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Typologies of decision-makers in the ICU:
A mixed methods study of ARDS and sepsis patients and their surrogates

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An abstract of
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By Michael S. Lava, M.D.

Poor communication between physicians and patients/surrogates in the ICU leads to increased burnout in clinicians and increased anxiety and depression in surrogates. Further there is low concordance between patient and surrogate decision making. Unfortunately, little is known about patient and surrogate's rationale for end-of-life decision making while in the ICU, which may improve communication. To develop hypotheses of patient and surrogate's rationale for decision making as well as assess patient and surrogate concordance, we pursued a mixed methods study of patients with ARDS or sepsis and their surrogates. 14 patients and 28 surrogates were given semi structured 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 or CPR). These interviews were analyzed using grounded theory and the constant comparative method on NVivo 10.0, as well as SAS for quantitative comparisons. We found that only 3 out of 10 dyads agreed completely across all possible outcomes, and a non-significant trend with surrogates more likely to find an outcome 'good' compared to patients. We also noted a non-significant trend towards an improved view of outcomes at 30 days compared to being in the ICU. Qualitatively, we identified 4 typologies of decision making rationale: 1) "Timers"- determined decisions based on 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. Our hypothesized typologies need validation in a prospective observational trial. If validated, they may allow for better clinician communication and more focused interventions on surrogates at risk of long term psychological morbidity.

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INTRODUCTION

The most prevalent conditions in medical Intensive Care Units (ICU's) are sepsis and Acute Respiratory Distress Syndrome (ARDS), with 660,000 and 190,000 cases respectively in the US annually. (1, 2) Sepsis, often known as 'blood poisoning' is a syndrome of organ failure stemming from an over exuberant inflammatory response in the setting of infection.(3) ARDS occurs in the setting of damage to the lung, either indirectly through trauma or inflammation from sepsis, or directly through pneumonia or drowning. It manifests as respiratory failure, due to a breakdown in the lung, blood interface which allows fluid into the lungs, limiting the transfer of oxygen.(4) Both conditions are diagnosed based on clinical criteria, not by any available biomarker. Risk factors include advanced age and preexisting comorbidities-groups already at risk of poor health related quality of life and at higher risk of mortality. Mortality in these conditions is around 1 in 5,(4-7) and both have long term physical and psychological sequelae in patients and surrogates. These sequelae include persistent exercise limitations, memory difficulties, anxiety and depression. (8-17) In addition, delirium is very common in these syndromes.(18) Given the frequency, high case-fatality rate, and long term sequelae of these conditions, sepsis and ARDS are significant public health concerns.

Both syndromes require ICU level care, frequently with ventilator support and medication aimed at increasing blood pressure. Patients with sepsis and ARDS are almost always treated in medical ICU's. These units allow for more intense monitoring and a higher level of nursing care with fewer patients assigned to each nurse. In addition, it allows support of organ failure, including ventilatory support for breathing, as well as medicine to increase blood pressure and the ability of the heart to pump.(19)

The goal of these interventions in organ failure is to allow the patient to survive long enough so that their organs can recover function. Unfortunately, it is difficult to predict who will recover,(20) and many patients are unable to be removed from this support. 1/5th of deaths in the US occur in the ICU or shortly following discharge, with the majority preceded by withdrawal of life supporting therapy.(21-23) Due to the severity of illness in these situations, and the limited use of advanced directives, it is rare that patients are able to participate in the decision of whether to withdraw life support.(15, 24, 25) Thus, family members or other surrogates such as romantic partners or close friends who know the patient well are called upon to make this decision.(26) Frequent decisions occurring at end of life that patients and surrogates are called upon to make include: whether to be placed on a breathing machine (ventilator), to have CPR if their heart stops, to have a tracheostomy for long term ventilator use, to have a feeding tube placed, or to decelerate care and pursue hospice in lieu of further supportive and curative treatment. Unfortunately, surrogate decision makers have low concordance with their loved ones outside the ICU. The concordance of patients and surrogates in the ICU setting is not known. Further, little is known about what rationale patients and surrogates use when making these decisions.

We undertook a series of semi-structured interviews with patients and surrogates of patients with ARDS or sepsis to elicit their preferences for specific care outcomes. The overarching aim of the study was to identify distinct typologies of rationale for end-of-life decision making by utilizing narrative information based on a complex array of factors they considered in their own life history, clinical, and caregiving situations. Typologies are groups or taxonomies based on different attributes assigned to the group. The second aim is to evaluate paired patient surrogate concordance in the ICU setting and subsequent concordance from the ICU to 30-day follow-up to assess if views changed.

BACKGROUND

In the event that patients are unable to participate in decision making, physicians meet with the surrogate decision-maker(s), often in the form of a family meeting.(27) The purpose of this meeting is for the physician to explain patient prognosis, as well as to explore the surrogates understanding of what the patient would want. Surrogates are asked to speak for the patient, based on either prior discussion with the patient about what they would want in such a circumstance, or lacking this information, making this decision for the patient (substituted judgement). Unfortunately, despite multiple calls to action and large trials aimed at improving communication between physicians and patients/surrogates, communication remains poor.(27-30)

Limitations in communication occur on both the physician and patient or surrogate side. Physicians often do not communicate information considered essential to surrogates and patients. For instance, physicians tend to use vague language when discussing prognosis.(31) Decision-makers rate quality of life outcomes as importantly as mortality; however, in the majority of family meetings physicians do not discuss the long-term sequelae of their critical illness.(32) Further, the ICU environment and complexity of care makes it difficult for physicians to communicate, despite best efforts.(28, 33, 34) Following a family meeting, fifty percent of family members fail to understand the patients' prognosis.(33) Contributing to this difficulty in understanding, significant stress in the ICU makes decision making and cognitive processing more difficult for surrogates.(35) Furthermore, many surrogates exhibit an optimism bias, in which they overestimate the probability of a good outcome when told there is a low chance of survival.(36)

Unfortunately, poor communication leads to decreased satisfaction with care, and increased psychological sequelae in patients and surrogates. Interventions to improve communications and related outcomes have had mixed results.(28, 37) Certain structural aspects of care, as well as physician communication impact the rate at which these sequelae occur. Having a separate and dedicated room for family meetings, as well as relaying consistent information to surrogates has been associated with decreased rates of PTSD and depressive symptoms in family members of ICU patients.(38) The effect of participating in end of life discussions has been mixed in the literature. Simply being involved in end of life discussions lead to higher rates of PTSD,(15) while in other studies, end of life discussions were associated with increased patient and surrogate quality of life.(39) Certain interventions aimed at improving communication have led to improved outcomes in surrogates. For instance, a brochure aimed at educating surrogates about bereavement decreased rates of PTSD in surrogates from 69% to 45%.(37) Further, more frequent communication has been shown to increase satisfaction with care.(40, 41) In fact, clinician-family communication has been found to be the highest determinant of family satisfaction with care.(42, 43)

In addition, on the healthcare provider side, poor communication between patients/surrogates and ICU physicians/nurses leads to moral distress.(44) Moral distress occurs when a clinician feels that there is a morally correct course of action, but that they are not able to carry it out due to patient or surrogate decisions. In the ICU, this is commonly seen in end-of-life decision making where the clinician feels that aggressive care is non-beneficial, and the family or patient decides to pursue aggressive care.(45) Moral distress has been described in both ICU physicians and nurses,(46, 47) and is compounded by poor communication.(44) Moral distress leads to burnout.(48)

While certain interventions have improved satisfaction with care and the rates of PTSD, anxiety and depression, communication between clinicians and patients/surrogates could be improved. Unfortunately, to our knowledge there is no literature examining how patients and surrogates rationalize their end-of-life decisions. A better understanding of the reasoning that patients and surrogates use to make end of life decisions would allow more focused interventions aimed at supplying surrogates with the specific information needed to make decisions on an individualized basis.

Unfortunately, even if communication is ideal, concordance between patient and surrogate decision-makers has been found to be as low as 50%.(26, 49, 50) Concordance is not improved with advanced directives or prior discussion of wishes.(50) Furthermore, in patients who prefer DNR (do not resuscitate) status, there is a significantly higher rate of discordance than in those who prefer to be full code.(51) This is true even with spousal surrogates, suggesting that poor personal knowledge of the patient is not the cause of discordance.(52) Pilot data from a survey project of ICU survivors and their surrogates (submitted) suggests that shared experiences in the ICU may increase concordance in end of life decision making.

METHODS

This study was a single center study primarily undertaken to identify typologies of decision-making rationale drawn from those with recent clinical experiences in the ICU. As no clearly testable hypotheses were found in literature review, a mixed methods design was used to generate new hypotheses. The secondary aim was to identify concordance in views on end-of-life between surrogates and patients, as well as to see if these views were static over time.

Inclusion criteria included patients meeting criteria for severe sepsis(53) and/or ARDS(4) in either the surgical or medical ICU at Emory University Hospital or the medical ICU at Emory University Midtown Hospital, both in Atlanta, GA. Patients were excluded if they: 1) screened positive for delirium using a CAM-ICU screening tool,(54) 2) were diagnosed with dementia, 3) did not speak English, or 4) did not have a surrogate decision-maker. Enrollment occurred from March to July 2016.

