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Storytelling in the early bereavement period to reduce emotional distress among surrogates involved in a decision to limit life support in the ICU: A pilot feasibility trial

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Abstract

Background—Surrogate decision makers involved in decisions to limit life support for an incapacitated patient in the ICU have high rates of adverse emotional health outcomes distinct from normal processes of grief and bereavement. Narrative self-disclosure (storytelling) reduces emotional distress after other traumatic experiences.

Objective—To assess the feasibility, acceptability, and tolerability of storytelling among bereaved surrogates involved in a decision to limit life support in the ICU.

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Methods—We conducted a pilot single-blind trial of storytelling among bereaved surrogates from 5 ICUs across 3 hospitals within a single health system between June 2013 and November 2014. Both storytelling and control conditions involved printed bereavement materials and follow-up assessments. Storytelling involved a single 1–2 hour home or telephone visit by a trained interventionist who elicited the surrogate’s story. The primary outcomes were feasibility (rates of enrollment, intervention receipt, 3- and 6-month follow up), acceptability (closed and open-ended end-of-study feedback at 6 months), and tolerability (acute mental health services referral).

Results—Of 53 eligible surrogates, 32 (60%) consented to treatment allocation. Surrogates’ mean age was 55.5 (SD=11.8) and they were making decisions for their parent (47%) spouse (28%), sibling (13%), child (3%) or other relation (8%). We allocated 14 to control and 18 to storytelling, 17/18 (94%) received storytelling, 14/14 (100%) and 13/14 (94%) control subjects and 16/18 (89%) and 17/18 (94%) storytelling subjects completed their 3- and 6-month telephone assessments. At 6-months, 9/13 (69%) control participants and 16/17 (94%) storytelling subjects reported feeling “better” or “much better,” and none felt “much worse”. One (8%) control subject and 1 (6%) storytelling subject said the study was burdensome, and 1 (8%) control subject wished they had not participated. No subjects required acute mental health services referral.

Conclusion—A clinical trial of storytelling in this study population is feasible, acceptable, and tolerable.

Keywords

intensive care; terminal care; surrogate decision making; bereavement; mechanical ventilation; life-supporting treatment; ethics; treatment withdrawal; post-traumatic stress disorder; anxiety; depression

Twenty percent of Americans die with intensive care unit (ICU) services.¹ Decisions to limit life-sustaining therapy, ranging from withholding of cardiopulmonary resuscitation via a “do not resuscitate” (DNR) order to withdrawal of mechanical ventilation often precede such deaths.^{2–5} Family members participate in these decisions as surrogate decision makers.^{6,7} Surrogates experience acute stress from participating in these decisions^{8–13}, which translates into high rates of post-traumatic stress disorder (PTSD), anxiety, depression, and complicated grief symptoms in the months after the patient’s death.^{7,14–21} The Society of Critical Care Medicine recently proposed the term Post-Intensive Care Syndrome – Family (PICS-F) to describe the cluster of symptoms families experience after exposure to a loved-ones’ critical illness.²²

To date, the most common interventions used in clinical trials to reduce surrogate distress involve providing emotional and decision support to surrogates while the patient is in the ICU.^{23,24} Examples of ICU-based interventions include decision support using informational pamphlets, pen-and-paper decision aids, and values clarification exercises^{19,25–29} or psychological and communication support using structured family meeting, a patient navigator, nurse or social worker.^{30–32} While these ICU-based interventions mitigate distress somewhat, they do not fully prevent adverse emotional health outcomes.

To address this gap, we developed a post-ICU bereavement intervention, called “surrogate storytelling.”³³ Surrogate storytelling allows surrogates to tell the story of their experience making decisions for a loved one in the ICU approximately one month after the patient’s death. We chose a storytelling intervention because surrogates report using storytelling as a coping strategy,³⁴ narrative ethics theorizes that the act of telling one’s story is the way humans make sense of their circumstances^{35,36}, and decades of research suggests that storytelling after traumatic events improves physical and emotional health.^{37–39} The purpose of the current study, therefore, was to test the feasibility, acceptability, and tolerability of conducting a clinical trial of storytelling among bereaved surrogates of ICU patients.

