

Official Title: ICU experience among family members of ICU patients

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Protocol

Title: ICU experience among Family Members of ICU Patients

Location of Research: Intermountain Medical Center

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Sponsor: Intermountain Research and Medical Foundation

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Purpose of the Study:

The purpose of this study is to investigate whether an expressive writing intervention increases post-traumatic growth (PTG) in family members of patients admitted to the ICU with a serious illness and explore the association between coping phenotypes and PTG. PTG will be compared between the intervention group receiving the expressive writing intervention and the control group (non-expressive or fact-based writing). The primary outcome will be PTG at 12 weeks, with secondary outcomes of depression, anxiety and posttraumatic stress disorder (PTSD) at follow up.

Hypothesis/Research Questions:

In two hypotheses evaluated in two specific aims, we will investigate whether an expressive writing intervention increases PTG in family members of patients admitted to the ICU with a serious illness and explore the association between coping phenotypes and PTG. PTG will be compared between the intervention group receiving the expressive writing intervention and the control group (non-expressive or fact-based writing). The primary outcome will be PTG at 16 weeks, with secondary outcomes of depression, anxiety and PTSD at follow up.

Specific Aim 1: Examine the association between participating in an expressive writing intervention and development of post-traumatic growth.

Primary outcome: Post-Traumatic Growth Inventory at 4 months

Secondary outcomes: Impact of Events Scale-Revised (IESR), Hospital Anxiety and Depression Inventory (HADS) at 4 months

Hypothesis 1a: Participants in the intervention group will have higher levels of post-traumatic growth at follow-up than participants in the control group.

Hypothesis 1b: Participants in the intervention group will have lower PTSD, depression, and anxiety scores at 4 months.

Specific Aim 2: Explore whether individual coping phenotypes predict PTG. Predictors for consideration include acute perceived stress (Perceived Stress Scale-4 [PSS-4], personality characteristics (Big Five Inventory [BFI]) coping ability (Brief COPE), social relationship quality (Social Relationship Inventory (SRI abbreviated), measures of disability in activities of daily living and instrumental activities of daily living caregiver burden (Groningen Activity Restriction [GARS] Scale), patient age and severity of illness (APACHE score).

Hypothesis 2a: ICU families coping phenotypes (stress, personality characteristics, and coping) will be associated with PTG.

Hypothesis 2b: Other variables related to the ICU (APACHE IV score, age, sex, ethnicity, whether the patient dies before follow-up) and post-ICU (care giver burden) experience will be associated with PTG at 3 mos.

Background and Significance:

Post-ICU psychological distress is common and important

The intensive care unit (ICU) is a stressful and challenging place for patients and their families, who must navigate illness and its associated discomforts as well as complex decision making in an environment characterized by tremendous uncertainty¹⁻³. Negative emotions including stress, fear, anger, and fatigue are extremely common during an ICU admission^{4,5}. Many family members experience anxiety, depression, and posttraumatic stress disorder (PTSD) during and after the ICU experience that persists years after their loved one is discharged from the ICU^{3,6-8}.

During an ICU stay, it is common for patients to be too ill to participate in decision making in the ICU⁹ – and medical decision making will generally be made by the family members designated surrogate decision makers⁷. Surrogate medical decision making may be intense and stressful and may contribute to development of anxiety, depression and posttraumatic stress disorder (PTSD) in family members³.

Persistent psychological distress after ICU admission is part of a recognized syndrome called post-intensive care syndrome-Family (PICS-F)¹⁰. The reasons for PICS-F in response to the emotional trauma of the ICU are multifactorial, and include pre-existing risk factors, failures to meet informational needs, threat of death or serious disability, and decision-related stress, given the heavy psychological burden associated with decision making about matters of life and death^{1,3}. Traumatic experiences, however, can also result in positive psychological outcomes – including better relationships, improvements in spiritual well-being, greater self-efficacy, and personal development. Such positive post-trauma outcomes are known as post-traumatic growth (PTG)¹¹ and may represent an alternative to the PTSD and anxiety that have come to the hallmark of PICS-F.

