



## Decision conflict and regret among surrogate decision makers in the medical intensive care unit



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### ABSTRACT

**Introduction:** Family members of critically ill patients in the intensive care unit face significant morbidity. It may be the decision-making process that plays a significant role in the psychological morbidity associated with being a surrogate in the ICU. We hypothesize that family members facing end-of-life decisions will have more decisional conflict and decisional regret than those facing non-end-of-life decisions.

**Methods:** We enrolled a sample of adult patients and their surrogates in a tertiary care, academic medical intensive care unit. We queried the surrogates regarding decisions they had made on behalf of the patient and assessed decision conflict. We then contacted the family member again to assess decision regret.

**Results:** Forty (95%) of 42 surrogates were able to identify at least 1 decision they had made on behalf of the patient. *End-of-life decisions* (defined as do not resuscitate [DNR]/do not intubate [DNI] or continuation of life support) accounted for 19 of 40 decisions (47.5%). Overall, the average Decision Conflict Scale (DCS) score was 21.9 of 100 (range 0–100, with 0 being little decisional conflict and 100 being great decisional conflict). The average DCS score for families facing end-of-life decisions was 25.5 compared with 18.7 for all other decisions. Those facing end-of-life decisions scored higher on the uncertainty subscale (subset of DCS questions that indicates level of certainty regarding decision) with a mean score of 43.4 compared with all other decisions with a mean score of 27.0. Overall, very few surrogates experienced decisional regret with an average DRS score of 13.4 of 100.

**Conclusions:** Nearly all surrogates enrolled were faced with decision-making responsibilities on behalf of his or her critically ill family member. In our small pilot study, we found more decisional conflict in those surrogates facing end-of-life decisions, specifically on the subset of questions dealing with uncertainty. Surrogates report low levels of decisional regret.

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### 1. Introduction

Being the surrogate decision maker of a patient in the intensive care unit (ICU) is associated with significant psychological morbidity. There is a prevalence of both anxiety and depression in greater than 30% of surrogates while his or her family member is in the ICU [1,2]. Symptoms of depression and anxiety tend to taper off over time; however, they often evolve into clinically relevant posttraumatic stress symptoms in a significant proportion of patient families [3].

A recent systematic review of the effect on surrogates making treatment decisions for others revealed that approximately one third of decision makers face a negative emotional burden [4]. Azoulay and colleagues [3] demonstrated that the prevalence of posttraumatic stress disorder (PTSD) among surrogates of ICU patients is common. Surrogates involved with everyday decision making for a patient in the ICU

had a PTSD prevalence of almost 50%. When the decision making involved end-of-life decisions, the prevalence of PTSD exceeded 80% [3]. These studies indicate that it could be the decision making itself that is the source of the psychological morbidity associated with being a surrogate decision maker. The burden of being a surrogate in the ICU is so profound that a new term was recently coined by a Society of Critical Care Medicine task force to refer to the cluster of symptoms that family members of ICU patients confront. This is known as *post-intensive care syndrome—family* [5].

Most studies that examine the decision-making process in the ICU are retrospective and focus on a limited range of decisions (typically involving end-of-life decisions) [3,6–8]. Less is known about the broader scope of decisions that surrogates confront when patients are in the ICU.

In our preliminary study we sought to determine the feasibility of prospectively assessing the range of decisions surrogates themselves face while his or her family member is still in the ICU. To better understand these decisions, we applied 2 separate validated questionnaires: the Decision Conflict Scale (DCS) and, in a follow-up period, the Decision Regret Scale (DRS). We hypothesized that those family members that face end-of-life decisions will experience greater decisional conflict

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vs all other decisions. We further hypothesized that family members of ICU patients with worse functional outcomes will experience greater decision regret.

## 2. Materials and methods

### 2.1. Setting

This is a single-center prospective study based in the medical intensive care unit (MICU) of a large tertiary referral hospital. The MICU is a closed unit at a teaching institution and is staffed by intensivists, trainees, advanced practitioners, and medical students. The nurse to patient ratios is 1:2. Additional support staff included pastoral care, social workers, and an on-site palliative care nurse 12 hours per day. It should be noted that the family meetings held by the ICU staff would be best described as “usual care.” At the time of our enrollment period, our ICU had no standardization for timing, structure, or content of the family meeting. In addition, there was no formal ICU meeting curriculum for ICU staff.

The project was approved by the Wake Forest Baptist Medical Center institutional review board and was found to be in accordance with the ethical principles set forth by the Declaration of Helsinki. Consent was obtained in person or over the phone with the primary decision maker for enrolled patients.