The interview guide was initially created based on the authors experience with family meetings while working in the ICU. This version was then revised in conjunction with the authors primary mentor (JS), an experienced ICU practitioner. The revised interview guide was shared with the entire mentor team, consisting of a second experienced ICU clinician (GM), an experienced qualitative methodologist (PF) and a critical care clinician and patient decision making researcher (ND). Finally, this instrument was field tested with several critical care fellows and patients. A Flesch-Kincaid score-a validated measure of comprehension ease- was calculated for the interview and scored between a 5th and 6th grade level.(55)

Following informed consent as approved by the Emory IRB, a brief, recorded interview was done on the day of enrollment with the patient and/or surrogate decision-maker. The interview was performed by the author or a supervised and trained team member. The initial interview explored what the surrogate and patient would consider to be a good outcome for their stay.

Ethics, Consent, and Permissions

IRB approval was obtained via the Emory University IRB. An amendment was approved to extend the study from Emory University Hospital to Emory University Midtown Hospital. Written informed consent was obtained at initial interview from patient and or surrogate, and a waiver was obtained for written consent of the follow up phone interview.

Sample Selection

Purposive sampling was performed for patient selection. Purposive sampling is a non-probability (also known as qualitative sampling) technique which allows the researcher to select subjects to enroll based on current study needs. (56) Representative sampling was used to ensure that subjects represented older and younger patients, both genders, those with and without prior ICU admissions, and black and white race. In this case, a goal sample of 15-20 final interviews was based on review of the qualitative literature. Considering anticipated attrition due to death and delirium, we planned to enroll 30 initial patients in the ICU. The sampling was aimed at achieving saturation of our data, which would occur when no new themes emerged during coding. This was defined for our study when all substantive phrases were able to be appropriately coded by existing typologies. (57)

Measures

Initially an open-ended question was asked: “What would you consider a ‘good’ outcome for your current illness?” Following their answer, several options were given for outcomes, and the patient or surrogate was asked to identify which would be a ‘good’ outcome for the ICU stay. The four outcomes were: “1) going home but not back to work, 2) going home but needing significant help with bathing/dressing/eating, 3) surviving but being in a nursing home for the rest of your life, and 4) going home and going back to work." Basic demographic information, as well as SOFA score(58) to evaluate severity of illness and Charlson comorbidity index (59) was extracted via chart review at the time of the initial interview.

Patients and or surrogates were contacted via telephone 30 days following their initial interview. Please see Table 1 for key interview questions. Semi-structured recorded interviews were performed by trained staff, exploring pre-admission patient functioning, family support, ICU experience of the patient and surrogate, and multiple questions aimed at evaluating the end of life decision making process. Examples include: "If you were to go through this process again, would you want your loved one: To be put on a ventilator (breathing machine)? Why? What factors make you more or less likely to pursue this option? Did your experience in the ICU impact your decision?" Similar questions queried interviewees on decisions such as tracheostomy, CPR, feeding tube placement and hospice care. Wording was modified slightly for surrogates of patients who had died to reflect this event.

Both contact phone numbers and email addresses (if applicable) were collected from interviewed subjects. The retention plan included three calls to the number listed by the patient or surrogate, and if no contact was made, alternate phone numbers listed in the electronic medical record were called. If phone contact was unable to be achieved, email was used as a backup method of contact. This retention plan was based on well validated methodology for research in the critically ill. (60)

Interview Process

Interviews were undertaken to explore how patients and surrogates make specific, common, end of life decisions in the ICU. These included the decision to undergo CPR, be placed on a ventilator, have a tracheostomy or feeding tube placed, or to pursue hospice. Initial interviews were conducted in the ICU room of the patient to ensure a private and confidential setting.

Trained interviewers undertook these discussions with guidance from our interview guide. Participants were not compensated for involvement. All interviews were digitally recorded.

Transcription

Interviews were recorded and uploaded to a centralized HIPAA compliant online account, and downloaded by professional transcriptionists. All interviews were transcribed verbatim in English. Transcripts were cleaned of all identifying information, and reviewed for accuracy and completeness by study site personnel prior to upload into NVivo 10.0 software (QSR International, Australia) for coding.(61)

Data Analysis

Codebook Development

An initial codebook was developed in Excel corresponding to the broad outline of questions asked during the interview. For instance, responses to the question “were you employed prior to your illness?” would be included generally in the sociodemographic tab, and specifically under the “housing’ code. This codebook was used to initiate coding in NVivo. Subsequent iterative coding changes were updated both in NVivo and Excel.

Structural Coding and Preliminary Analysis of Interview Qualitative Data

The concept of grounded theory was used exploiting the constant comparative method.(62) Using NVivo 10.0, open coding was performed on all transcripts. Open coding was aimed at identifying text which was associated with a specific question in the interview (e.g., sociodemographic, family support). We (PF, ML) performed preliminary data analysis over two face to face meetings. Data was analyzed from a subset of transcripts, and from these we described prevalent themes and developed a mutually agreed upon coding framework.

Initial broad themes were identified from major domains that included “sociodemographics”, “prior functionality”, “ICU family support”, “ICU experiences”, “provider interactions”, “diagnosis” and “outcome.” “Sociodemographics” included responses to questions about where and with whom patients were living with prior to their hospital stay as well as their current relationship status (married, divorced, widowed, single). Further, details of current or former employment were included in this section. The “prior functionality” domain included responses to questions about the patients’ ability to function independently prior to hospitalization. Specific daily living skills included the ability to drive, bathe and shop for groceries without help. The “ICU family support” domain included details of who, and with what frequency, family members visited the patient while in the ICU. Specifically, the presence of spouse and children were queried. In the “ICU experience domain,” responses to questions about both open ended and specific common issues experienced by these patients in the ICU were gathered. These included pain, confusion, nightmares/fear, experience with the breathing tube if intubated, noise, sleep difficulty, anxiety and other issues.

Coding for the “provider interactions” domain included comments on provider interactions generally, as well as healthcare staff, knowledge of the disease process (ARDS or sepsis depending on patient), overall quality of care and goals of care. Facets in the healthcare staff category included general perceptions, cultural competence, goal of care discussions, and sepsis or ARDS diagnosis discussion. The “interventions” domain looked at five major treatments at the end of life: intubation, tracheostomy, feeding tube placement, cardiopulmonary resuscitation (CPR) and hospice. Patients and surrogates were asked if they would want these treatments performed if they or their loved ones were to become ill again. Facets of this topic area included comments on prior experience in the ICU impacting their decision.

The “diagnosis” domain looked specifically at whether a provider in the ICU talked about their diagnosis of ARDS or sepsis. Specific facets included discussion of complications and knowledge of the disease.

The “outcomes” domain coded responses to a question about what would be considered a ‘good’ outcome if the patient or loved one were to get sick again. This was phrased in similar fashion to our initial intake interview. Interviewees were initially asked in open ended fashion what would constitute a ‘good’ outcome from a hypothetical critical illness in the future. Following their response, they were asked to classify the following outcomes into a binary ‘good’ or ‘not good’ category. These included: going home and back to work, going home but not back to work, going home but needing significant help with bathing, dressing and eating, or going to a nursing home.

Axial Coding

All samples underwent advanced systematic coding and analysis (38). The initial coding phase consisted of review of transcripts and development of codes and early identifiable themes by five trained coders. Following this, axial coding was undertaken to relate basic themes to each other, during which sub-codes and categories were defined (e.g. prior experience in ICU impacting decision). Selective coding was then undertaken, including code category review and sub-coding statements within each category (hierarchical coding, e.g. physician prognostication, emphasis on use of life support machine). During coding, study staff continually identified new codes and modified existing codes in keeping with the constant comparative method.(62) To form typologies, the author and one mentor (PF) independently reviewed 10 interviews. Typologies were compared and found to be in agreement. They were then added to the coding schema. No new codes or themes were encountered in the transcripts during subsequent open and axial coding, achieving saturation.

Intercoder Reliability (ICR)

ICR was calculated following the initial coding process by using NVivo 10.0 software. ICR was obtained by having all coders double-code all transcripts. By independently coding all transcripts, the data were consistently monitored to ensure that coders were resolving any discrepancies with coding definitions as expeditiously as possible. By the end of the coding process, the complete coding structure across all hierarchical nodes including typologies and initial open codes achieved a k= 0.96, consistent with a very high level of cross-coding accuracy.

Data analyses of Concordance of Outcomes between Patient/Surrogate

A cluster analysis for word type was performed using NVivo 10.0. Both intermodal and extranodal correlations were examined. A cutoff for Pearson's r of greater than 0.7 was used to define a high correlation.(63)

Overall concordance for what was thought to be a 'good' outcome was calculated between surrogates and patients upon entry into the trial. A fisher's exact test was used to compare patients compared to surrogates for each possible outcome.

Exploratory data analysis of each dyad (where both surrogate and patient were initially interviewed) was performed to evaluate for overall concordance, as well as concordance for each specific 'good outcome.'