Post-traumatic growth

Post-traumatic growth is a positive change in a person's sense of self that is part of a complex narrative or personal life story that occurs after a difficult life experience. An individual's world view with the accompanying goals, beliefs, and habits of managing emotional feelings and stress can be shaken by traumatic experiences and then, over time, are rebuilt into a new positive view of the self and life¹¹⁻¹³. Post-traumatic growth (PTG) has been observed in response to a wide variety of traumatic experiences including medical illnesses (chronic illness, cancer, AIDS), military combat, man-made disasters (e.g., shootings) and natural disasters (e.g., tornadoes)^{14,15}. Patterns of PTG vary based on aspects of the trauma and the individual's characteristics. Some evidence suggests that the traumatic events associated with the greatest PTG represent intermediate levels of harm. Personal characteristics associated with PTG, include openness, extraversion, agreeableness and conscientiousness alternatively neuroticism is associated with less PTG. Greater PTG is associated with -focused coping and cognitive processing of the traumatic event, involvement in religious activities and high levels of perceived social support¹⁵⁻¹⁷. Overall, some degree of emotional processing of the traumatic event must take place for PTG to occur,¹² and such processing is most likely to result in post-traumatic growth in a particular personal and social context.

Post traumatic growth takes time to emerge, with most positive changes occurring within 2 months after the trauma¹⁸ while the level of PTG remains stable 3 to 8 years following the trauma^{19,20}.

Potential Benefits of Expressive Writing

Although PTG is a naturally occurring process, deliberate interventions can increase its likelihood. Some interventions are time-consuming and expensive – such as cognitive behavioral therapy. But, in some contexts, interventions centered on a specific type of journaling known as “expressive writing” have increased PTG. Semi-structured expressive writing was developed by James Pennebaker, Ph.D. as a structured technique for recording deep thoughts and feelings about a traumatic event in a structured setting²¹. Expressive writing facilitates coping with trauma by helping people process – emotionally and cognitively – a traumatic event. Participating in expressive writing – commonly three 20-minute sessions on three consecutive days – includes writing about emotions and thoughts associated with the traumatic event. Variations include providing participants with a journal and asking them to complete the writing at set times at home²² or using an internet-based journal²³. In many studies expressive writing interventions are associated with improved outcomes including fewer reports of physical symptoms, a reduction in PTSD and greater PTG²²⁻²⁴. In addition, expressive writing is associated with reduced healthcare utilization, fewer physical symptoms, and fewer PTSD symptoms on follow-up^{21,22,25}.

Family members and patients enter the ICU with unique characteristics that may affect their risk for psychological distress²⁶. In other trauma-exposed populations, individual attributes have been associated with development of PTSD^{26,27}. Personalizing the experience of family members by offering post-ICU support strategies, such as writing interventions, may decrease psychological distress and improve positive outcomes and PTG^{11,28}.

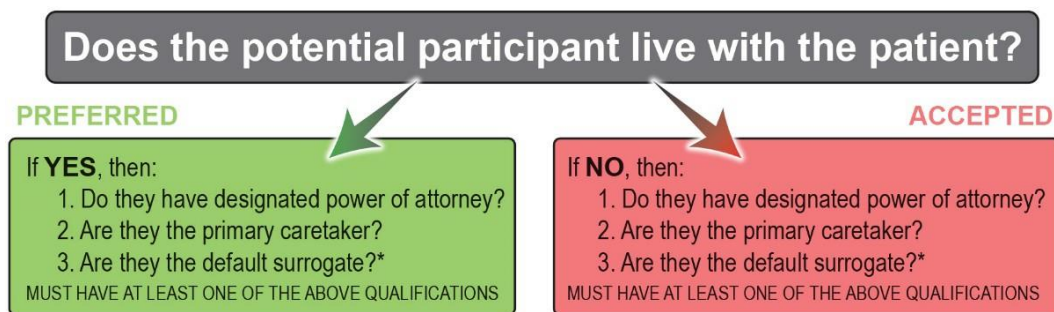
In prior work, we identified ICU family member coping phenotypes that would identify individual attributes, preferences, and vulnerabilities (personality dimensions, shared decision-making preferences, coping styles, and social support) that might be relevant to the experience of ICU surrogates²⁹. We identified three coping phenotypes including adaptive copers, maladaptive copers, and disengaged copers. Coping phenotypes differed primarily on coping styles, personality, quality of their closest social relationship, and history of anxiety and depression.²⁹ Early work suggests that individuals in certain coping phenotypes may have different approaches to surrogate decision making and different satisfaction with the shared decision making during a simulated ICU experience. They may also have different probabilities of PTG.

