Introduction and Problem

Background

Do Not Resuscitate (DNR) and Allow Natural Death (AND) orders are becoming more common in practice in Saudi Arabia, specifically when dealing with terminally ill and dying patients. The international literature reports that patients and families are increasingly part of the decision-making process when it comes to deciding to introduce Cardio Pulmonary Resuscitation CPR in emergency situations and critical care. Patients and families can assign a proxy to take a decision on their behalf if they are not in a position to do so. Being able to make such a decision in agreement with their healthcare professionals, gives patients autonomy over life and death decisions. How is this applied in our population in Saudi Arabia as a practice?

Traditionally, healthcare system and healthcare professionals, act using a paternalistic approach. Healthcare professionals make treatment decisions for their patients, and this is a societal expectation as they are seen to have the knowledge and expertise necessary to make such decisions.

Currently in Saudi Arabia, patients and their families are in a position where they like to be informed and involved in the decision-making process during disease trajectory. Taking into consideration the sensitivity of a DNR order, this is becoming a crucial topic for discussion and communication.

The impact of such decisions on patients and their families can be frightening, highly emotional, distressing, and might be considered neglecting the patient’s rights. Health providers may not keep informed about disease progression, the condition and status of their loved-ones, and were excluded from the decision-making process.

Purpose and Objectives

Purpose:

This study looked at the prevalence of DNR/AND practices in three major hospitals in different regions of the Kingdom of Saudi Arabia. It examined if patients or families had been informed of such decisions. This study also explored if referral to palliative care was adequate and if patients or families had not been informed about disease progression, the condition and status of their loved-ones, and were excluded from the decision-making process.

Methodology

Design: Medical records of patients with a documented DNR order between 2011 and 2016 were retrospectively reviewed after receiving IRB approval from each hospital.

Sample Selection: The investigators included medical records of patients who were diagnosed with terminal life-threatening illnesses at 18 years of age and above and were put on DNR status. The settings included three institutions: King Fahad Medical Center, Riyadh (KFMC); King Abdulaziz Medical City, Jeddah (KAMC); and King Fahad Specialist Hospital, Dammam (KFSH). Any record that did not meet eligibility criteria was excluded from the study. The researchers were able to successfully collect information required for the study from more than 300 patient records.

Instrument: A data collection sheet comprising two parts was used. Patient demographics included age, diagnosis, etc. The DNR form used in each institution was also used to gather data for the study. Data Collection: The researchers obtained a list from each hospital of all patients who had a DNR order between 2011-2016. In each hospital, the Medical Records, Palliative Care and Oncology departments were involved in providing the data. Patient medical records were accessed and reviewed to extract the required information for the study. Patient records that did not meet eligibility criteria for the study were excluded.

Ethical Consideration: The research proposal and documents were sent to the Institution Review Board (IRB) of each institution for approval. The study was approved by all IRBs. Since this is a retrospective study and did not involve actual patient and family contact, informed consent was not required. Confidentiality and anonymity was considered by the inclusion and collection of data from patient records and using data in an aggregate form without individual identifying information. There was no patient/family/physician contact at any point.

Data Collection: Data were collected manually in a locked cupboard in a locked office with access only allowed by the primary researcher. The data were also electronically stored in a folder in a password protected computer only accessible by the primary researcher.

Data Analysis: Data were collected and assigned serial code numbers. The primary investigator is responsible for all data from all hospitals.

Results

Is there a relationship between patient demographics and patient/family awareness of a DNR decision?

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Results

• 99% of patients had their DNR form signed. 86% of patients had the DNR form signed in an inpatient area, 7% as outpatients and 3% in the emergency room. (Table 1)

• 76% of patients died, and of those, 67% died in a hospital ward while the place of death was unknown for 25% (Table 2).

• 9% of patients were aware of their DNR status, while 57% of the families had been informed about the patient’s DNR status (Table 3).

• 54% of patients had documentation about DNR status discussed with family (Table 4).

• DNR discussion with patient/family took place prior to DNR signature in 39% and 25% after obtaining the DNR signature.

• In regard to DNR documentation, only 54% of discussions were related to DNR and plan of care and in 40% nothing was reported in this respect.

• Only 47% of families had a reaction towards awareness about DNR status. Only 42% agreed on the care and decision; however, only 6% of families requested transfer to other facilities, while in 52%, family reaction documentation was not found.

• 99% of patients were referred to palliative care, and 89% of patients palliative and supportive Plan of Care was started for them.

• 42% of the care plans were initiated to control physical symptoms for patients, while 47% were a combination of both physical and psychological symptom control.

• Although, end of life protocol is a hospital policy in KFMC, only 17% of patients had an end-of-life protocol started for them.

• The average age of patients is 61 years. The average number of admissions before DNR signature is 4 admissions and SD of 6 compared to 1 admission after DNR signature with SD of 2 admissions. The average length of stay from diagnosis to palliative care referral is 600 days with SD 716 days. The average length of stay from DNR signature to palliative care referral is 87 days with SD of 171 days (Table 5).

• The average length of stay days from palliative care referral to death is 68 with SD of 102 days. The average length of stay from DNR signature to death is 93 days with SD 143 days. The average number of days from diagnosis to patient diagnosis to patient death was 637 days with SD of 721 days (Table 5).

Conclusion

Based on the preliminary results, there is a notable fact that patients are not informed about their DNR status, but more family members are. Documentation of DNR status and plan of care remains an issue. There is a delay in referring patients to palliative care services which results in patients not receiving the appropriate care and symptom management that is needed. Early referral to palliative care remains the ultimate goal for compassionate care.

References