A fisher's exact test was performed to evaluate changes over time, comparing what was considered a 'good' outcome in interviews early in the ICU stay to the follow up interviews among all subjects. Percentage of 'good' responses among our four possible outcomes was compared during and after the ICU stay. McNemar's test was used to test whether changes in what was considered to be a 'good' outcome shifted in a statistically consistent direction following the ICU stay. Data was limited to surrogates or patients interviewed at intake and at 30 days.

A fisher’s exact test was also done to compare the different typologies to each other for each potential outcome, comparing percentage in each group describing an outcome as ‘good.’ Only post ICU stay data was used for this evaluation as the typologies were determined during that interview.

RESULTS

188 total patients screened positive for sepsis or ARDS from the beginning of enrollment in March 2016 until saturation was reached in July 2016. Of these, 156 were excluded due to limited staff availability, lack of an available surrogate decision-maker, dementia or being a non-English speaker. 32 patients were enrolled in the study, with initial interviews done with patient, surrogate or both patient and surrogate.

Of these 32 patients, 21 follow up interviews consisting of 7 patients and 14 proxies (with 3 patient and surrogate interviews) were performed 30 days after enrollment. 6 patients died, 1 patient withdrew from the study, and 7 patients and proxies were lost to follow up despite repeated phone and email contact.

Thirty-two patients were enrolled in the study, with a mean age of 56.3 (SD=12.1). 18 (56%) were male (see Figure 1: Study Flow Sheet). Thirty patients (94%) were diagnosed with sepsis, 5 (16%) with ARDS, with some patients diagnosed with both sepsis and ARDS. Mean SOFA score was found to be 7.2 (SD 3.0) with a mean Charlson Comorbidity Index of 5.3 (SD 2.9). 18 (56%) enrolled patients were Caucasian, 11 (34%) African-American or black, with 1 (3%) Hispanic, 1 (3%) Asian and 1 (3%) missing. 12 (38%) of patients identified as Christian and 1 (3%) as Buddhist, with the remainder either missing or not choosing a religion. Most patients (n=22, 69%) were married, with the remainder single. 17 (53%) patients were employed prior to admission, 9 (28%) described themselves as unemployed, and 6 (19%) did not provide this information.

A sensitivity analysis was performed to evaluate whether our screened (156) and enrolled patients (32) represented a different population based on SOFA and Charlson Comorbidity Index (CCI). Screened patients had a mean SOFA of 6.07 (SD 3.14) compared to enrolled patients with a SOFA of 7.24 (SD 3.02). Screened patients had a CCI of 4.95 (SD 2.62), while enrolled patients had a 5.30 (SD 2.89). Please see Figure 2 for patient demographics and Figure 3 for sensitivity analysis.

Concordance between patients and surrogates

Comparing unmatched initial surrogate responses to patient responses, 100% of both groups considered going home and back to work as a 'good' outcome. 71% and 75% of patients and surrogates, respectively, considered going home but not back to work a 'good' outcome (p=0.28). 36% of patients and 54% of surrogates considered going home with significant help a 'good' outcome (p=0.15). Finally, no patients and 18% of surrogates considered long term care in a nursing home to be a 'good' outcome (p=0.12).

Exploratory analysis of ten patient-surrogate dyads showed 100% concordance between responses for an outcome which resulted in the patient returning home and going to work. Only 7 of 10 dyads, however, were concordant when asked if going home and not back to work, or going home with significant help was a 'good' outcome for the patient. Nine of ten dyads were concordant in viewing going to a nursing home as a 'good' or not good outcome. Overall, only 3 in 10 dyads showed complete concordance across all four possible outcomes. Please see Figure 4 for paired patient and surrogate concordance, and Figure 5 along with Graph 1 for unpaired concordance data.

Impact of time and discharge on ICU outcome views

Twenty-one patients and surrogates had both intake interviews and follow up interviews (65.6% of all enrolled at baseline). All patients and surrogates found going home and going back to work to be a 'good' outcome at intake as well as in follow-up. Similarly, all but one patient and surrogate found long term nursing home care to be a not 'good' outcome at both intake and follow-up. At intake, 76% of patients and surrogates found going home and not back to work to be a 'good' outcome, compared to 90% following the ICU stay (p=0.21). At intake, 38% of respondents rated going home but needing significant help with bathing, dressing and eating as a good outcome, compared to 52% of respondents following the ICU stay (p=0.35).

In evaluating paired responses, 24% of respondents changed whether they considered going home but not back to work as 'good.' 1 respondent changed their view from 'good' to 'not good', and 4 respondents changed from 'not good' to 'good' following the ICU stay. 15 responded that this was a 'good' outcome both during and after the ICU stay, while 1 found it 'not good' at both time points. These changes were not statistically significant in any direction (p=0.38). Please see Figure 6 and Graph 2 for these data.

62% of respondents changed their view of an outcome of going home but needing significant help with activities of daily living. Five respondents changed their view from 'good' to not 'good' following the ICU stay, while 8 respondents changed from not 'good' to 'good.' Three respondents found this to be consistently 'good', while 5 found this outcome consistently not 'good.' This was not statistically significant (p=0.58). Please see Figure 7 for the McNemar test analysis.

Qualitative Data

Typologies for Decision Making Rationale

Surrogates and patients referred to several rationales for making end of life goals and deciding on interventions. There were four major decision making themes that could be assigned to an end of life decision making typology. From most to least prevalent, these include those who: 1) decided based on length of time on life support ("Timers") 2) relied on physician for decision making and prognostication ("Deferrers") 3) rejected interventions that would involve use of a 'machine' ("Natural Livers") and 4) relied on a higher power to decide what would and should happen ("Believers"). Further, many subjects used more than one rationale, noted as 'overlapping' typologies. Please see Table 2 for a comprehensive list of quotes.

A majority of patients and surrogates identified length of time on life support as a factor impacting the decision-making process at end of life. These “Timers” identified specific knowledge about how long (from vague to very specific time lines) they or their loved ones would have to be on life support to determine whether they would want to pursue these interventions. “Deferrers” identified physician prognostication and/or physician recommendations about end of life care decisions as the most significant factor which would help them make decisions. “Natural Liver’s” suggested that their decision hinged in large part on whether or not a machine (e.g., ventilator or defibrillator) would be needed to keep living. Finally, “Believers” focused on their belief in a higher power to make the end of life decision process.

T*imers: Determining decision based on length of time on life support*

A majority of interviewed surrogates and patients (12 of 18) noted making end of life decisions based on the expected length of time that a patient would need life support. Many, but not all respondents focused on this without a discussion of how quality of life following life support might impact their decision.

In many cases, surrogates and patients provided vague timelines for making a decision. A surrogate for a 58-year-old African-American male responded:

> *In his trachea for a prolonged period of time? Not for a long time, no. Neither of us have said okay what we consider a long time.*

The surrogate for a 47-year-old African-American male noted:

> *He doesn't want to live if he's going to be on a breathing tube for ever and ever. If it's just temporary, then that's okay.*

Some surrogates were more specific with the amount of time on life support that they would find acceptable. One surrogate for a 69-year-old Caucasian male noted a more specific timeframe, but still left quite a wide window for uncertainty:

> *If we were talking, you know, a breathing tube for a week, 10 days, maybe even two weeks, yes. But if they're saying, you know, it could be six months or even longer, probably not because I know that we've had it in for five days he was miserable for those five days. So I don't think that he would want it in for that long a time.*

On the other end of the spectrum, one surrogate for a 46-year-old African-American male provided a highly specific timeline:

> *Because to me, being on a tube for more than two weeks is not life.*

Many patients and surrogates communicate the difficulties in making end of life decisions, even if it were known what their future might look like. Some patients clearly struggle with this decision, even considering aggressive end of life interventions such as intubation and tracheostomy if this would be required for the entirety of life. Even with a poor expected quality of life, this was a consideration for patients. A 49-year-old African-American female patient stated:

> *I would want the machine if there was a possible chance that I could live longer. If I had to, yes, I mean depending on when you say prolonged time, I mean… No, that one is a hard one because just meant that I had to be on a breathing tube the rest of my life. Huh, I don't know. That one is… That one is hard…You know was there a chance that I could come back and breathe on my own, or I had to have that breathing tube down my windpipe for the rest of my life and I wouldn't be active, I don't know. That one is hard.*

Some patients point to the desire to know the length of time on life support, but at the same time mention the inherent limitations in predicting healthcare outcomes. A 47-year-old Caucasian female eloquently stated:

> *If it was just a temporary thing, temporary but how do you know that? It's like a rhetorical question, how do you know it's only going to be a week? Do you know what I mean, you don't know? 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: Rejecting interventions that would involve use of a 'machine'

A substantial minority (8 of 18) patients and surrogates noted specifically that they would not want their loved ones hooked up to a 'machine' that would make them live longer. 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.*

Several surrogates also pointed to prior discussion of this topic with their loved ones, all stating that the involvement of a life support 'machine' would lead them to limit aggressive care. The surrogate of the previous patient stated:

> *Well, because I know that he specifically has said that he does not want to have a machine keeping him alive, that that's no life and so I would want to respect his wishes.*

Similarly, a surrogate for a 58-year-old African-American male noted:

> *No, he's always said he did not want machines.*

Several surrogates make a distinction between the potential purposes of the machine. While comfortable with a machine used for resuscitation, they are not comfortable with a machine, which, if withdrawn, would lead to death. This is best exemplified again by the surrogate of our 69-year-old Caucasian male patient:

> *Well, because I would want him to do whatever he really could to keep him alive short of hooking him up to a machine. So I know that electrical shocks and pumping the chest sometimes can be done with a machine and obviously the electrical shock is done with that. But, you know, if it was something that was keeping him alive and if your 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.*

While most interviewees used the need for life support as a clear factor which would lead them to limit aggressive end of life care, some did include potential quality of life following life support, as well as invoking the life support timeline as a decision-making factor. One surrogate for a 46-year-old African-American male noted when asked about resuscitation preferences:

> *Yes, I would like to, I would like for him to be resuscitated, only with a goal that he would be better, that we were going towards working, having a good quality—you know, having not just time but time and quality, you know. I wouldn't want him to be resuscitated just to be on the machines forever.*

Deferrers: Reliance on physician for decision making and prognostication

Many surrogates and patients base their decision on physician prognostication (7 of 18). Frequently, patients and surrogates deferred completely to the doctor's recommendation for end of life interventions. When queried about factors leading to an end of life decision, one 69-year-old Caucasian male seemed to put his faith in the physician to weigh prognosis and quality of life:

> *What the doctor says, I guess*

Similarly, a 77-year-old Caucasian male patient noted their view on specific end of life interventions:

> *Tracheotomy, well, I would want it if it's necessary, if the doctor says you need to have that done. I'm one of these people that the doctors know more about medicine than I do.*

Others respondents defer to the physician prognostication, but explicitly outline their goal. One 49-year-old African-American female stated her goal to live, without physician prognostication regarding quality of life:

> *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. So if that meant pumping my heart, pump it, you know, putting me on a breathing machine, please do it if you see that there is a possible chance that I would live.*

Further, this patient described her thoughts in even more explicit fashion, suggesting that it was the physician's primary duty to extend life:

> *I mean I want the doctors to do all that they can, I mean, until there's nothing left to do, I mean, absolutely they have given it their best, they have done all that they could do, so I mean as low as possible, you know, just work on me. And if there's no chance of me living then let me go but don't let me go because, you know, you think but I want you to try. That's their job, is trying to save my life.*

Some interviewees described their use of physician prognostication as binary. In this description of decision making, the doctor would provide a prognosis of either 'no chance' or 'more than no chance.' For instance, a surrogate of a 65-year-old Caucasian female stated:

> *Well, I let them do what they wanted to do if there was a chance she'd come back.*

Similarly, surrogates and patients defer to the doctor's advice, but explicitly want that advice to incorporate quality of life following the ICU stay. Both surrogates and patients express this view. One surrogate for a 46-year-old African-American male relayed:

> *If the doctor says he's not going to get better then I wouldn't want him to be on a breathing tube that long.*

The patient himself noted:

> *I mean I say yes, you know, hoping that I would get better*
> *but it would be, you know, listen to whatever doctors had to say,*
> *what the doctors say, I had to care about the future.*

Some surrogates were quite explicit about the types of quality of life predictions would impact their decision making. One surrogate for a 60-year-old Caucasian male specified neurologic functioning as an example of physician prognostication that would lead to limited end of life care:

> *If a doctor said outlying things, for example, this time he's had so*
> *much oxygen deprivation that he has severe issues with his brain,*
> *he will never be able to lead a normal life, he will never be able to*
> *live at home, that sort of thing.*

Some interviewees also noted that while physician prognostication would impact their decision, they believed that this was limited by the inherent limits of prognostication and previous experience with incorrect prognostication. The same surrogate noted:

> *But through this experience I can tell you also that we*
> *had more than one doctor tell us 100% that he would not survive.*
> *One doctor went so far as to say, "He will die in five minutes when*
> *he comes off this ventilator.", and he's still here. So, they do not*
> *know 100%. That's what I'm saying, if they said, 100% he will*
> *never come off this, it would give me great pause, but I would*

> *also temper that with they do not know enough to make those kind of definitive statements usually. He did not have the tracheostomy for a while because he was on ECMO and quite frankly, my opinion is that the doctors didn't want to do it because they didn't think he was going to survive. But I know he was tenuous and all of that. So, when the doctor took him off ECMO and informed us emphatically that he was going to die and wanted to turn off several of his medications that were going to help regulate his heart and his blood pressure, we had told him ahead of time that we wanted to go through this under the assumption that he was going to be successful, even though they told us he wasn't.*

Believers: Reliant on a higher power

A minority of patients and surrogates interviewed (4 of 18) discussed the impact of a higher power in their end of life decision making. Those that did frequently focused extensively on this topic.

Patients noted deferring to the decision of a higher power, pointing out that their own deliberations were not meaningful. As one surrogate for a 58-year-old African-American male commented:

> *You know, I really can't answer that. That would be something that I would seriously have to go before the Lord for and say okay, Lord, I need your wisdom now. So which just I did that quite*

> *often, so these past few months. So I would like to think that I wouldn't make any decision based on an emotion."* Other respondents explicitly pointed to a higher power taking over the decision-making process for them: *"That's the only thing you had to go on, and that's when your faith in God takes over and after that takes over, then you're doing pretty good.*

Not only did respondents point to their own limits in making decision, surrogates and patients also suggested that their belief in a higher power led them to believe that physicians and technology were present to provide all available assistance, and that a higher power would be the final arbiter of the decision. One surrogate of a 74-year-old Caucasian male 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 female related:

> *the whole time I was sitting there in the ICU with you and with other people, most people in that ICU, including the doctors and the nurses who even took care, didn't think she was going to live. But I told you, and I told them and in fact I told them the day that she would come off that vent and 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.*

Some patients and surrogates noted that their religion and belief in a higher power was important for a physician to be aware of. When asked to name the most important thing for the ICU physician to know regarding the patient, our aforementioned surrogate for a 58-year-old African-American patient noted:

> *I don't know if I'm answering your question or not but what your medical knowledge is and everything, that he respects that but in all capital letters, "I BELIEVE IN A HIGHER POWER."*

The use of a shared belief in a common power was also a powerful tool not only on the individual level, but to reach consensus when deliberating end of life decisions as a family. The daughter of a 58-year-old Asian male pointed out:

> *Yeah, that was one other thing too, because we do have five siblings and because there are some that have, our opinions are different from one another and usually the religion was the thing that was the deciding factor.*

While most respondents that invoked a higher power in their decision making opted to pursue aggressive end of life care, some used similar values to reach the opposite conclusion.

Interestingly, the above surrogate described doing this in the absence of an expected poor outcome:

> *We were very religious as a family, so we're noticing that he started to speak like, "Mom", "Dad", and he would reference to different people that were coming to take him… Buddhists believe that whatever he did wrong, people, they're all coming for him… he would raise his hands and he would say, "Oh, I'm going, I'm going, help me, help me." So for us, that was the determining factor that we wanted to stop the medication, even though we see that the antibiotics were responding, that he was responding well. Then if he stayed in ICU then he would have a chance.*

Overlapping Typologies

Several patients and surrogates demonstrated more than one of the decision-making typologies discussed above. Four of eighteen interviewees were "Timers," "Deferrers" and "Natural Livers." A 69-year-old Caucasian male makes use of all three of these decision points:

> *Would you want to be put on a ventilator-a breathing machine? (...) I don't want to prolong life. (…) I don't want to be put on a machine that's making me live or die. Okay. What factors would make you more or less likely to pursue this option? What the doctor says I guess.*

Two of eighteen patients used both their religious beliefs and length of time information to aid in decision making. This is best exemplified by the surrogate of a 58-year-old Asian male, who commented on how length of time information and religion allowed his family to make a cohesive decision:

> *Yeah, that was one other thing too, because we do have five siblings and because there are some that have, our opinions are different from one another and usually the religion was the thing that was the deciding factor. (…) 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.*

Cross Typology Analyses

To further characterize relationships between different typologies, cluster analysis was performed to evaluate intranodal correlations. "Deferrer" and "Timer" typologies correlated highly, with a p=0.80. No other combination of typologies was highly correlated. No extranodal correlations reached 0.7.

Impact of Typologies on Outcomes

In order to evaluate whether different typologies view ICU outcomes in different ways, the post ICU evaluation of outcomes ('good' or not 'good') across typologies were compared using fisher's exact test. All subjects in each typology viewed going home and back to work as a 'good' outcome (p=1.0). 83%, 88%, 86% and 100% of "Timers," "Natural Livers," "Deferrers" and "Believers," respectively, found going home but not back to work to be a 'good' outcome (p=0.86). 42%, 38%, 57% and 50% of "Timers," "Natural Livers," "Deferrers" and "Believers," respectively, found going home but needing significant help to be a ‘good’ outcome (p=0.88). 8% of “Timers” and 0% of the other typologies found going to a nursing home to be a good outcome (p=0.65). Please see Figure 8 for these data.