METHODS

Design and setting

We conducted a pilot single blind trial of storytelling among bereaved surrogates involved in a decision to limit life support for a loved one in 5 ICUs (trauma, cardiovascular, 2 medical, and 1 mixed medical-surgical) across 3 hospitals (a tertiary referral hospital, a cancer center, and a community hospital) in 1 academic health system in Pittsburgh, PA, between June 2013 and November 2014. Assessors completing 3- and 6-month telephone follow-up were blind to the surrogates’ treatment assignment.

Participants

We used a two stage procedure to recruit surrogates. First, we approached surrogates in person at the bedside of the patient in the ICU to obtain proxy consent for patient medical record review (to assess trial eligibility, i.e. patient death) and surrogate consent for re-contact. Surrogates eligible for approach in the ICU included those whose loved one was incapacitated and on life-support (e.g., mechanical ventilation, hemodynamic support, dialysis, enteral or parenteral feeding). Exclusion criteria included being non-English speaking, evolving legal issues with the hospital (as perceived by bedside nurses), and being a paid caregiver (i.e., a non-family member hired to care for the patient). We initially excluded subjects who lived more than 50 miles from the hospital, but removed this exclusion criterion when we modified the protocol to allow telephone intervention delivery.

Second, among those who provided consent for medical record review and contact, we reviewed the patient’s medical records to assess eligibility for surrogate re-contact. If the patient died, we re-contacted the surrogate by letter 1 week after the death and by phone 2 weeks after the death to obtain consent for continued participation, collect baseline measures of symptom burden, and allocate the surrogate to treatment arm.

Treatment Allocation

An automated program sequentially allocated surrogates to the control condition or the storytelling intervention, stratified by study ICU. For those who declined treatment allocation, we asked permission to re-contact them at 6 months (observation group).

Control Condition

Identifying the optimal control condition for behavioral intervention trials requires complex trade-offs.⁴⁰ Despite its theoretical advantages, we rejected an attention control condition due to the threat of contamination – surrogates spontaneously telling their story to the interventionist during an attention control visit focused on, for example, legal and financial issues – in favor of an enhanced treatment as usual condition.⁴¹ We refer to the control condition as “enhanced” because treatment as usual typically involves no contact from the hospital after the patient’s death, except for administrative matters (e.g., insurance; though in some U.S. hospitals family members may receive bereavement cards).

The enhanced treatment as usual control condition involved a mailed letter of condolence, a *Journeys* “Newly Bereaved” newsletter with information about grief, and a guide with information about local and national grief support resources at 1-week after the death, and invitation to complete a storytelling interview after 6-months (i.e., “waitlist”). Blinded assessors followed detailed, constrained scripts for completing baseline, 3-month, and 6-month follow-up assessments to discourage any extraneous conversation (e.g., spontaneous storytelling). However, we did not seek to prevent control participants from telling their story to other persons in their lives outside of the study.

Intervention

Intervention subjects received the same written materials as control subjects, plus a 1–2 hour home visit or telephone call at approximately 4 weeks after the death by a trained interventionist. The 2 interventionists were licensed social workers who delivered the storytelling intervention following a detailed manual. We previously published a detailed description of the intervention.³³ Briefly, the interview involved non-judgmental elicitation of the story of the events leading up to the patient’s ICU admission, the ICU experience and decision process, and the aftermath of the patient’s death. The interviewer responded to the story with empathic reflective statements and probes of interpersonal and intrapersonal content, rather than historical details.

Intervention training and fidelity monitoring

The 2 interventionists’ 6 hours of storytelling training included an in-person didactic and experiential seminar, detailed review of the manual, and study of “gold standard” interview exemplars. We audio-recorded, then later transcribed each storytelling intervention session. Members of the team reviewed each audio file and transcript and one member reviewed the transcript with the interventionist, providing detailed constructive feedback. Two independent raters conducted qualitative content analysis of the sessions using a standardized form to measure adherence to prescribed behaviors and frequency of proscribed behaviors (See Supplementary Digital Content – Appendix 1: Intervention Fidelity and Protocol Adherence Checklist).