Research Subjects:

Inclusion Criteria:

Family members of ICU patients are eligible for the study. We will enroll **one** study participant per patient admitted to a study ICU (Shock Trauma or Respiratory ICU at Intermountain Medical Center) who meets the following inclusion criteria:

- Participant can be a family member of a patient admitted to a study ICU for >24 hours and ≥ 1 of the following:
 - mechanical ventilation via endotracheal tube for ≥ 12 hours
 - non-invasive ventilation (CPAP, BiPAP) for > 4 hours in a 24-hour period provided for acute respiratory failure in an ICU (not for obstructive sleep apnea or other stable use)
 - high flow nasal cannula or face mask O₂ with FiO₂ ≥ 0.5 for ≥ 4 hours
 - use of vasopressors for shock of any etiology for >1 hour
- The priority for enrollment is outlined in the picture below.



* A default surrogate can include (in order of preference):

- | | |
|---|-----------------------|
| 1. Spouse (unless divorced or legally separated OR if court finds spouse acted in a manner that should preclude him/her from having a priority position) | 2. Adult child |
| | 3. Parent |
| | 4. Sibling |
| | 5. Grandparent |
| | 6. Grandchild |

- Both participant and ICU patient must be adult (age ≥ 18 years of age)
- Participant must be able to read, speak, and write in English
- Participant must be enrolled within 72 hours of the patient's meeting mechanical ventilation criteria.

Participants who live with the patient will be accorded higher priority than those who do not live with the patient because they are more likely to be involved as caregivers. The preference would be for the

participant to be the designated power of attorney; if there is no designated power of attorney living with the patient, then the primary informal caregiver (identified either by the patient or by the family) would be enrolled; if either of these is not available, the default surrogate (defined in figure 1) would be enrolled. If no one living with the patient meets these criteria, then family members and informal caregivers not living with the patient will be screened for the study. The preference would again be for first, the designated power of attorney, then a primary caregiver and a default surrogate. An informal caregiver provides care without reimbursement.

Participant Exclusion Criteria:

- Pregnant or breastfeeding females
- Prisoners
- Children (age <18 years of age)
- Known history of PTSD, dementia, or schizophrenia. Presence of these illnesses will be per participant report of physician diagnosis and treatment
- If a patient has been transferred from another ICU after an ICU course greater than 24 hours, or if the patient has had a previous ICU or long-term acute care (LTAC) admission in the last 90 days, the family member or caregiver will be excluded.
- Patients admitted for hospice
- Participants who live more than 200 miles away or who have no specified domicile
- Non-English speaking

Because ICUs are sometimes used for simple monitoring of patients with low severity of illness and that experience is likely to be quite different from an admission for critical illness, we restrict to patients with at least a moderate severity of illness as judged by >48 hours of mechanical ventilation. We exclude participants who have underlying mental disease such as PTSD, dementia, and schizophrenia because these participants may process trauma-related information very differently from other participants. The intervention features expressive writing so understanding, speaking, and writing in English is critical as we will not have the capacity to conduct data analysis of the writing sample in other languages. We are most interested in subjects who have experienced acute stress at an identifiable time (during the ICU admission) thus family members who have already been in ICU or in other critical care environments may not be undergoing acute stress.

