End-of-Life Care Decisions Among Terminally Ill Patients: Demographic Characteristics of Patients With and Without a Do-Not-Resuscitate (DNR) Order and Reasons for Patients' Decision to Have No DNR Order

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A. Study Purpose and Rationale

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Patients with terminal illnesses often have not made final decisions in regards to end of life care, specifically pertaining to signing a DNR order. In an effort to improve palliative care in terminally ill cancer patients, this study will explore demographic characteristics of patients with and without DNR a order in an effort to identify target patient populations for additional discussion and education. Furthermore, patients identified to not have a signed DNR order will be further studied to examine the reasons for their decision.

Hypotheses

Low socioeconomic status and belonging to a minority racial group will be associated with not having a DNR order as part of advanced care directives. Advanced age and having more advanced disease will be associated with increased likelihood of having a DNR order. The relation between sex and having a DNR order is unknown.

Reasons for not having a DNR order will likely: limited knowledge of his/her disease and prognosis, lack of understanding of the significance of DNR, and suboptimal communication with caregivers about plans for end-of-life care.

Background and Literature Review

As a large cancer treatment center, Columbia University medical staff frequently communicates with patients who are terminally ill and their families about end-of-life care issues. Terminally ill cancer patients are often admitted to ward and acute care settings without evidence of advanced care directives, including DNR orders. A DNR order explicitly mandates that cardiopulmonary resuscitation is not initiated in a patient who has cardiac arrest. Limited studies have shown that many terminally ill patients have not incorporated DNR orders into their end-of-life care plan until the time they die (Levin, TT et al. 2008). Efforts to expand the current knowledge of the characteristics of patients with and without DNR orders and the reasons why terminally ill patients without such orders make this decision will improve the quality of the care they receive at the end of their life, facilitate identification of target groups of patients with whom end-of-life discussions might be more challenging and will provide useful training information for physicians involved in facilitating this important discussion.

DNR utilization studies have been well documented in nursing home patients (Messinger-Rapport et al 2005). In cancer patients, the incidence of DNR was examined in a study of over 200,000 patients in a large cancer institution, and showed that the use of the order increased between the years 2000 and 2005. In this single-institution study, demographic characteristics of patients with and without DNR orders are reported, with evidence that females, Hispanics, and high socioeconomic status were associated with increased likelihood of being DNR. (Levin, TT. et al 2008). Interestingly, this study showed that the median time to signing a DNR order and time of death was 0 days, meaning that among patients with and without capacity, DNR orders were signed on the day of death. A study of hospitalized patients in Germany showed that 65% of patients had DNR orders, and these prders were signed an average of 5 days before death (Becker, G et al. 2007). These findings suggest a need for strategies to target terminally ill patients earlier to provide optimal palliative care.

Discussions regarding end-of-life treatments are often complex and difficult, incorporating emotional and moral aspects of both patients' and caregivers' attitudes. Both patient-derived and physician-derived factors are responsible for underutilization of DNR orders. Patient-related factors include lack of understanding of their diagnosis and prognosis, denial, a sense of hope that their disease may improve, and misinterpretation of "do-not-resuscitate" to mean "do not treat", therefore fearing that if the order is put in place, they would not receive adequate treatment (Olver I et al 2008). An observational study in heart failure patients suggested that in patients with a DNR order, quality assurance parameters such as assessment of left ventricular function and pharmacologic treatment to block the renin-angiotensin system were performed less frequently compared to patients without a DNR order. (Chen, JL, 2008). Similarly, a study of the effect of a DNR order on the care plan in a critical care setting showed that significant changes to care were made after such order was designated, often withholding or withdrawing certain treatments. (Carrion Torre, M 2008). Patients and their families may also perceive such decisions as making a choice between life and death, which can present an ethical and moral as well as religious dilemma (Eliott J, Olver I). Physician factors involved in the underutilization of DNR may include fear of damaging patient-doctor relationship, lack of confidence in having such discussion stemming from inadequate training (Sulmasy et al J Med Ethics. 2008 Feb;34(2):96-101), and having a sense of doing everything possible to preserve life. On this latter point, it is interesting to note that delays in proper prognostication and discussion of end-of-life care issues occur when physicians know their patients better (Levin TT 2008). The underlying message is the need for better communication between patients, their families, and physicians regarding preparation for the end of life, in an effort to optimize palliative care for the patient.