Data

We provide a full list of measures collected about surrogates and the patients on whose behalf they were making medical decisions in the Supplementary Digital Content, “Appendix 2: Full Compendium of Measures.” Recruiters collected socio-demographic

characteristics in person from all surrogates who consented to re-contact and proxy-reported socio-demographics and pre-ICU Karnofsky functional status of the incapacitated patients. Among patients who died, study staff abstracted from the electronic medical record the reason for ICU admission, APACHE III score, life-sustaining treatments received, palliative care involvement, and ICU length of stay. Among the surrogates of these patients who agreed to treatment allocation, we completed 3 telephone assessments: 2-weeks (baseline), 3-months, and 6-months. Surrogates allocated to the storytelling intervention received the intervention at 4-weeks. Baseline measures included preferences for involvement in decision making using the Control Preferences Scale⁴², whether patient had a pre-existing advance directive, whether the surrogate had discussed treatment preferences in the event of a serious illness with the patient prior to their ICU admission, the surrogate's preparedness for the death on a 1 to 7 scale, self-reported mental health diagnoses, current mental health treatment and/or grief support, resilience using the Brief Resilience Scale⁴³, post-traumatic stress symptoms using the Impact of Events Scale-Revised (IES-R)⁴⁴, anxiety and depression using the Hospital Anxiety and Depression Scale (HADS)^{45,46} and Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD-PHQ)⁴⁷, and decision regret using the Decision Regret Scale (DRS).^{48,49} Three- and 6-month measures, collected by a blinded assessor, included IES, HADS, PRIME-MD-PHQ, DRS, and self-reported mental health/grief support utilization. The 6-month assessment included all these measures, plus the Inventory of Complicated Grief (ICG).²¹ We assessed subjective units of distress (SUDS) on a scale of 0–100 before and after every study contact. Finally, after measure completion at 6 months, we elicited the surrogates' end of study feedback using a combination of closed-ended Likert scale items (How participation made them feel, whether participation was burdensome, and did they wish that they had not participated) and associated open-ended responses.

Additionally, we collected the IES, HADS, ICG, and DRS at 6-months from the observation group by telephone or mail. The rationale for this data collection was to assess selection bias; specifically, we were concerned that surrogates who refused study participation might have the highest symptom burden.

Study Outcomes

Prior to initiating enrollment, we defined *a priori* benchmarks for determining feasibility, acceptability, and tolerability (Table 4).

Additional outcomes included symptom burden, defined as the scale score from of each of the individual symptom scales (IES, HADS, PRIME-MD-PHQ, ICG) and the proportion of subjects meeting criteria for PICS-F (i.e., scores equal to or greater than scores proposed as cut-offs suggestive of syndromic burden on one or more of the scales for anxiety, depression, post-traumatic stress, or complicated grief).

Analysis

We did not conduct power analyses. We targeted screening 300 patients in the ICU based upon what was achievable with the time and resources allotted to this pilot. We summarize participant socio-demographics by level of participation. We summarize measures of

feasibility, acceptability, and tolerability, and symptom burden by arm, and of treatment fidelity for completed storytelling intervention visits. We made the *a priori* decision not to conduct tests of efficacy given concerns about inadequate power and sampling error in a pilot of this small size.⁵⁰

Human subjects

The University of Pittsburgh Institutional Review Board reviewed and approved the study. Subjects received \$20 for each telephone assessment (baseline, 3-months, and 6-months) and, for those assigned to storytelling, \$50 for the storytelling intervention visit.

RESULTS

We summarize screening and enrollment in the Figure. We summarize socio-demographics of surrogates who agreed to treatment assignment in Tables 1 and Table 2, and the demographics and clinical characteristics of the patients in Table 3. (See Supplementary Digital Content – Appendix 3: Characteristics of all consented surrogates, including those who consented to be followed, those who became eligible for re-contact, and those who agreed and did not agree to treatment assignment.)

Feasibility

We met all *a priori* feasibility, tolerability, and acceptability targets (Table 4).