DISCUSSION

Through the gathering of narrative information from patients and caregivers who have been affected by sepsis/ARDS diagnoses, this study was able to identify four typologies of end of life decision-making. These typologies describe the information used by patients and surrogates to decide whether to pursue CPR, intubation, tracheostomy, or feeding tube placement ("aggressive care"), or to pursue hospice care.

"Timers" describe those who seek information about length of time on life support to aid their end of life decision making. Among our typologies, this group was the most prevalent, suggesting that this is a common piece of information that surrogates and patients use when deciding whether to pursue aggressive care. There was significant variation in both the degree of specificity of this timeline, and the spread of what is considered an acceptable length of time. "Natural Livers" characterize decision-makers whose main focus is on avoiding reliance on a machine to further life, while "Deferrers" tended to make significant use of physician prognostication or rely on their opinion altogether. Both of these later typologies were frequently seen in our population of patients. Several patients and surrogates described using all three of these methods to come to a conclusion on aggressive end of life care, weighing heavily the physician prognosis regarding length of time on ventilator and incorporating their comfort level with the use of a 'machine' to continue life. This information varies from the typical information discussed in family meetings, which tend to focus on likelihood of death.

"Believers" describe a decision-making process that incorporates the patient or surrogate's religious or spiritual beliefs into their decision-making process. While our least prevalent group, these decision-makers relied heavily on their faith, and did not tend to ask for physician prognostication. Finally, significant overlap was seen between these groups with qualitative analysis. Nodal correlations suggest a particularly high association between "Timers" and "Deferrers."

Our study highlighted two decision making groups which tend to ignore or dispute physician prognostication when making their end of life decisions. The 'believers' tend to ignore physician prognostication, as they see God as the only arbiter of prognosis. Some 'deferrers', also pointedly ignore prognostication due to prior experience with inaccurate physician prognostication. This is highly congruent with data in the qualitative literature, which suggests surrogates lack of belief in prognostication stems from a belief that God can alter the outcome of their loved ones illness, and prior experience with inaccurate physician prognostication.(36) Further, our most prevalent group, the 'timers,' tend to concentrate on quality of life, not mortality. This underscores the finding that quality of life is as important to surrogate decision-makers as prognosis in terms of mortality.(32)

Our small sample suggested discordance between surrogates and patients in views on what constitutes a 'good' outcome. This is consistent with studies of other patient populations,(26) as well as a large study looking at views on CPR in the ICU.(51) To our knowledge, this is the first time that discordance in what constitutes a 'good' outcome has been evaluated real time in the ICU.

Our study is in large part limited due to its small sample size. Many of our statistical questions were not powered to reach significance. Thus, while we report trends in our data, none of our findings were statistically significant. Also, despite a robust retention plan, our loss to follow up was higher than anticipated. Our findings would be more robust had we incorporated surrogate demographic data into our data collection. Of note, we were skewed towards sepsis as our underlying etiology, perhaps due to the time of year we were enrolling.

Further, our single center study lacks robust generalizability. For instance, most of our subjects were either Black or Caucasian, and mostly Christian. Other regions and countries not represented in our study may have different cultural norms, and we are unable to account for these potential differences. Involving hospitals that deal with indigent care, or nations with a lower overall socioeconomic status (SES) may bring out different typologies. To name but one possible unaccounted for typology, the impact of cost on decision making rationale may be common in lower SES countries. Also, a more diverse sample would have likely allowed us to add more depth to each typology. For instance, regions with large populations of other religions, such as Hinduism, may fall into the "Believers" typology, but make different treatment related decisions than our overwhelmingly Christian population. Thus, our study may not fully represent all existing typologies, and the typologies we identified may not fully describe the variability and complexity of decision making rationale in other cultures and regions.

Dismissing for a moment the issues with generalizability, and assuming we have fully identified all relevant decision making rationales, it is worth noting that we cannot be sure that our findings are of clinical value. It is possible that we have identified robust typologies, but we cannot be sure these groupings are useful when it comes to communication or psychological sequelae in the ICU.

Strengths of our study included a diverse population in terms of age, gender and severity of illness. Selection bias is unlikely based on a sensitivity analysis, which looked at all patients screened compared to just those enrolled, and did not reveal a clinically significant difference in comorbidities or severity of illness. Further, our study had high intercoder reliability.

Future Directions

This study demonstrates four distinct decision making typologies in those making end of life care decisions. Better understanding how these decisions are made will allow clinicians to tailor family meetings and develop communication strategies to address the issues and concerns raised by their surrogates and patients, and possibly decrease moral distress amongst nurses and physicians. Further, our finding of poor patient-surrogate concordance, and that most of this occurs in outcomes with lower quality of life will allow more focused research on this group of patients. Finally, the change in what constitutes a 'good' outcome following an ICU stay, but not in a consistent direction highlight another area which needs more research.

Conclusions

Improving our understanding of how end of life decisions are made in the ICU may help to aid communication between healthcare professionals and patients/surrogates, and thus enhance patient and surrogate satisfaction.(28, 35, 37, 39, 42, 43) Further, this knowledge may relieve some degree of moral distress and associated burnout that is seen in ICU providers.(44-47) A more thorough understanding of how decision-makers come to their end-of-life conclusions may allow clinicians to better cope with this moral distress through more realistic expectations of their communications. Further, this information will allow for more focused interventions aimed at improving patient and family satisfaction, in lieu of a one size fits all approach that has had mixed results. This could theoretically lead to less clinician burnout and decrease the psychologic sequelae of surrogates in the setting of end-of-life decision making. Similar typology focused treatments in the literature include the use of Lesch alcoholism typology to focus interventions in the treatment of alcoholism(64) and psychiatric treatment of adult offenders based on personality typology.(65)

There are several lessons to be taken from this data. For possible interventions, we propose several changes to family meetings and overall end of life discussions which exploit this knowledge. Probing questions aimed at identifying which typology or typologies a decision-maker falls into would allow the clinician to focus the conversation on information that would help the surrogate to make their end of life decision. First, changing the focus of family meetings to explicitly discussing the length of time a loved one would be on life support may be an important intervention to help surrogates determine whether to pursue these interventions. Further, education about how the specific ‘machines’ in the ICU work would likely be valuable for decision-makers, and allow more specific recommendations on which interventions align with the patient or surrogate’s world view. Also, forming relatively focused prognostications while also being open about the limits of physician prognostication would be a valuable strategy in those patients focused on length of time. Finally, identifying “Believers” would allow clinicians to delve into the patient’s and surrogates’ religious values, create an opportunity for early involvement of the chaplain, and limit frustrated efforts at convincing decision-makers to become congruous with clinician preferences.

Our findings also found a high percentage (7 of 10) of patient-surrogate dyads were not completely concordant while in the ICU. Further, our results suggest that concordance between groups of patients and surrogates on what is deemed a ‘good’ outcome decreases, albeit non-statistically, as quality of life decreases. This finding highlights more specifically where patient-surrogate discordance exists, and will allow more focused study of how these discrepant views arise. Further, this gives evidence to physicians that a significant amount of attention must be paid to surrogates who want to pursue aggressive interventions in the face of a likely poor quality of life, even if successful. This is a group of surrogates who are ideal for a focused intervention to ensure their views are likely to match their loved one. This could take the form of a simple recommendation for further family discussions of what the loved one would want.

The data also show a large percentage of respondents change their view on what is thought to be a ‘good’ outcome following illness in the ICU. Interestingly, despite a high percentage of changing views, these were not statistically significant, suggesting that respondents were similarly likely to change to viewing an outcome more or less positively. This could be due to the current status of the patient, or due to their experience in the ICU. Further study will be needed to identify the reasons for these changes, and to further dichotomize reasons that the ICU experience has differing impacts on end of life decision making for different people.

Further directions for this research include enrolling a larger number of patients with similar questionnaire based data to increase statistical power and subsequently assessing patient/caregiver reported outcomes.

In terms of our qualitative results, our first and most important next step would be rigorous validation of our typologies. It is unclear if other researchers with similar experience would hypothesize the same four typologies from our data. Thus, initial efforts to validate these typologies would take the form of finding similarly trained colleagues in our institution unfamiliar with our results, and having them code our transcripts to independently create typologies. If their results were similar to ours, the next step would be to assess the generalizability of our data. This would be done by performing a similar experiment with a new set of patients with different diseases than what we’ve studied. Using the same methodology, a new set of critically ill post-operative patients would be enrolled in a population unique from this study. An ideal population would be an indigent care hospital on the west coast of the United States, as this would allow for recruitment of different races, religions and social mores which may impact end-of-life decision making. Recruiting from a surgical ICU, as opposed to a medical ICU would allow for generalization beyond ARDS and sepsis. Similar findings in this study would reassure the authors that our findings were both reliable and valid, as well as generalizable to the US population and critically ill patients with diverse disease etiologies. Were money and time not an issue, an ideal study would involve multiple hospitals throughout several continents, representing extremes of SES and age and carefully recruiting representatives from different races, religions, cultures and health care systems to ensure cross-cultural validity.

