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Typologies of Decision-Makers in the ICU: A Qualitative Study of Patients With Acute Respiratory Distress Syndrome and Sepsis and Their Surrogates

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Objectives: To develop hypotheses of patient and surrogate's rationale for decision-making.

Design: We pursued a qualitative study of patients with acute respiratory distress syndrome or sepsis and their surrogates. Fourteen patients and 28 surrogates were given semistructured interviews while in the ICU and again 30 days later. The interviews focused on goal outcomes for the ICU stay and why a patient or surrogate would want a specific intervention (e.g., intubation and cardiopulmonary resuscitation).

Setting: ICU of tertiary care academic hospital.

Patients: Fourteen acute respiratory distress syndrome or sepsis patients and 28 of their surrogates.

Interventions: None.

Measurements and Main Results: Interviews were analyzed using grounded theory and the constant comparative method on NVivo 10.0 (QSR International, Melbourne, Australia). We identified the following four typologies of decision-making rationale: 1) "Timers"—determined decisions based on the length of time on life support; 2) "Natural Livers"—rejected interventions using a "machine"; 3) "Deferrers"—relied on physician for decision-making and prognosis; and 4) "Believers"—relied on a higher power for guidance.

Conclusions: Our hypothesized typologies need validation in a prospective observational trial. If validated, they may allow for better clinician communication.

Key Words: communication; decision-making; goals; prognosis; sepsis

Despite an increased focus on patient-centered care, suboptimal communication and discordance between patient/surrogate and clinician goals and prognosis remains prevalent in the ICU (1–4). Poor communication is associated with decreased satisfaction with care, increased rates of psychologic sequelae in patients and surrogates (including higher rates of posttraumatic stress disorder and depression) (5), and moral distress in clinicians (6). A better understanding of the reasoning that patients and surrogates use to make end-of-life decisions may allow for improved communication.

We conducted a series of semistructured interviews with patients and surrogates of patients with acute respiratory distress

syndrome (ARDS) or sepsis to elicit their preferences for specific interventions. The overarching aim of the study was to identify distinct typologies of approaches to end-of-life decision-making.

MATERIALS AND METHODS

Participants were interviewed from March 2016 to July 2016 by the first author (M.S.L.) or a single interviewer trained by the author. Patients meeting criteria for severe sepsis (7) and/or ARDS (8) in the surgical or medical ICU of an urban medical center (Emory University Hospital in Atlanta, GA) were screened. Surviving patients with dementia or delirium (9) at the time of interview were excluded. The study was approved by the Emory Institutional Review Board, and written informed consent was obtained.

The interview guide was created based on the author's clinical experience and revised with three experienced ICU providers (N.W.D., G.S.M., J.E.S) and an experienced qualitative methodologist (P.M.F.). Field testing was performed with critical care fellows and patients not involved in the study. Questions focused on how a patient or surrogate would determine their desire for several critical care interventions (intubation, cardiopulmonary resuscitation [CPR], tracheostomy, feeding tube, or hospice; see **Table 1** interview questions) if the patient needed ICU care again.

A brief, recorded interview was performed in the ICU with the patient and/or surrogate decision-maker to establish rapport. If the patient was unable to be interviewed due to clinical state, delirium, or dementia, then only the surrogate was interviewed. These brief interviews did not contribute to our analysis. A lengthier interview was undertaken 1 month later via telephone, which formed the basis for our typologies. Interviews were extended to all surviving patients as well as all surrogates independent of patient outcome. In the case of surviving patients, an effort was made to interview both the patient and the surrogate. Questions focused on the ICU experience and the end-of-life decision-making process. Purposive sampling was used to ensure reasonable representation based on age, sex, and race (10). Demographic data were collected from chart review. Interviews were transcribed verbatim and analyzed using NVivo 10.0 (QSR International, Australia) (11).

A preliminary coding framework was developed inductively by the research team. The coding framework was further refined

TABLE 1. Key Interview Questions

1) What would you consider a "good" outcome for your current illness?

  a) Let me give you a few different options: (order to be randomized)

    i) Going home but not back to work

    ii) Going home but needing significant help with bathing/dressing/eating

    iii) Surviving but being in a nursing home for the rest of your life

    iv) Going home and going back to work

2) If you were to go through the process again, what would you consider to be a good goal for your loved one?

  a) Let me give you a few different options: (order to be randomized)

    i) Going home but not back to work

    ii) Going home but needing significant help with bathing/dressing/eating

    iii) Surviving but being in a nursing home for the rest of their life

    iv) Going home and going back to work

3) If they were to develop Sepsis/acute respiratory distress syndrome again, and the need arose, would you want your loved one: (order to be randomized)

  a) To be put on a ventilator (breathing machine)? Why?