Recruitment:

Qualified study participants will be consented prior to commencing any research-related activity. These individuals will be approached in the patient's room or waiting room in the ICU or by telephone.

Methods/Procedures: Baseline Assessment

Participants will be enrolled in the study if they meet study inclusion and no exclusion criteria and signed informed consent. Participants will be administered baseline questionnaires, randomly assigned to the intervention or control condition, participate in intervention or control writing condition at 4 weeks (range 2 to 8 weeks) after enrollment, and administered follow-up questionnaires at three months after the writing intervention (\pm 2 weeks) by telephone.

Questionnaires

Participants will complete baseline questionnaires including³², PSS-4, BFI, Brief COPE, HADS and the IESR.

Table 1. Questionnaires administered at study enrollment

Instrument	Measures	Scale	Scoring
Hospital Depression and Anxiety Scale	Depression and anxiety	14 items (7 each for anxiety and depression). Items scored 0 to 3. Total scores for each scale range from 0 to 21.	Scores of 8 or higher indicate symptoms or depression or anxiety. ³³
Impact of Event Scale Revised (IES-R)	Screens for PTSD	22-item scale measuring intrusion, avoidance and hyperarousal; each item scored from 0-4	A mean score of ≥ 1.6 indicates PTSD symptoms. ^{34,35}
Perceived Stress Scale	Feelings of stress	4 items with scores that range from 0 to 4	Higher scores indicate greater stress. ^{36,37}
Brief COPE	Coping with stress	14 dimensions with 2 questions per dimension	Higher scores indicated greater use of a given coping strategy. ³⁸
Social Relationship Inventory (abbreviated)	Quality of Social Support	3 dimensions of relationship for the person closest to the respondent, helpfulness, upset, and unpredictability rated from 1 (not at all) to 6 (extremely)	Higher scores on each dimension indicate greater helpfulness, upset, and unpredictability.
Big Five Inventory	Personality dimensions: openness to new experiences, conscientiousness, extra version, agreeableness and neuroticism.	10 items	Higher scores indicate greater degree of a specific personality characteristic. ³⁹

Random Assignment and Intervention

Random assignment to condition will be completed using random number generator. Participants will receive instructions for participating in the intervention.

The intervention will take place in person at 4 weeks (± 2 to 8 weeks). Participants will participate in a semi-structured 20-minute expressive writing session in person or at home with instructions. For those in the experimental expressive writing condition, the instructions (adapted from Stanton & Danoff-Burg)²⁴ will be:

“What I would like you to write about for these three sessions are your deepest thoughts and feelings about your experience with your family member in the Intensive Care Unit (ICU). I realize that people with a loved one in the ICU experience a full range of emotions and thoughts, and I want you to focus on any and all of them. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You might think about all the various feelings and changes that you experienced before your loved one was hospitalized in the ICU, after the diagnosis that led them to the ICU, during treatment, and now. Whatever you choose to write, it is critical that you really focus on your deepest thoughts and feelings. Ideally, I would like you to focus on feelings, thoughts, or changes that you have not discussed in great detail with others-private feelings. You might also tie your thoughts and feelings about your experiences with having your loved one in the ICU to other parts of your life, i.e., your childhood, people you love (this loved one and others), who you are, or who you want to be. Again, the most important part of your writing is that you really focus on your deepest emotions and thoughts. The only rule we have is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. Don’t worry about grammar, spelling, or sentence structure. Don’t worry about erasing or crossing things out. Just write.”

Participants in the control condition will receive the following instructions:

“What I would like you to write about for these three sessions are all the facts about your experience with your family member in the Intensive Care Unit (ICU). We are not interested in your thoughts and emotions. Please do not include them. We are interested in all the facts about how your loved one came to the ICU and the facts about your experiences in the ICU with your loved one. The only rule we have is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. Don’t worry about grammar, spelling, or sentence structure. Don’t worry about erasing or crossing things out. Just write.”