If our results are validated, we then must evaluate whether they represent clinically relevant typologies. As mentioned above, having valid typologies does not guarantee that these grouping are clinically relevant. The clinical value of our research depends on how utilization of these typologies might be integrated in clinical practice. As examples of how future research may be developed from our findings, we next propose several research questions and possible interventions to test the hypotheses the underlie each of these questions.

First, we will ask whether increased clinician knowledge of our typologies improves communication in the ICU and thus improves familial satisfaction with care, which is closely associated with high quality communication.(28) Our proposed intervention will be a brief 15-minute teaching session to ICU nurses and physicians on typologies of decision making. It will include suggestions on how to identify which typology is present in a given patient or surrogate and incorporate this into discussions regarding end-of-life care. The control will consist of a 15-minute teaching session on how to document goals of care in the critically ill patient. The choice of this control allows for a similar subject matter to be discussed. These interventions will be block randomized to different hospitals in different health systems to ensure that no clinicians overlap in the control and intervention ICU's. Our outcome measure will be family satisfaction with care one month following discharge, using the Family Satisfaction in the Intensive Care Unit (FS-ICU) questionnaire,(66) which will be mailed to family members. We hypothesize that family members of patients treated in the intervention ICU's will have higher satisfaction with care on the FS-ICU at one month, compared to the control ICU's.

We will next ask whether increased clinician understanding of patient and surrogate decision making rationales decreases moral distress in nurses and doctors. Possible explanations for this improvement could be that this understanding improves communication, thus decreasing moral distress, or that moral distress is decreased directly. (44, 45) Our intervention will consist of the aforementioned 15-minute teaching session on the typologies, identification of patients with a particular typology, and suggestions for tailoring end-of-life discussions based on the patient and surrogate typology. The measured outcome will be the Moral Distress Scale. (67) This questionnaire will be given to participating nurses and physicians each month for three consecutive months prior to intervention, and three months following the intervention. Participants will serve as their own control in this pre-post study. We hypothesize that the average moral distress scale score following the intervention will be lower than the score prior to the intervention.

Third, we will ask whether or not better clinician understanding of typologies leads to lower rates of PTSD in surrogate decision makers. We hypothesize that this would occur via improved communication, as poor communication is associated with higher rates of PTSD in surrogates. (39) A 15-minute nurse and physician teaching session of similar structure to our aforementioned interventions will be performed. These will be block randomized by hospital to minimize the risk of crossover in the groups. The control ICU will have a 15-minute teaching session on goals of care in the ICU, but not involve any education on typologies. Our outcome will be PTSD in surrogates of deceased patients, as measured by the Hospital Depression and Anxiety Scale. (68) We hypothesize that surrogates of deceased patients from intervention ICU's will have lower rates of PTSD as determined by the Hospital Depression and Anxiety Scale when compared to surrogates of deceased patients in control ICU's.

Finally, assuming we find an improvement in PTSD rates with our intervention, we will compare this to the gold standard treatment for prevention of PTSD in surrogates. Currently the standard intervention is the inclusion of bereavement material upon admission to the ICU; this has been found to significantly decrease PTSD among family members of ICU patients that die. (37) In this study, we would have three arms. The interventions would be our aforementioned 15-minute nurse and physician teaching session and the use of bereavement materials to surrogates. The first arm would have the teaching session alone. The second arm would have the bereavement materials for surrogates without any clinician education component. The third arm would employ both the clinician education and the surrogate bereavement material. These arms would be block randomized by hospital. Our main outcome of interest would be diagnosis of PTSD at 1 month in surrogates of deceased patients, using the Hospital Depression and Anxiety Scale. Our three-arm design will allow us to compare the two interventions directly, as well as evaluate for interaction between the interventions. We hypothesize that the surrogates of deceased patients treated in ICU's with bereavement material and our 15-minute typology education session will have lower rates of PTSD at one month compared with those in ICU's treated with either intervention alone. We further hypothesize that the surrogates of deceased patients treated in ICU's with the 15-minute typology education session will have lower rates of PTSD at one month compared to those treated in the bereavement material arm.

These immediate and long term studies will allow for validation of our typologies, ensure generalizability, and confirm (or refute) their clinical meaningfulness. Overall, we hope that our hypothesized typologies will allow improved surrogate and clinician communication, as well as potentially decrease moral distress in clinicians and psychological comorbidities in surrogates and patients.

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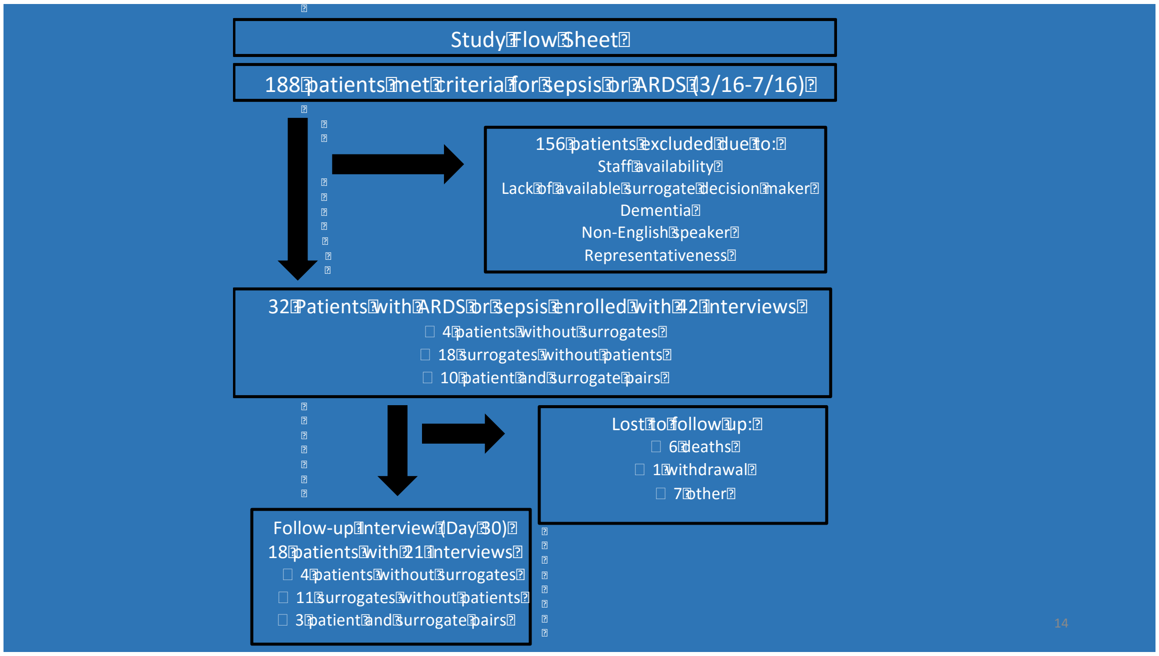
TABLES/FIGURES

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/ARDS 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?*

Figure 1: Study Flow Sheet



Study Flow Sheet

188 patients met criteria for sepsis or ARDS (3/16-7/16)

156 patients excluded due to:

Staff availability

Lack of available surrogate decision maker

Dementia

Non-English speaker

Representativeness

32 Patients with ARDS or sepsis enrolled with 42 interviews

- 4 patients without surrogates
- 18 surrogates without patients
- 10 patient and surrogate pairs

Lost to follow up:

- 6 deaths
- 1 withdrawal
- 7 other

Follow-up Interview (Day 30)

18 patients with 21 interviews

- 4 patients without surrogates
- 11 surrogates without patients
- 3 patient and surrogate pairs

Figure 2: Patient Demographics (All enrolled and 30 day interviews)

	All Enrolled	**30 day interviews**
Patient Characteristics	(n=32), n (%)	(n=18), n (%)
Age (years)	56.3 (SD=12.1)	59.7 (SD=9.8)
Gender		
Male	18 (56)	12 (66)
Female	14 (44)	6 (33)
Admitting Diagnosis*		
Sepsis	30 (94)	16 (89)
ARDS	5 (16)	2 (11)
SOFA Score (mean)	7.2 (SD=3.0)	6.3 (SD=2.5)
Charlson Comorbidity Index (mean)	5.3 (SD=2.9)	4.9 (SD=2.8)
Race/Ethnicity		
Caucasian/White	18 (56)	11 (61)
African-American/Black	11 (34)	6 (33)
Asian	1 (3)	1 (6)
Hispanic	1 (3)	0 (0)
Missing	1 (3)	0 (0)
Religion		
Christian	12 (38)	7 (39)
Buddhist	1 (3)	1 (3)
Missing	19 (59)	10 (56)
Relationship Status		
Married	22 (69)	13 (72)
Single	10 (31)	5 (27)
Missing	0 (0)	0 (0)
Employment Status		
Employed	17 (53)	9 (50)
Unemployed	9 (28)	9 (50)
Missing	6 (19)	0 (0)