Enrollment rates—Between June 18, 2013 and April 15, 2014, ~ 1.2 full-time equivalent (FTEs) recruiters (5 volunteers and part-time employees at 3 hospitals) assessed 329 patients and/or surrogates for eligibility (Figure). A bedside nurse approached 171 eligible surrogates to request permission to introduce study personnel and 116 (68%) provided proxy consent for medical record screening and consent for surrogate re-contact (1 later withdrew all consent). Common reasons for declining included: 1) being uncomfortable with providing access to the patient's medical record; and 2) being emotionally overwhelmed. One barrier to completing the consent process among those potentially interested was insufficient time, i.e., the surrogate asked for more time to consider participation, then the patient died before the recruiter could re-connect with the surrogate. Overall, recruiters consented 1 surrogate per 5–7 days of FTE coverage per ICU.

Treatment allocation, receipt, and fidelity—We allocated 14/32 (44%) to control and 18/32 (56%) to storytelling. Of the 18 assigned to storytelling, 17 (94%) completed the intervention. On average, interventionists delivered 22/27 (81%) prescribed interview protocol content objectives (Table 5). The most commonly missed content included: 1) reviewing the community resource guide with the participant at the end of the interview (92%), 2) retrospectively probing the most difficult part of the story to tell, including eliciting SUDS (48%), 3) eliciting SUDS prior to commencing storytelling (43%), and 4) probing what was unexpected or surprising about the ICU experience (43%). The frequency distribution of interventionist statements met all of our *a priori* targets for prescribed and proscribed communication behaviors (Table 5).

Follow-up rates—Overall, 14/14 (100%) and 13/14 (94%) of control participants and 16/18 (89%) and 17/18 (94%) of storytelling participants completed their 3-month and 6-month telephone assessments, respectively. There was < 1% missing data in both arms across all assessments.

Non-participants—The 21 surrogates who declined treatment allocation had similar socio-demographics to those who consented (See Supplementary Digital Content – Appendix 3: Characteristics of all consented surrogates). Seven (33%) declined any further contact; of the 14 (66%) who permitted re-contact, 7 (50%) completed the IES, HADS, ICG and DRS via telephone or mailed survey at 6-months (see Symptom burden, below).

Acceptability

Overall, 9/13 (69%) control participants and 16/17 (94%) storytelling subjects who completed end-of-study feedback at 6-months reported feeling “better” or “much better” after participating. Subjects in both groups spontaneously reported that altruism motivated their participation. Storytelling subjects frequently reported that helping others by participating in the study helped them: “I became more in touch with myself and I want to help other people. It gives me a purpose and I feel my father’s death was not in vain. It is like both of us have joined together to help other people.” (ID#169 – storytelling). Many storytelling participants praised the intervention: “Through the interview I was able to pinpoint exactly the reason I missed my mom so much. I was also able to recognize exactly what vexed me about the ICU.” (ID#122 – storytelling).

Open-ended negative feedback most commonly came from control participants and related to telephone assessments. For example: “[I felt] worse when doing it [the questionnaires] because it brought up a lot of feelings and made me sad.” (ID#127 - control) There was no negative feedback about the storytelling intervention. A handful of participants suggested expanding the focus on decision making to include decisions *before* the ICU. For example: “The ICU experience may be the easiest part in terms of making the decision because [the patient] is suffering so much. But all the things that go wrong beforehand that cause [the patient] to go to the ICU because people didn’t listen to what you were saying and care was not done well [are important].” (ID#39 – storytelling) We summarize detailed qualitative data regarding acceptability in the Supplementary Digital Content – Appendix 4: Detailed acceptability data.

Tolerability

The safety protocol involved screening participants for active suicidality if they endorsed the relevant question on the PHQ-9 (“Thoughts that you would be better off dead or of hurting yourself in some way”) or reported suicidal ideation during a storytelling interview. There were a total of 10 instances over all control assessments and 8 instances over all storytelling assessments during which a participant endorsed suicidal ideation. None went on to report active suicidality and none required acute referral to mental health services as a result of participating in the study.

Symptom burden

Control and storytelling subjects reported a high symptom burden that decreased between baseline and 6 months (Table 6) on all of the symptom assessment measures. We constructed a composite score based on the measures to indicate the presence or absence of PICS-F. While the sample sizes are too small to make any inferences, descriptively the prevalence of PICS-F at the final assessment was lower in the storytelling group than in the control group and non-participants who completed observation assessments at 6 months had higher symptom burden at 6 months than those in either the control or storytelling group.