### 2.2. Eligible patients

Enrollment in our study took place during the 9-month period from April 2014 to December 2014. We enrolled a convenience sample of patients older than 18 years who had received mechanical ventilation greater than 96 hours along with his or her surrogate decision maker. If we were unable to contact the surrogate after the fourth day of mechanical ventilation, we attempted to contact him or her again every 24 to 48 hours for 10 days, until the 14th day of the patient being mechanically ventilated. We chose 96 hours of mechanical ventilation for several reasons. First, based on Diagnosis-Related Group data and previous studies, it is known that patients receiving mechanical ventilation greater than 96 hours experience a high mortality rate and often do not return home immediately after hospitalization [9–12]. By enrolling surrogates of patients receiving prolonged mechanical ventilation, we presumed that there would be a high likelihood that the surrogates would face important medical decisions. In addition, we felt that surrogate decision makers would have adequate exposure to the ICU setting at this time, where they could become accustomed to the daily staff exposure and intensity of patient care. We excluded MICU patients if they maintained independent decision-making capacity or if they lacked a surrogate or next of kin. We also excluded patients who were receiving mechanical ventilation before the hospital admission, and those who received urgent tracheostomy on admission or less than 96 hours after initiation of mechanical ventilation.

### 2.3. Questionnaires

The DCS is a validated instrument to assess conflict with medical decision making [13]. The 16-item scale captures factors associated with decision conflict on 5 subscales. The 5 subscales include informed, values clarity, support, uncertainty, and effective decision. The scale measures personal perceptions of uncertainty in choosing options, modifiable factors contributing to uncertainty (with informed, values clarity, and support subscales), and effective decision making (with uncertainty and effective decision subscales). The questionnaire is scored on a 5-point Likert scale which has been converted to a 0 to 100 scale with larger numbers indicating greater decisional conflict [14]. The DRS is another validated instrument to assess regret associated with health care decisions [15]. The 5-question scale is scored on a 5-point Likert scale and is converted to a 0 to 100 scale with higher numbers

indicating greater decisional regret. More detailed descriptions of the 2 questionnaires used in this study along with the various psychometric properties are available on the Ottawa Hospital Research Institute's Patient Decision Aid Website: <https://decisionaid.ohri.ca/index.html>. It should be noted that neither the DCS nor the DRS has been used to evaluate end-of-life decisions in the ICU.

### 2.4. Participant selection and study design

The goal of study was to query the surrogates regarding medical decisions in the ICU that were made on behalf of his or her loved one. Previous studies that enrolled surrogates to explore the decision-making process in the ICU have focused on predefined decisions such as tracheostomy or feeding tubes [16,17]. We sought to have the surrogate identify a decision that they had to make in the ICU. If multiple decisions were identified, the surrogate was asked to identify the decision that they deemed most important. If the surrogate could not identify any decision, we did not administer the questionnaire. In recognition that a variety of decisions would be identified, an attempt was made a priori to separate decisions into broad categories: end-of-life decisions and non-end-of-life decisions. We defined *end-of-life decisions* as those pertaining to decisions regarding resuscitation in the setting of cardiac arrest (DNR) or intubation in the setting of respiratory failure (DNI) as well as those decisions concerning withdrawal of life-support measures such as dialysis, vasopressors, or mechanical ventilation.

Once the surrogates identified a decision, they completed the initial questionnaire, which included the DCS. The surrogates also were asked to provide written responses to open-ended questions about the decision-making process and identify who was primarily responsible for the decision. In addition, he or she was asked to describe the patient's functional status before admission using the predefined scale: independent, mostly independent, mostly dependent, and completely dependent. The surrogate was contacted again 30 to 60 days after the initial contact and asked to respond to a second questionnaire that included the DRS and the same assessment of the patient's functional status.

### 2.5. Sample size calculation and data analysis

Using the DCS as our assessment tool, we concluded that to identify an effect size of 0.4, an  $\alpha$  of 0.05, and power of 80%, we would need to enroll approximately 200 patients. However, our goal was simply to assess the feasibility of using these tools to assess decision making in surrogates. For our feasibility study, we concluded that we should enroll 40 participants or 20% of the required sample size. Normalized scores were evaluated and compared between groups and reported as means. Confidence intervals, standard deviation (SD), and standard error of the mean (SEM) were reported where appropriate.

## 3. Results

### 3.1. Enrollment

A total of 53 patients met criteria, had an identified surrogate, and were approached by the study team. Of these, a total of 42 (75%) surrogates agreed to participate in the study. Forty (95%) of 42 surrogates were able to identify a decision that they had made on behalf of the patient. In the follow-up period, 34 patients responded to the follow-up questionnaire (Fig. 1).

### 3.2. Patient and surrogate characteristics

Table 1 shows the characteristics of the patients enrolled in the study. The mean patient age was 58 (range 24–85) years, and 45% were female. The majority (90%) lived at home. Mean ICU and hospital length of stay were 15 and 22 days, respectively. Half of all patients

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