**Three patients with both ARDS and sepsis*

Figure 3: Sensitivity Analysis: Charlson Comorbidity Index and SOFA

	Mean	SD
SOFA Screened	6.07	3.14
SOFA Interviewed	7.24	3.02
Charlson Screened	4.95	2.62
Charlson Interviewed	5.30	2.89

Figure 4: Patient and Surrogate concordance, paired (n=10)

Outcome	Concordant	Discordant
Home and return to work	10/10 (100%)	0/10 (0%)
Home but not back to work	7/10 (70%)	3/10 (30%)
Home with significant help	7/10 (70%)	3/10 (30%)
Nursing Home	9/10 (90%)	1/10 (10%)

Figure 5: Patient vs. Surrogate concordance, unpaired

Home and return to work

	Positive	Negative
Patients	14/14 (100%)	0/14 (0%)
Surrogates	28/28 (100%)	0/28 (0%)

Home but not back to work

	Positive	Negative
Patients	10/14 (71%)	4/14 (29%)
Surrogates	21/28 (75%)	7/28 (25%)

Fisher Exact test p=0.28

Home with significant help

	Positive	Negative
Patients	5/14 (36%)	9/14 (64%)
Surrogates	15/28 (54%)	13/28 (46%)

Fisher exact test p=0.15

Nursing home

	Positive	Negative
Patients	0/14 (0%)	14/14 (100%)
Surrogates	5/28 (18%)	23/28 (82%)

Fisher exact test p=0.12

Graph 1: Percent finding outcomes 'good,' patient vs. surrogates

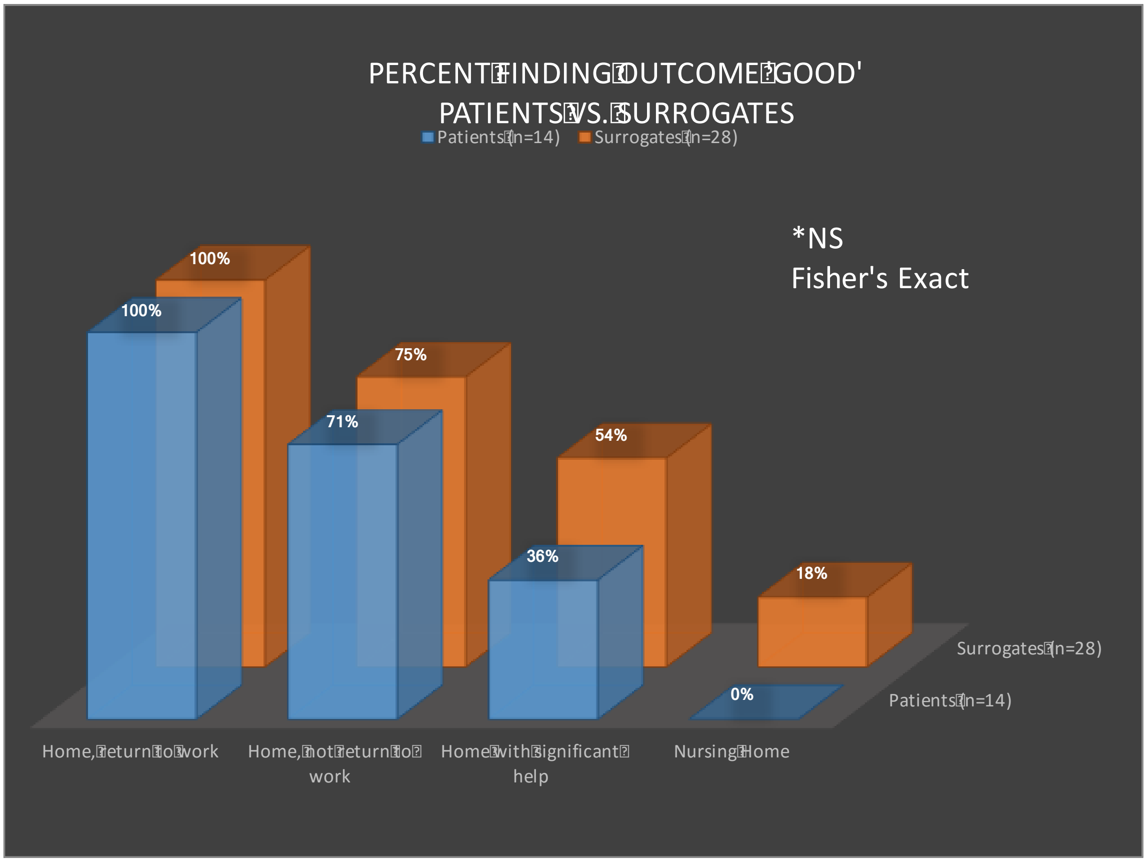


Figure 6: Stability of views on what constitutes a ‘good’ outcome

Percent of respondents finding outcome ‘good’	ICU (n=21)	Post ICU (n=21)	p-value (chi square)
Home and return to work	21/21 (100%)	21/21 (100%)	n/a
Home but not back to work	16/21 (76%)	5/21 (90%)	p=0.21
Home with significant help	8/21 (38%)	11/21 (52%)	p=0.35
Nursing Home	1/21 (5%)	1/21 (5%)	n/a