DISCUSSION

In this phase II pilot of surrogate storytelling, a novel behavioral intervention for acutely-bereaved surrogates involved in a decision to limit life support in the ICU, we met or exceeded all of our a priori feasibility, acceptability, and tolerability benchmarks, heard promising claims of subjective benefit from our subjects, and learned many lessons that will strengthen a future phase III efficacy study.

Our measures of feasibility related to trial conduct. We were able to recruit surrogates during the emotionally-charged time of an ICU admission of their loved one. Our recruitment outcomes likely underestimate potential success that would be achievable with dedicated recruiters. Due to the limited budget for this pilot, we relied on part-time staff and volunteers to recruit participants in the ICU. Nonetheless, we enrolled 116 surrogates over 10 months. Two strategies contributed to this success. First, we consented surrogates for medical record review and re-contact early in the patient's ICU admission rather than waiting for a family meeting to signal likely treatment limitation decisions. The rationale for this decision was that if we waited for this milestone, then the surrogate was typically emotionally distraught in the face of the patient's failure to recover. This strategy increased the surrogate consent rate, but it introduced some inefficiency, since more than half of surrogates who consented to re-contact became ineligible because the patient recovered. Second, after 3 months of trial enrollment, we removed the requirement that the surrogate live within 50 miles of the hospital because we found that 20% of otherwise eligible subjects lived more than 50 miles away.

We met our pre-specified target for consent during the early bereavement period after the loved one's loss (60%). This is similar to other studies in this population^{7,16,18}, but lower than in our earlier pilot (70%).³³ One of the reasons we hypothesize for the lower rate of "conversion" from consent for re-contact to consent for treatment allocation is that a different staff member contacted the surrogate at 2-weeks than had recruited the surrogate in the ICU, whereas in our earlier pilot there was continuity between phase I and phase II recruitment, which may have increased rapport. Therefore, to increase consent rates in the phase III trial, we plan continuity between recruitment in the ICU and recruitment in the early bereavement period. The most common reason for declining consent in the ICU and after bereavement was being emotionally overwhelmed. It is possible that this introduces selection bias such that the most distressed surrogates do not participate. Although we did not collect baseline distress measures from those who did not consent, we did invite these participants to complete 6-month assessment measures. Only one-third ultimately did so;

however, their 6-month symptom scores appeared to be higher than either the control or storytelling groups for all measures except depression, consistent with selection bias. This is a particular concern since those with the highest distress also have the greatest potential to benefit from an effective intervention. One strategy for engaging participants is to mention the opportunity to help others by participating in research. We found that altruism strongly motivated participation: subjects felt that if they could do anything to help others through this trying experience they would like to do so. Reassuringly, our high rates of follow-up – 94% through 6-months – exceeded our expectations and protect against selection bias in outcomes assessment. It is possible that if we are more successful at enrolling the most distressed surrogates at baseline that our rates of loss-to-follow up would increase. Despite possible selection, the symptom burden of those who did agree to participate was very high and deserving of intervention. Particularly notable is the finding that 30% of subjects reported syndromal-level scores on the ICG at 6-months, compared to 7–10% of community samples of bereaved persons. The unique stressors of the ICU environment may explain these high rates.

We found moderate to high treatment fidelity. Specifically, there were high rates of prescribed interventionist behaviors and low rates of proscribed interventionist behaviors. We identified common “missed” content objectives. We can focus on these when training future interventionists.

Our measures of acceptability included subjective perceptions of efficacy, burdensomeness, and participation regret, as well as open-ended feedback. We met all benchmarks in both arms. Of interest, more intervention than control participants felt the study made them feel better (e.g., subjective benefit), intervention participants universally appreciated the opportunity to tell their story to an empathic listener, and the desire to help others (altruism) both motivated participation and arose as a potential independent mechanism of benefit. Of concern, control participants in particular felt that answering symptom burden questions was emotionally painful, and some questioned how this could help others. Several control subjects expressed disappointment when they were not assigned to storytelling. To address this, late in the trial we added a “waitlist control” and invited control participants to complete a storytelling interview after their 6-month assessment.