Participants will write for 20 minutes for 3 sessions that will occur over a 2-hour period on the participation day (8 weeks after the hospitalization). Participants who are comfortable typing will type responses into a REDCap website via a tablet and keyboard which will measure the amount of time spent writing or at home on their computer and will email the writing sample to the study coordinator.

Participants who use handwriting will be observed by the project coordinator if in person. Instructions will be sent to the participant if completing the writing at home.

- a. Study coordinator will call the study participant to assess if they are willing and able to do the writing at home and set up a date and time for them to do the writing follow-up at home.
- b. Each participant will be sent a unique identifier (ex. 193JTA) that we will link to study ID and them they will be instructed use the code to identify their writing instead of their name.
- c. An instruction sheet will be emailed or sent to the participant via email or regular mail if writing long hand.
- d. The participants will be instructed to use the identifier in the subject line of email when they send the writing sample back to the study coordinator Mardee Merrill at Mardee.Merrill@imail.org or to Ramona Hopkins, PhD at Mona.Hopkins@imail.org.

- e. If writing is done long-hand a self-addressed stamped envelope will be included to send back the writing to the study coordinator.

Manipulation checks include completion of the Essay Evaluation form in which participants will rate how personal, meaningful, and reflective of their feelings their essay is. Participants in the control condition should rate this very low in comparison to participants in experimental conditions. All participants who complete follow up will receive a gift card after completing the writing intervention.

4 Month Follow-up

Four months after the writing exercise, participants will be contacted to complete an instrument battery by telephone. Follow-up measures include IES-R, HADS, PSS-4, Groningen Activities Restriction Scale (GARS) for assessing impact of the traumatic event on functional and emotional health and Posttraumatic Growth Inventory (PTGI). Following participation participants will receive gift card payment in the mail.

4 Month Follow-up			
Hospital Depression and Anxiety Scale	depression and anxiety	14 items (7 each for anxiety and depression). Items scored 0 to 3. Total	Scores of 8 or higher indicate symptoms or depression or anxiety. ³³
Impact of Event Scale Revised (IES-R)	Screens for PTSD	22-item scale measuring intrusion, avoidance and hyperarousal	A mean score of ≥ 1.6 indicates PTSD symptoms. ^{34,35}
Perceived Stress Scale	Feelings of stress	4 items with scores that range from 0 to 4	Higher scores indicate greater stress. ^{36,37}
Brief COPE	Coping with stress	14 dimensions with 2 questions per dimension	Higher scores indicated greater use of a given coping strategy. ³⁸
Post-Traumatic Growth Inventory	Positive perceptions of change following a traumatic event	21 items that use a 6 point Likert scale (0-5)	Higher Scores Indicate greater PTG
Physical Symptoms Inventory – 13 Item Version	Examines physical symptoms experienced during previous 30 days adapted to include medical utilization	13 items that use a 5 point Likert Scale (1-5)	Higher scores indicate more symptoms on more days. ^{21,24}

Groningen Activity Restriction Scale (GARS)	Assess degree of restriction experienced due to providing care in 11 categories: caring for him/herself, caring for others, eating habits, shopping for him/herself, visiting friends, working on hobbies, sports and recreation, going to work, and maintaining friendship. Developed and used in ICU populations, ⁴⁶⁻⁴⁹ shopping for him/herself, visiting friends, working on hobbies, sports and recreation, going to work, and maintaining friendship. and used in ICU populations. ⁴⁶⁻⁴⁹	11 items scored from 1 to 4	Scores range from 11 to 44 with higher scores indicating greater activity restriction.
Groningen Activity Restriction Scale (GARS)	Assess degree of restriction experienced due to providing care in 11 categories: caring for him/herself, caring for others, eating habits, sleeping habits, doing household chores, going	11 items scored from 1 to 4	Scores range from 11 to 44 with higher scores indicating greater activity restriction.
Essay Evaluation Measure	Perception that essay was personal, meaningful and revealing of their emotions	Each item Likert 0-6 total range 0-18	Higher scores indicate that participants found the essay personal and meaningful and revealing of their emotions (0-18) ⁵⁰
Evaluation of essays not done with participant			