    i) Follow up: What factors make you more or less likely to pursue this option? Did your experience in the ICU impact your decision?

  b) To have a tube placed directly into their trachea (windpipe) so that they could be on the breathing machine for a prolonged period? Why?

    i) What factors make you more or less likely to pursue this option? Did your experience in the ICU impact your decision?

  c) To have a tube placed into their stomach through your skin so that they could be fed for a prolonged period? Why?

    i) What factors make you more or less likely to pursue this option? Did your experience in the ICU impact your decision?

  d) Instead of being kept alive with machines (such as a breathing machine), provided with care meant to make them comfortable in terms of pain, anxiety, and shortness of breath, but that was not aimed at making them live longer? Why?

    i) What factors make you more or less likely to pursue this option? Did your experience in the ICU impact your decision?

  e) In the event their heart stopped pumping, would you want someone to try to restart their heart by pumping on their chest and giving them electrical shocks? Why?

    i) What factors make you more or less likely to pursue this option? Did your experience in the ICU impact your decision?

as transcripts were reviewed, consistent with the constant comparative method, and applied to the entire cohort once it was agreed that no new themes were emerging (data saturation) (12). Transcripts were independently coded by two separate research staff, with any discrepancies resolved by consensus. During subsequent open and axial coding with the final codebook, no new codes emerged. Intercoder reliability between two coders prior to resolution by consensus was found to be high (k = 0.96).

RESULTS

One-hundred eighty-eight patients met criteria for ARDS or sepsis during our study. One-hundred fifty-six patients were excluded due to staff availability or lack of a surrogate decision-maker in cases where patients were unable to be interviewed (see **Fig. 1**). Thirty-two patients or their surrogates were initially interviewed, of whom 21 patients completed follow-up interviews. Among the 21 participants, seven participants were patients and 14 participants were surrogates; there were three patient-surrogate pairs. The average patient age was 59.7 ± 9.8 years, and 16 participants were admitted for sepsis (**Table 2**).

Surrogates and patients fell into one or more of the following four typologies, or approaches to end-of-life decisions: "Timers," "Natural Livers," "Deferrers," and "Believers." These typologies reflect decision-making rationale and not necessarily aggressiveness of care. There were participants characterized by each typology who preferred aggressive care or deceleration, and some participants exhibited more than one typology.

"Timers" (n = 11) focused on the length of time on life support as the basis for their decisions, and they varied in the specificity of their rationale. A surrogate for a 58-year-old Asian man noted: "We asked him, I mean if there is a cure and to let's say he just needed to do it for one week and there would be a cure for him,

then yes. But if there's no cure but just to prolong him, then no," whereas a surrogate for a 46-year-old African-American man provided a highly specific timeline: "being on a tube for more than two weeks is not life." A 47-year-old Caucasian woman eloquently stated: If it was just a temporary thing, temporary but how do you know that?... Maybe if it was temporary, yes, but if it was going to be long-term, I just don't think I would want it."

"Natural Livers" (n = 7) rejected interventions that would involve use of a "machine." A 69-year-old Caucasian male patient declared: "I don't want to be put on a machine that's making me live or die." His surrogate stated: "But, you know, if it was something that was keeping him alive and if you turned the machine off that he would die then we wouldn't want to do that. But if someone can perform CPR or, you know, give him a shock to kick start his heart again we would obviously want that to be done." Similarly,