A concern about the study was whether it would be too emotionally distressing for participants. While the storytelling interview was emotionally activating, SUDS were typically lower after the interview (data not shown). Additionally, while only a crude measure, we did not have the occasion to initiate our safety protocol involving acute mental health services referral for any of our participants. Although it is possible that participating in the study could be harmful to some, the conceptual model underlying our intervention posits that, on average, a greater harm may stem from not talking about the experience at all.

We did not test efficacy. Experts in clinical trial design caution against making inferences regarding treatment outcomes from small pilot studies. Findings of positive or negative pilot trial results are more likely to be due to sampling variability than to treatment effect. We nonetheless note that subjects in the storytelling group appeared to have lower rates of the composite measure (PICS-F) and higher levels of subjective benefit. Those with the highest

IES scores at baseline saw greater reductions in 6-month ICG scores with storytelling than those with lower IES scores (data not shown); this could reflect regression to the mean or could reflect effect modification.

Our study has several limitations. Generalizability is limited due to selection of less-distressed surrogates, few minorities, and a disproportionate share of persons with active decision style preferences. We did not collect other relevant information about those who did not consent to participate, such as educational status. We used non-random (sequential) allocation, and we inadvertently included one subject who reported that she did not participate in a decision to limit life support (although there was a DNR order on the chart when the patient died.) We modified the protocol during enrollment (to remove distance as an exclusion criterion and to add telephone delivery of the intervention). We cannot draw conclusions to important questions from this study, such as: (1) Do reductions in symptom burden in both groups simply reflect time passage? (2) Does being in the study provide a safety net that participants find reassuring after the bouleversement of serving as a surrogate with control and intervention arms offering benefit? (3) Does the study provide an outlet for the expression of altruism, and altruism heals? (4) Are we measuring the right constructs; and (5) Do we have the right dose of the psychosocial intervention? Finally, we did not study the feasibility of identifying, recruiting, and training interventionists at hospitals without a network of behavioral interventionists on staff.

In conclusion, a clinical trial of storytelling among recently bereaved ICU surrogates is feasible, acceptable and tolerable. These subjects have a high symptom burden and report altruistic benefits from the opportunity to participate in research that might help others through this difficult experience in the future. This phase II study identified many opportunities to further enhance study feasibility and to optimize the experience of study participants in a future phase III study. While many questions remain regarding the optimal selective or indicated prevention strategy for this vulnerable group, we believe that storytelling deserves formal efficacy testing. Storytelling is attractive because it is low intensity and can be conducted by existing members of the workforce, such as chaplains or lay hospice volunteers, and may therefore be more scalable than behavioral therapy requiring multiple visits to a mental health provider.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. CONSORT Diagram

Participants screened, approached, enrolled, consented to treatment assignment, and followed-up.

Table 1

Socio-demographics of surrogate subjects

Variable	Control (n=14)	Storytelling (n=18)
Relationship to patient, n (%)		
Spouse/Partner	4 (28.5)	5 (27.7)
Parent	0 (0)	1 (5.5)
Child	8 (57.1)	7 (38.8)
Sibling	1 (7.1)	3 (16.6)
Other	1 (7.1)	2 (11.1)
Age, mean (SD)		
	55.9 (12.6)	55 (11.0)
Women, n (%)		
	12 (85.7)	11 (61.1)
Ethnicity, n (%)		
Hispanic or Latino	1 (7.1)	0 (0)
Not Hispanic or Latino	13 (92.8)	18 (100)
Race, n (%)		
Black or African American	1 (7.1)	0 (0)
White	13 (92.8)	18 (100)
Religious Preference, n (%)		
Protestant Christian	1 (7.1)	0 (0)
Roman Catholic	1 (7.1)	0 (0)
Other Christian	4 (28.5)	5 (27.7)
Jewish	0 (0)	0 (0)
Agnostic / Atheist / No religion	0 (0)	1 (5.5)
Other	7 (50.0)	6 (33.3)
No response	1 (7.1)	6 (33.3)
Religion/Spirituality Importance, n (%)		
Not at all important	0 (0)	1 (5.5)
Not too important	2 (14.2)	2 (11.1)
Fairly important	4 (28.5)	5 (27.7)
Very important	8 (57.1)	10 (55.5)