Although the epidemiology of DNR has been studied in various populations, the characteristics of terminally ill cancer patients who do and do not have signed DNR orders have not been reported. A study of nursing home residents showed racial disparities affecting end of life decisions in elderly residents. Compared to minority residents, white residents were more likely to have DNR orders (69.5% vs. 37.3%), living wills (39% vs. 5%), and health care proxies (36.2% vs. 11.8%; $p < .001$ for each). Age was also strongly correlated with advanced directives. (Reynolds, KS, 2008). Another study exploring the determinants of DNR orders in home palliative care patients found that in addition to proximity to death, incontinence, and sleep problems, acceptance of one's own situation and a preference to die at home are associated with DNR completion. (Brink P, et al. 2008).

In an effort to improve end-of-life care in terminally ill cancer patients, this study will identify demographic characteristics of terminally ill cancer patients with and without DNR orders. In patients who do not have a DNR order, further study with the use of questionnaires will be conducted to explore the factors associated with this decision. This information will help identify areas of focus to help caregivers more effectively communicate with their patients about end of life care and DNR specifically. Understanding these issues will help optimize palliative care for these patients in the face of imminent death.

B. Study Design and Statistical Analysis

Study Design

The first part of the study will be a retrospective case control analysis using medical records from cancer patients currently being treated at the Herbert Irving Comprehensive Cancer Center of Columbia University Medical Center. Oncologists will be asked to identify patients in their current practice who they deem as being terminally ill (defined by an estimated life expectancy of less than or equal to 6 months based on the specialists own expert knowledge). Patients may have any malignancy, solid or hematologic. Informed consent will be obtained from the patient to review their medical records and participate in the second part of the study. The medical records will be reviewed, and the patients will be divided between those who do (cases) or do not (control) have a DNR order in place. In each group, the following descriptive variables will be obtained from the records: Race, Sex, Age, and Address (as surrogate for socioeconomic status). The patient’s disease will also be recorded.

The second part of the study will explore reasons for their decision in patients identified in the first part as not having a DNR order. A questionnaire will be developed prior to initiation of the study that will incorporate elements related to the patient's decision to not have a DNR order. Questionnaires will be administered in English and Spanish.

Statistical Analysis

To study the association between DNR order versus no DNR order and patients' characteristics, chi squared tests will be used to analyze discrete variables. Regression analyses will be done to evaluate the different variables. A 2-sided α of .05 will be used as the criterion for significance.

Data obtained in the second part of the study will be evaluated separately, and responses will be described.

Sample Size

The sample size is limited by the number of available records at the Herbert Irving Comprehensive Cancer Center. As specific information regarding the incidence of the various demographic characteristics and the decision to have or not to have a DNR order is not well-described in the literature, sample size calculations are difficult. For example, using chi square test of proportions in two groups, assuming a 10% difference in the rate of having a DNR order between whites and minorities, 382 patients will be needed in each group for 80% power to detect a statistically significant difference at $p<0.05$. Overall, it is estimated that approximately 400 patients will be required in each DNR group to appropriately power the study.

C. Study Procedures

All oncologists in active practice at the Herbert Irving Comprehensive Cancer Center will be invited to provide patients in their practice who meet the inclusion criteria as described below. Given the sensitive nature of end-of-life discussion, the physicians will be asked to identify only those patients with whom the conversation regarding DNR has taken place, and it is clear that these patients have or have not decided to have a DNR order (as documented in the patient's medical record). Patients who are "undecided" about a DNR order will be counted in the "No DNR" group.

Patient records will then be reviewed, and patients will be divided into two groups: "DNR" vs. "No DNR", referring to whether or not the patient has decided to have a DNR order in place. Demographic characteristics will be compared between the two groups. The patient's diagnoses will also be recorded.

Identified patients in the “No DNR” group will be contacted by study personnel for informed consent for the second part of the study. The questionnaires will be administered, and answers will be recorded.

All data will be collected by study personnel and stored in a secure location within the Center building. Patient confidentiality will be maintained at all times.