Graph 2: Percent finding outcome 'good,' ICU vs. post discharge

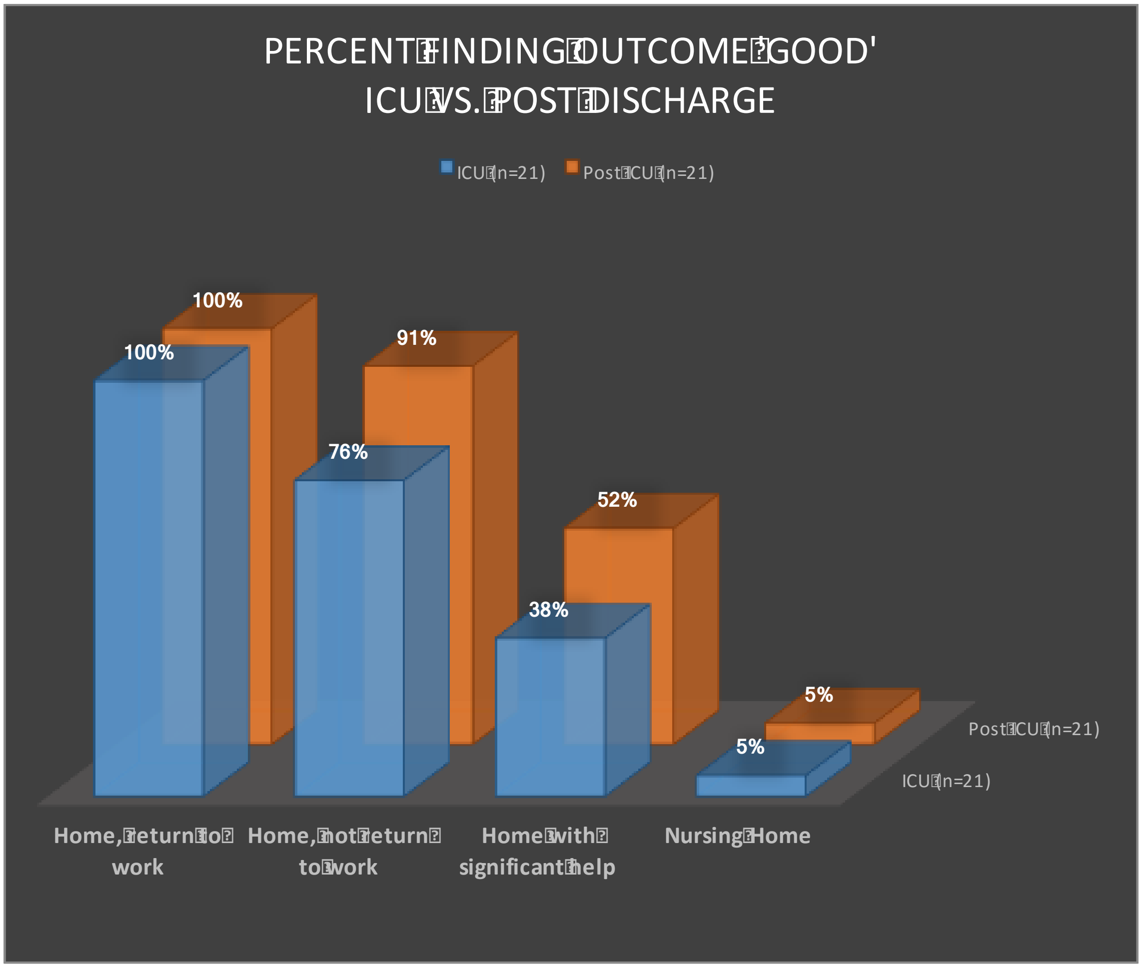


Figure 7: Stability of views on what constitutes a ‘good’ outcome, McNemar test

Home and return to work

		Post ICU	
		Positive	Negative
ICU	Positive	21	0
	Negative	0	0

***NS**

Home and don’t return to work

		Post ICU	
		Positive	Negative
ICU	Positive	15	1
	Negative	4	1

***p=0.38**

Home and need significant help

		Post ICU	
		Positive	Negative
ICU	Positive	3	5
	Negative	8	5

***p=0.58**

Nursing home

		Post ICU	
		Positive	Negative
ICU	Positive	20	0
	Negative	0	1

***NS**

Table 2. Quotes by typology

Factors	Quotes
Faith in a higher power	Him being a man I'd say I think he would want them to know that I understand what the medical books. I'm not sure… I don't know if I'm answering your question or not but what your medical knowledge is and everything, that he respects that but in all capital letters, "I BELIEVE IN A HIGHER POWER". You know, I really can't answer that. That would be something that I would seriously have to go before the Lord for and say okay, Lord, I need your wisdom now. So which just I did that quite often, so these past few months. So I would like to think that I wouldn't make any decision based on an emotion. Yeah, I would want him to be on a breathing machine again because, I mean, I just believe in God and God can change things. We were very religious as a family, so we're noticing that he started to speak like, "Mom", "Dad", and he would reference to different people that were coming to take him (..) For us, we believe that when you die, near the moment you're to die, it's the defining point in your life, not just this life or past lives, but all things are coming for you, like the good things—like, for example, my dad was a soldier. I knew whatever sin he committed in this life or past life, the Buddhists believe that whatever he did wrong, people, they're all coming for him. For us, we could see the fear that he was experiencing. He would make noise like "Ohhh, ohhh!", then he would raise his hands and he would say, "Oh, I'm going, I'm going, help me, help me." So for us, that was the determining factor that we wanted to stop the medication, even though we see that the antibiotics were responding, that he was responding well. Then if he stayed in ICU then he would have a chance. Yeah, that was one other thing too, because we do have five siblings and because there are some that have, our opinions are different from one another and usually the religion was the thing that was the deciding factor. That's the only thing you had to go on, and that's when your faith in God takes over and after that takes over, then you're doing pretty good. Because I remember reading it in Hebrews and it didn't make very much sense to me, at first, and then once I experienced I understood it. You don't become disciplined by normal things, even the problems you have in your everyday life, but you become disciplined by the things that afflict you. They really do you harm, and if you can maintain your discipline, then you win out. (…) You actually feel like you beat the devil, or something, because you were disciplined, you didn't give up, you maintained your focus because the whole time I was sitting there in the ICU with you and with other people, most people in that ICU, including the doctors and the nurses who even took care, didn't think she was going to live. But I told you, and I told them and in fact I told them the day that she would come off that vent and what I was going by was my belief in God, and what I had read and I obtained in the Bible. (…) I never gave that up and I knew this was going to happen, and by me thinking that way, and knowing and believing what God has told me all my life, me hard-headed and a foolish man like I had been all my life, until I got up to the understanding of what it all meant. (…) I said, "You give her the tools to fight with, she'll fight, and God will take care of the rest." (…) God did one thing for me that day, and it will stay with me for the rest of my life in eternity, he confirmed to me, his Sabbath, his rest, and he confirmed it to us. (…)I knew she was, she's going good right now, in fact, right now she's doing so good, just how God works.

	And by seeing all of this stuff, the only thing it did was sharpen my discipline, and sharpen my faith and my focus and it's still there, because me, my faith is the way I think and the way I pray to God, my wife going to come off that air, she's going to walk around again, the way she did before she became afflicted by this disease. And my faith and the way I think, that's what's going to happen, and I knew it was going to happen, it's just when God wills to do it. God gave you the talent to do what you do, to alleviate and relieve suffering on the earth, that's the mercy of God, to give man that ability, but only God has power of life and death. Once he decides a person is going to leave here, they're going to leave, and he already got everything sewed up in a bag and whatever you did here on earth, either you're going to hear from him or you're going to be forgiven by him. That's what I believe, because there's nothing you going to do, I believe every step I take is ordered by God, whether good or bad, he already knew before he created the world what I had done and what he has forgiven me or condemned me, that was done before this world was ever created.
Length of time	You know I guess it would depend on the diagnosis and how long that prolonged period would be. If we were talking, you know, a breathing tube for a week, 10 days, maybe even two weeks, yes. But if they're saying, you know, it could be six months or even longer, probably not because I know that we've had it in for five days he was miserable for those five days. So I don't think that he would want it in for that long a time. I wouldn't like them taking care of you the rest of your life. I mean that, as long as it's not forever, yes, we definitely would want that. Oh, gosh, I would say yeah but not really. I mean I don't want to be fed, you know, a tube in my stomach for the rest of my life, no. In his trachea for a prolonged period of time? Not for a long time, no. Neither of us have said okay what we consider a long time. He wants to live. But not at any cost. He doesn't want to live if he's going to be on a breathing tube for ever and ever. If it's just temporary then that's okay. Because to me, being on a tube for more than two weeks is not life. 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… Probably not, but it depends on what a prolonged period of time is. Especially since it was the second time, I would guess that his prognosis wouldn't be as good and when they said prolonged, I would probably say no. …if it was temporary, yes, but if it was going to be long-term, I just don't think I would want it. If I had to, yes, I mean depending on when you say prolonged time, I mean… No, that one is a hard one because just meant that I had to be on a breathing tube the rest of my life. Huh, I don't know. That one is… That one is hard.
Machine based interventions	I would want the machine if there was a possible chance that I could live longer. I don't want to be put on a machine that's making me live or die. I know that he specifically has said that he does not want to have a machine keeping him alive, that that's no life and so I would want to respect his wishes.

I would want him to do whatever he really could to keep him alive short of hooking him up to a machine. So I know that electrical shocks and pumping the chest sometimes can be done with a machine and obviously, the electrical shock is done with that. But, you know, if it was something that was keeping him alive and if your 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.

I would want the machine if there was a possible chance that I could live longer.

You know was there a chance that I could come back and breathe on my own, or I had to have that breathing tube down my windpipe for the rest of my life and I wouldn't be active, I don't know. That one is hard.

Yeah, well, because I think that just if my wife could not return back to the point of where she could be productive and it was just going to be machines and whatever keeping her alive and the medicine to make her comfortable I don't think she might not want to live that way.

No, he's always said he did not want machines. We both have always said we don't want the machine to be keeping us alive for an indefinite amount of time.

I wouldn't want him to be resuscitated just to be on the machines forever.

Reliance on physician prognostication/decision making	If I had to, yes, I mean depending on when you say prolonged time, I mean… No, that one is a hard one because just meant that I had to be on a breathing tube the rest of my life. Huh, I don't know. That one is… That one is hard. I mean I say yes, you know, hoping that I would get better but it would be, you know, listen to whatever doctors had to say, what the doctors say, I had to care about the future. You know was there a chance that I could come back and breathe on my own, or I had to have that breathing tube down my windpipe for the rest of my life and I wouldn't be active, I don't know. That one is hard. If the doctor says he's not going to get better then I wouldn't want him to be on a breathing tube that long. If somebody told me, "We're going to put him on the ventilator and there is no chance that he's going to come off.", it would make me think very carefully and ask a lot more questions. If they told me he wasn't going to live two or three days, then I might say no, if you know what I'm saying. I mean I say yes, you know, hoping that I would get better but it would be, you know, listen to whatever doctors had to say, what the doctors say, I had to care about the future. What factors would make you more or less likely to pursue this option? What the doctor says, I guess. 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. I mean I want the doctors to do all that they can, I mean, until there's nothing left to do, I mean, absolutely they have given it their best, they have done all that they could do, so I mean as low as possible, you know, just work on me. And if there's no chance of me living then let me go but don't let me go because, you know, you think but I want you to try. That's their job, is trying to save my life. If the doctor says he's not going to get better then I wouldn't want him to be on a breathing tube that long. But through this experience I can tell you also that we had more than one doctor tell us 100% that he would not survive. One doctor went so far as to say, "He will die in five minutes when he comes off this ventilator.", and he's still here. So, they do not know 100%. That's what I'm saying, if they said, 100% he will never come off this, it would give me great pause, but I would also temper that with they do not know enough to make those kind of definitive statements usually. My opinion is that the doctors didn't want to do it because they didn't think he was going to survive. (…) So, when the doctor took him off ECMO and informed us emphatically that he was going to die and wanted to turn off several of his medications that were going to help regulate his heart and his blood pressure. Tracheotomy, well, I would want it if it's necessary, if the doctor says you need to have that done. I'm one of these people that the doctors know more about medicine than I do.

Figure 8: Views on what constitutes a ‘good’ outcome, by typology

Percent of respondents finding outcome ‘good’	Timers (n=12)	Natural Livers (n=8)	Deferrers (n=7)	Believers (n=4)	p value (Fisher’s exact)
Home and return to work	12/12 (100%)	8/8 (100%)	7/7 (100 %)	4/4 (100%)	1.0
Home but not back to work	10/12 (83%)	7/8 (88%)	6/7 (86%)	4/4 (100%)	0.86
Home with significant help	5/12 (42%)	3/8 (38%)	4/7 (57%)	2/4 (50%)	0.88
Nursing Home	1/12 (8%)	0/8 (0%)	0/7 (0%)	0/4 (0%)	0.65