Table 2

Surrogate trial participants' decision style preference, recollection of advance care planning, preparedness for patient's death, and mental health history at baseline

Variable	Control (n=14)	Storytelling (n=18)
Control preferences scale, n (%); I preferred...		
to make the decisions.	1 (7.14)	2 (11.1)
to make the final decisions after seriously considering the doctor's opinion.	11 (78.5)	11 (61.1)
that the doctor and I share responsibility for the decisions.	1 (7.1)	4 (22.2)
that the doctor make the final decisions after seriously considering my opinion.	1 (7.1)	1 (5.5)
to leave all decisions to the doctor.	0 (0)	0 (0)
Prior discussion of treatment preferences with patient, n (%)	12 (85.7)	14 (77.7)
Patient had a living will/advance directive, n (%)	10 (71.4)	9 (50.0)
Preparedness for death [*] , mean (sd)	4.7 (2.0)	5.1 (2.1)
Past mental health history, n (%)		
Anxiety	4 (28.5)	6 (33.3)
Depression	4 (28.5)	7 (38.8)
PTSD	0 (0)	0 (0)
Currently receiving mental health treatment, n (%)	7 (50.0)	4 (22.2)

^{*} scale for 1 (well prepared) to 7 (totally unprepared)

Demographic and clinical characteristics of the incapacitated patients for whom surrogate trial participants made life-sustaining treatment decisions

Table 3

Variable	Control(n=14)	Storytelling(n=18)
Age, mean (SD)	72 (10.2)	67.8 (13.7)
Women, n (%)	7 (50)	9 (50)
Ethnicity, n (%)		
Hispanic or Latino	1 (7.1)	0 (0)
Not Hispanic or Latino	13 (92.8)	17 (100)
Race, n (%)		
American Indian/Alaska Native	1 (7.1)	0 (0)
Asian	0 (0)	0 (0)
Native Hawaiian or Other Pacific Islander	0 (0)	0 (0)
Black or African American	2 (14.2)	0 (0)
White	11 (78.5)	18 (100)
Pre-ICU Karnofsky score, median (IQR)	65 (50–90)	75 (50–100)
APACHE III score, mean (SD)	72.5 (28.3)	80.3 (33.7)
Reason for ICU admission, n (%)		
Acute Respiratory Failure	7 (50.0)	7 (38.8)
Coma	0 (0)	1 (5.5)
Shock	5 (35.7)	6 (33.3)
Acute Renal Failure	0 (0)	1 (5.5)
Cardiac Arrest	0 (0)	3 (16.6)
Other	6 (42.8)	5 (27.7)
Life Sustaining Treatments Received in ICU, n (%)		
Invasive Mechanical Ventilation	11 (78.5)	16 (88.8)
Vasopressors	10 (71.4)	13 (72.2)
Hemodialysis	5 (35.7)	4 (27.2)
Palliative care consultation	0 (0)	4 (22.2)

Variable	Control(n=14)	Storytelling(n=18)
Length of ICU stay (in days), mean (SD)	13.8 (10.5)	11.7 (10.5)

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Table 4

Benchmarks of feasibility, acceptability, and tolerability

Benchmark		
Feasibility		
60% enrollment rate among eligible subjects		
Consent 1 (medical record review and recontact)	116/171 (68%)	
Consent 2 (treatment allocation)	32/53 (60%)	
Control Storytelling		
80% storytelling intervention completion rate	-	17/18 (94%)
80% 3-month follow up rate	14/14 (100%)	16/18 (89%)
Within +/- 9 days	9/12 (64%)	13/16 (81%)
>70% 6-month follow up rate	13/14 (94%)	17/18 (94%)
Within +/- 18 days	10/13 (77%)	13/17 (76%)
<5% missing data elements	<1%	<1%
Acceptability		
<10% will report that...		
Participation made them feel "much worse"	0/13 (0%)	0/17 (0%)
Participation was burdensome	1/13 (8%)	1/17 (6%)
They wished that they had not participated	1/30 (8%)	0/17 (0%)
Tolerability		
<5% will require acute referral to mental health services		
	0/14 (0%)	0/18 (0%)

Table 5

Intervention fidelity measures

	Target	Actual
Content objectives	na	22/27 (81%)
Communication objectives; proscribed behaviors		
Emotion-handling (NURS) statements	40%	42%
Open-ended continuers (includes “explore” statements) [†]	25%	43%
Closed-ended continuers	na	32%
Emotional	40%	67%
Historical	<60%	33%
Communication objectives; proscribed behaviors		
Premature/false reassurance, agreement, rebuttal, or solution	<2%	1.2%
Psychotherapy tools (e.g., reframing)	<2%	1.4%

* NURS(E) is a mnemonic for classifying emotion-handling statements: N – naming; U – understanding; R – respect; S – support; (E – explore).

