonder whether all professionals, media leaders and health authorities have clear in mind the difference among care withdrawing, withholding and euthanasia (words are important).

In conclusion refer to the basic ethical principles (i.e. autonomy), recognize the need for limiting life prolonging treatments such as mechanical ventilation, keep the family totally informed, have clear in mind definitions, do not be "afraid" of the double effect (i.e. use opioids), and improve organization of Palliative Care.

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