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ICCR Study Proposal

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Family Satisfaction and End-of-life care in the ICU:

A prospective survey study

Study Purpose and Rationale

The principal goal of intensive care medicine is to help patients survive acute, severe illnesses and prevent long term morbidity that results from these severe illnesses. While the majority of patients admitted to intensive care units (ICUs) survive, approximately 22% of all deaths in the United States occur in the ICU, which accounts for over half of all hospital deaths.[1] Despite the frequency with which end-of-life issues arise in medical training, several studies have demonstrated that medical residents often feel inadequately prepared to discuss end-of-life issues with patients and their families.[2] Reasons include lack of time, lack of training, discomfort with uncertainty, discomfort with dying patients, and lack of continuity in patient relationships.[2]

In recent years, there has been increasing emphasis on the importance of end-of-life issues among patients and their families. Increasingly, patients, or more commonly their families, choose to withhold resuscitation or withdraw life-supporting therapies such as ventilators and dialysis. A study of 136 ICUs found that 74% of 5910 dying patients had some form of treatment withheld or withdrawn before death.[3] As a result of this shift, medical residents in an ICU setting must help families make informed decisions which are both medically appropriate and in line with patients and patients' families wishes. In the ICU, effective and empathetic communication between medical staff and a patient's family is essential to this process. The medical community has a responsibility to patients and their families to ensure that residents are properly trained to participate in important end-of-life discussions.

The goal of this study is to use a survey format to identify and compare levels of satisfaction with communication by medical staff regarding end-of-life issues, as evaluated by the loved ones of patients who have died in the two medical intensive care units at Milstein Hospital. The three primary purposes of this study are as follows:

- To describe levels of satisfaction with critical care among families and loved ones of patients who have died in the ICU;
- To determine which variables correlate with high degrees of satisfaction (e.g., language, level of education of family member or loved one);
- To determine whether satisfaction with care varies between Medical Intensive Care Unit A (MICU A), staffed by medical residents, and Medical Intensive Care Unit B (MICU B), staffed by physicians' assistants.

My hope is that this information can then be used to develop teaching tools for medical residents, using the study to target variables identified as having high correlation to satisfaction of family and loved ones.

Study Design and Statistical Analysis

This is a prospective survey study completed by the primary contact person for patients who die in MICU A and MICU B over an 18 month period. One family member per patient will be identified and consented at the time of admission to either MICU A or MICU B. That family member should be the primary contact person for the medical staff in the ICU. The contact person may be, though is not limited to, a family member, health care proxy, surrogate and/or close loved one. If a patient dies during the course of his or her time the ICU, the identified contact person will be mailed a questionnaire four weeks after the death, in order to all the family members an appropriate period of grieving while still allow for a period of time in which their memories of the ICU experience will be relatively fresh. If there is no response from the contact person, a second copy of the questionnaire will be mailed again after another four week period.

Data will also be collected describing the demographic characteristics of the patients, (e.g., age, gender, race, cause of death) and relevant details of their hospital stay, including primary admission diagnosis, number of co-morbid conditions, APACHE II score, length of stay, onset of death (gradual vs. acute), and level of life support at death (e.g., withdrawal of life support, withholding resuscitation, withholding life support, or full resuscitation). We will also collect demographic data describing the characteristics of the contact people completing the survey, including their relationship to the patient, age, race, level of education, language spoken, and whether they lived with the patient.

The survey used will be the Family Satisfaction with care in the Intensive Care Unit (FS-ICU[24]), a 24-question survey that provides an overview of the satisfaction of loved ones. Details regarding the questionnaire are listed below. Scoring for each item will be based on the following scale, adapted from the survey designers4: Excellent or completely satisfied = 100, very good or very satisfied = 75, good or mostly satisfied = 50, poor or slightly dissatisfied = 25, very poor or very dissatisfied = 0. A composite score will be calculated and an unpaired t-test will be performed to identify differences in satisfaction between communication skills of medical staff in MICU A (residents) and MICU B (physicians' assistants). Estimated response rate based on data from prior similar survey studies is between 62-70 percent. The study will last for 18 months, with a goal of 180 responses as a sample size (based on estimate composite score 84 with SD ±15. Sample size of 180 survey respondents can show a difference of 6.7 using unpaired t-test (80% power and α 0.05). A multiple regression analysis will be also performed to identify variables that are highly correlated with high levels of satisfaction.

Study Procedures

No procedures will be involved in this study.

Study Questionnaires

The questionnaire used is the 24-question Family Satisfaction with care in the Intensive Care Unit (Addendum 1), which has been independently developed and validated.[5] The purpose of the questionnaire is to provide a broad overview of satisfaction with care and a more detailed assessment of satisfaction with decision making.

Study Subjects

Inclusion Criteria:

- Responders must be the primary contact person for medical staff during the patient's ICU admission;
- The patient must have been admitted to the ICU for at least 48 hrs and died during their ICU admission;
  Responders must be able to read and write English or Spanish at a minimum of a sixth grade level.

Exclusion Criteria:

- Medical staff may request that families not be approached or contacted after the death of the patient in certain instances (e.g. cases of litigation).

Recruitment

A research assistant working in the ICU will prospectively identify consecutive eligible patients. If an eligible patient dies, we will record the contact information of contact person for that patient. Four weeks after the death of the patient, a questionnaire will be mailed to the contact person for each eligible patient. If no response is received, a second questionnaire will be mailed after another four weeks.

Confidentiality of Study Data

All patient contact information will be kept confidential, and the questionnaire responses will be depersonalized and identified by a number which will correlate to each patient contact person. No medical staff will be able to identify the responders.

Potential Conflict of Interest

In order to avoid a potential conflict of interest, physicians' assistants and medical residents will not be involved in recruitment of patient contacts for the study.

Potential Risks

There are no potential physical risks. One potential emotional risk is the exacerbation

of grieving of the loved one. To minimize this risk and aid the bereaved, contact information on local resources for grieving family and friends will be made available upon request (e.g., counseling services, clerical resources).

Potential Benefit

This study will help assess the level of satisfaction among family members and loved ones of patients who die in the ICU. It will also allow clinicians to better understand the variables associated with family/loved one satisfaction. The results of such a study can be used to develop teaching tools to better prepare medical residents to communicated with families and discuss end-of-life issues in the ICU setting.

Alternatives

An alternative technique to this study might be to conduct either a phone or in-person interview, which, as opposed to a written questionnaire, would allow us to obtain information from those loved ones who cannot read or write in English or Spanish. It may also increase our response rate.

Compensation

The postal fees associated with mailing the completed questionnaire will be covered by study group.

References

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