TABLE 2. Demographics of Patients Forming Typologies

Patient Characteristics	Patients Represented at 30 d
	(n = 18), n (SD)
Age (yr)	59.7 (SD = 9.8)
Sequential Organ Failure Assessment score (mean)	6.3 (SD = 2.5)
Charlson Comorbidity Index (mean)	4.9 (SD = 2.8)
Sex, n (%)	
Male	12 (67)
Female	6 (33)
Admitting diagnosis, n (%)	
Sepsis	16 (89)
Acute respiratory distress syndrome	2 (11)
Race/ethnicity, n (%)	
Caucasian/White	11 (61)
African-American/Black	6 (33)
Asian	1 (6)
Religion, n (%)	
Christian	7 (38)
Buddhist	1 (6)
Missing	10 (56)
Relationship status, n (%)	
Married	13 (73)
Single	5 (27)
Employment status, n (%)	
Employed	9 (50)
Unemployed	9 (50)
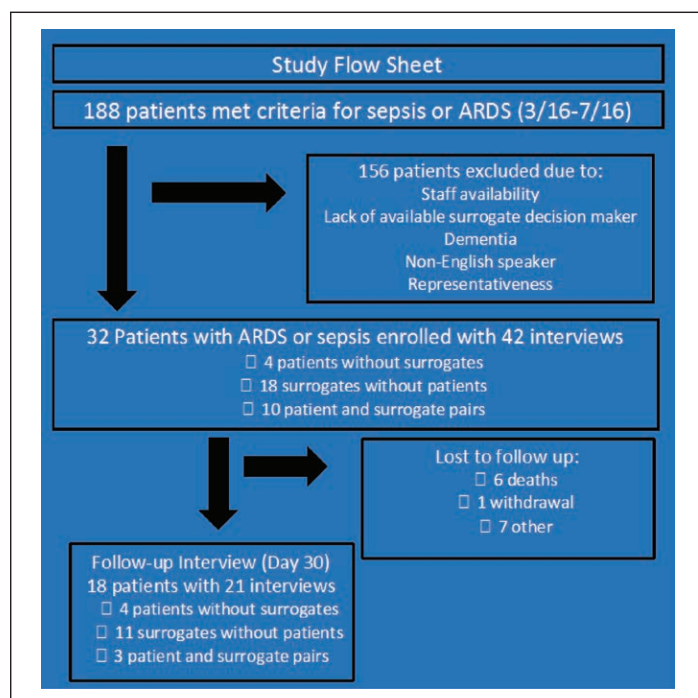
Figure 1. Study profile. ARDS = acute respiratory distress syndrome.

a surrogate for a 58-year-old African-American man noted: "No, he's always said he did not want machines."

"Deferrers" (n = 6) noted their reliance on their physician for decision-making and prognostication. When queried about factors leading to an end-of-life decision, one 49-year-old African-American woman stated: "Well the factors are that in the doctors' view if they thought that I did have a chance of living, also for myself, please do everything that you can."

"Believers" (n = 4) relied in a higher power to decide what they should do. Of note, this cohort did not necessarily identify with a particular religion. Not only did respondents point to their own limits in making decisions, but they also suggested that their belief in a higher power led them to believe that physicians and technology were present to provide all possible support. One surrogate of a 74-year-old Caucasian man noted: "I would want him to be on a breathing machine again because, I mean, I just believe in God and God can change things." Another surrogate for a 57-year-old African-American woman related: "what I was going by was my belief in God, and what I had read and I obtained in the Bible … I think he thought I was crazy, but I had told him, I said, "You give her the tools to fight with, she'll fight, and God will take care of the rest … because every day when she wakes up, every day I see her, that's God's will, that's the only will I live by."

DISCUSSION

This study was able to identify four typologies, or approaches, to end-of-life decision-making through interviewing patients and caregivers who have been affected by sepsis/ARDS diagnoses. These typologies describe information used by patients and surrogates to decide whether to pursue CPR, intubation, tracheostomy, or feeding tube placement or to pursue hospice care.

The challenges that exist in communication and concordance between ICU clinician goals and ICU patients/surrogate goals are well recognized (1, 2). By recognizing these typologies in family meetings and end-of-life care discussions, clinicians may be able to focus conversation on information that is most helpful to the patient or surrogate. This may improve communication and clinician sensitivity to the origins of discordance between themselves and patients/surrogates. Thus, identification of potential decision-making typologies is an important first step in this process.

As an example, for "Timers," changing the focus of family meetings to explicitly discuss the length of time a loved one would be on support may be an important intervention to help surrogates determine whether to pursue aggressive treatment. With "Natural Livers," education about how specific "machines" in the ICU work might be valuable for decision-makers, allowing more specific recommendations about which interventions align with the patient's or surrogate's world view. Furthermore, identifying "Believers" would clarify the need for clinicians to explore those patients' and surrogates' religious values and ensure chaplain availability. We have no specific recommendations on how to approach "Deferrers."

Our study is limited by small sample size and moderate cohort retention. Furthermore, by design we were limited to observations about retrospective decision-making, as all data come from interviews undertaken 1 month after the index ICU visit. Thus, we are unable to comment on how patients and surrogates may make decisions in the acute setting, or whether the ICU experience changes decision-making in the future. Furthermore, we are unable to conclude whether the views of patients and surrogates would be concordant. Strengths include reaching saturation for our cohort based on age, sex, and severity of illness

Future studies will be needed to validate these typologies and evaluate their clinical usefulness in tailoring treatment approaches. Specifically, it will be important to see whether these decision-making typologies remain static over time and whether they are applicable in the acute setting of critical illness as well as in those who have not experienced the ICU before.

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