[†] Example open-ended continuer: “Tell me more about that.” For the purposes of fidelity assessment, we classified statements exploring emotion in open-ended continuers rather than emotion-handling statements.

Table 6

Surrogate decision makers – Outcomes measures, by time point

Variable Time Point	Control (n = 14)	Storytelling (n = 18)	Observation (n = 7)
Impact of Events Scale – Revised, mean (SD) *			
Baseline	35.8 (16.8)	36.1 (21.0)	
3-months	29.4 (19.5)	29.6 (17.9)	
6-months	25.6 (18.6)	24.8 (18.1)	25.4 (19.7)
Hospital Anxiety & Depression Scale – Anxiety Subscale, mean (SD) †			
Baseline	8 (5.3)	7.4 (6.1)	
3-months	8.4 (5.3)	7.3 (5.6)	
6-months	7.5 (5.9)	6.4 (5.5)	8.4 (6.8)
Hospital Anxiety & Depression Scale – Depression Subscale, mean (SD) †			
Baseline	8.6 (5.1)	7.0 (5.4)	
3-months	6.0 (5.6)	6.8 (5.2)	
6-months	5.9 (5.9)	5.8 (5.6)	5.7 (4.6)
Inventory of Complicated Grief, mean (SD) ‡			
6-months	22.4 (15.4)	22.8 (16.8)	24.8 (15.5)
PICS-F (HADS-A, HADS-D 8, IES 24; and/or ICG 25), n (%)			
Baseline	11/14 (79)	13/18 (72)	
3-months	9/14 (64)	10/16 (63)	
6-month	9/13 (69)	9/17 (53)	5/7 (71)
Decision Regret Scale, mean (SD) §			
Baseline	13.6 (17.5)	19.9 (21.3)	
3-months	19.3 (20.9)	13.7 (14.1)	
6-months	16.3 (16.1)	20.5 (19.7)	28.3 (25.8)
PHQ-9 Depression Scores, n (%)			
Severe Depression (PHQ-9 Score ≥ 20)			

Variable	Control (n = 14)	Storytelling (n = 18)	Observation (n = 7)
Time Point			
Baseline	2 (14)	4 (22)	
3-months	1 (7)	3 (17)	
6-months	2 (14)	0 (0)	
Service use since last contact, n (%)			
Consulted with mental health specialist			
Baseline	2 (14)	2 (11)	
3-months	3 (21)	2 (11)	
6-months	4 (29)	2 (11)	1 (17)
Counseling for nerves, mood, sleep			
Baseline	0 (0)	2 (11)	
3-months	4 (29)	2 (11)	
6-months	3 (21)	2 (11)	0 (0)
Medication for nerves, mood, sleep			
Baseline	8 (57)	7 (39)	
3-months	8 (57)	5 (28)	
6-months	5 (36)	5 (28)	1 (17)
Met with clergy			
Baseline	5 (36)	6 (33)	
3-months	3 (21)	4 (22)	
6-months	2 (14)	3 (17)	
Grief support group			
Baseline	0 (0)	0 (0)	
3-months	0 (0)	0 (0)	
6-months	1 (7)	1 (6)	

* IES-R: range 0–88, higher is worse and scores > 24 considered high and 33 are considered syndromic.

[†] HADS: range 0–28, higher is worse and scores on each subscale of 8 or higher are considered syndromic.

[‡] ICG: range 0–76, higher is worse and scores 25 are considered high and 30 are considered syndromic.

PICS-F – Post intensive care syndrome – family

[§] DRS: range 0–100, higher is worse and scores 25 reflect high regret.