

Death and Dying in the ICU- The Chamber of Torture

Manuel Lois*

Department of Medicine, John Peter Smith Hospital, 1500 South Main, Fort Worth, Texas, USA

*Corresponding author: Manuel Lois, MD, FCCP, FACP, Department of Medicine, John Peter Smith Hospital, 1500 South Main, Fort Worth, Texas, USA; E-mail: mlois@jpshealth.org

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Opinion

When patients get sick and seek medical attention, they expect doctors will help them get back to “normal”. Contrary to what many television shows depict, many ICU patients are those with chronic or incurable diseases; often in the terminal stage. When you walk through the ICU what you actually see are patients connected to ventilators, dialysis machines, numerous IV pumps and restraints to prevent them from removing all that equipment. Families seldom see their loved ones attempting to remove their endotracheal tube, or grimacing as nursing staff adjust those tubes that have been placed into the lungs or stomach, or when they are being treated for bed sores from prolonged immobilization.

Patients too often suffer in vain attempts to prolong life, because of the mandate to “do everything.” Death and dying does not happen to us, but to someone else”. We have a “replacement mentality” and therefore “Americans not only don’t want to die, they are unwilling to accept the reality of death.” Fact is we all are going to die.

Doctors frequently are afraid of facing death and are reluctant to disappoint a patient with the grim truth, and knowingly or not, keep false hopes alive. Physicians are not educated on death and dying and therefore are not prepared to help patients or families face these critical times. To make things worse, patients and families not only overestimate the power of modern medicine, they are also often in shock, faced with serious questions that are frequently overlooked or considered before tragedy hits. Is it God’s will for us to do everything possible to prolong his/her life, no matter how much our beloved is suffering? Are we playing God and fighting God’s will? Is it suicide to refuse medical care or is it murder not to give it? Is it a sin? How are we to decide when the people we love can no longer speak for themselves?

The reality is that with technology we defy natural selection. We help patients with curable conditions while their body recovers; However in the majority of cases we make them survive just to endure a chronic, debilitating condition or worst we prolong death.

Fortunately, two new fields are providing relief to all this tension and providing guidance for families and physicians in navigating these difficult times.

Bioethics is the philosophical study of the ethical controversies brought about by advances in biology and medicine. Bioethicists are concerned with the ethical questions that arise in the fields of life

sciences, biotechnology, medicine, politics, law, philosophy, and theology. Many bioethicists are made up of philosophers, religious leaders, physicians, nurses, administrators, and lawyers that help bridge the gap between families and physicians and ease the moral and legal burdens of decisions faced during these critical times.

Hospice and palliative medicine focuses on improving a patient’s quality of life by managing pain and other distressing symptoms of a serious illness. They provide emotional and physical support for patients and families, helping them have a more natural and dignified dying process.

Modern medicine can achieve great things, but all too often when patients have no hope of surviving, technology and drugs are still used to simply keep people “alive”, as long as possible.

Both physicians and families need to understand that there is a moral, ethical, and legal right to allow natural death and avoid further unnecessary suffering. The treatment goals at the end of life should focus on providing emotional and medical support while maintaining quality of life. Making the final outcome a more pleasant and less painful experience for families and most importantly, the patient.

Research of AYAs with cancer has developed significantly over the last 20 years. The research has demonstrated that AYAs with cancer are a forgotten population, who require closer study in order to understand their unique issues. This paper examines family members’ experiences of adolescents and young adults (AYAs) during the dying stage of their cancer trajectory.

The results are drawn from a larger study titled ‘From Go to Woe; Family Members’ Stories of Adolescents and Young People Living with and Dying from Cancer, which storied the family members’ experience of the diagnosis, treatment, dying and death of an AYA family member, utilizing Armstrong-Coster’s (2004) four stages of the cancer trajectory. The principal researcher’s motivation to understand and story these experiences was related to her own isolation and lack of information when her 16 year old son Anthony, was diagnosed with and eventually died of cancer at 17 years of age.

The significance of this study is the contribution made to the identification of issues that can inform health policy/guidelines. The findings have the potential to increase understanding of, and prepare family members and AYAs with cancer, for the experience of the death and dying stage of the cancer trajectory.