D. Study Drugs

Not applicable

E. Medical Devices

Not applicable

F. Study Questionnaires

A simple questionnaire will be used to guide patient interviews for the second part of the study. This questionnaire was developed by the investigator and has not been statistically validated. It is meant to be a descriptive tool to explore reasons underlying a patient’s decision to not have a DNR order.

G. Study Subjects

Inclusion criteria

1. Adult patients with any hematologic or solid organ malignancy
2. Patient must be deemed by their Oncologist as having a predicted life expectancy of less than or equal to six (6) months.
3. Patients must be able to read in English or Spanish
4. Patients must have legal capacity to be able to provide informed consent in English or Spanish.

Exclusion criteria

Providing the inclusion criteria are met, there are no exclusion criteria.

H. Recruitment of Subjects

Patients will be referred to the study by their Oncologist. Recruitment advertisements can be displayed at Oncologists’ offices to prompt the to ask their Doctor about the study.

I. Confidentiality of Study Data

Participant information will be coded to preserve confidentiality, and will be stored in a secure location accessible only to study personnel.

J. Potential Conflict of Interest

There are no conflicts of interest.

K. Location of Study

The study will be conducted at New York Presbyterian Hospital Columbia University Medical Center and associated sites.

L. Potential Risks

The questionnaire in the second part of the study deals with issues that may be of a sensitive and emotional nature. Emotional distress related to the patient's poor prognosis is a potential risk to the patient.

M. Potential Benefits

As a participant in this study, patients will be able to discuss issues related end-of-life care, which may improve palliative measures.

N. Alternatives:

The patient may choose not to participate in the second part of the study. Patients may be referred to the Center's Palliative Medicine Service if they are interested in discussing end-of-life issues outside the present study.

O. Compensation to Subjects:

Compensation will not be provided.

P. Costs to Subjects:

There will be no costs to the patient.

Q. Minors as Research Subjects:

Not applicable

R. Radiation or Radioactive Substances:

Not applicable

References

Becker G, Sarhatlic R, Olschewski M, Xander C, Momm F, Blum HE. End-of-life care in hospital: current practice and potentials for improvement. J Pain Symptom Manage. 2007 Jun;33(6):711-9.

Brink P, Smith TF, Kitson M. Determinants of do-not-resuscitate orders in palliative home care. J Palliat Med. 2008 Mar;11(2):226-32.

Carrión Torre M, Zubizarreta Iriarte E, Sarasa Monreal MM, Margall Coscojuela MA, Asiain Erro MC. [Effect of the do-not-resuscitate orders on the critical patient care plan]. Enferm Intensiva. 2008 Jan-Mar;19(1):14-22. Spanish.

Chen JL, Sosnov J, Lessard D, Goldberg RJ. Impact of do-not-resuscitation orders on quality of care performance measures in patients hospitalized with acute heart failure. Am Heart J. 2008 Jul;156(1):78-84. Epub 2008 Apr 14.

Eliott J, Olver I. Choosing between life and death: patient and family perceptions of the decision not to resuscitate the terminally ill cancer patient. Bioethics. 2008 Mar;22(3):179-89.

Eliott JA, Olver IN. The implications of dying cancer patients' talk on cardiopulmonary resuscitation and do-not-resuscitate orders. Qual Health Res. 2007 Apr;17(4):442-55.

Levin TT, Li Y, Weiner JS, Lewis F, Bartell A, Piercy J, Kissane DW. How do-not-resuscitate orders are utilized in cancer patients: timing relative to death and communication-training implications. Palliat Support Care. 2008 Dec;6(4):341-8.

Messinger-Rapport BJ, Kamel HK. Predictors of do not resuscitate orders in the nursing home. J Am Med Dir Assoc. 2005 Jan-Feb;6(1):18-21.

Olver I, Eliott JA. The perceptions of do-not-resuscitate policies of dying patients with cancer. Psychooncology. 2008 Apr;17(4):347-53.

Reynolds KS, Hanson LC, Henderson M, Steinhauser KE. End-of-life care in nursing home settings: do race or age matter? Palliat Support Care. 2008 Mar;6(1):21-7.

Sulmasy DP, Sood JR, Ury WA. Physicians' confidence in discussing do not resuscitate orders with patients and surrogates. J Med Ethics. 2008 Feb;34(2):96-101.