Informed Consent:

Study-designated Intermountain Healthcare employees (either the research coordinator(s) or the study investigator(s)) will obtain informed consent from the study participant. The study staff member obtaining consent will provide the participant with the current IRB-approved Informed Consent Form and will be available to answer any questions the participant may have. Individuals approached for consent will be given as much time as they require to consider enrollment in the study.

The ICU patient will not be approached or questioned. They are indirectly involved, as the study participant is defined by their relationship to the patient. Minimal information will be obtained about the patient from the medical record to allow assessment of the effects of acute severity of illness or length of stay. The ICU patient will not be consented as they are not the subject of the study and minimal information is collected regarding these individuals. We will ask for a waiver of informed consent to gather this data.

Waiver of Informed Consent

The ICU patients are not directly involved and will not be approached or questioned. Minimal information will be obtained about the patients. The ICU patients will not be consented as they are not the subject of the study and minimal information is collected regarding these individuals. We will ask for a waiver of informed consent to gather this data. We feel it is not necessary or appropriate to obtain consent from the ICU patients for these reasons.

Only the minimum PHI needed will be collected. We will only collect names, hospital ID number and dates necessary to determine hospital and length of ICU stay. The study data will be stored on secure computers and will be de-identified. We will protect confidentiality and privacy in a HIPAA- and Good Clinical Practice- compliant way. Subjects will be given an anonymous study ID. In addition to managing only non-identified data, we will also protect that data by storing it only on secure computers. The only data sharing will be with our collaborator Dr. Jorie Butler at the University of Utah. All other data sharing such as might be required for regulatory reasons or to comply with editorial requirements of scientific journals, will be deidentified.

Risks:

Based on prior research in psychology and in critical care, we anticipate that there will be only minimal risk to those participating in this research. Patients may experience some discomfort from answered survey questions and writing about their family members ICU experience. In our experience surveying many hundreds of patients and families during and after an ICU admission, this is very uncommon. Participants are always free to decline to answer any question or further participation. Breach of confidentiality is a potential risk, but the data will be appropriately safeguarded against inappropriate disclosure.

Benefits:

Data indicate that ICU admission results in adverse psychological outcome including depression, anxiety and posttraumatic stress disorder. If the intervention enhances PTG, we will be able to help family members of critically patients develop positive outcomes. Our ultimate goal is to understand, predict, and improve psychological outcomes (depression, anxiety and PTSD) in patients and their family members after ICU admission. This study may help future ICU patients and their family members by helping us to understand how PTG may affect psychological wellbeing for family of patients admitted to the ICU

Impact on Intermountain

Intermountain Medical Center is a pioneer in the study of long-term outcomes after critical illness and patient- and family-centered intensive care. We plan to expand these investigations into a better understanding of the long-term outcomes and acute patient- and family-related experiences associated with an ICU admission more generally. This work will allow us to expand prior expertise and reputation in the field of long-term outcomes after critical illness and to establish Intermountain Medical Center as a leader in interventions during critical illness that improve long-term outcomes. We see this research project as a key way to further cement Intermountain's profound leadership in creating ICUs that are carefully attuned to the human side of serious illness.

Compensation:

If participants decide to participate in the study, to compensate them for their time and effort, at the writing exercise visit, they will receive a \$50 gift card or be mailed a \$50 check. After the 4-month follow-up phone call, they will receive another \$50 gift card or be mailed a \$50 check. Thus, if they complete the study, they will receive a total of \$100 for the two visits.

Data Collection:

Demographic Characteristics: Participant age, sex, ethnicity, years of educational attainment, identification with religion (e.g., Buddhism, Christian, Muslims well as “Spiritual but not religious” or “other”) were collected. The importance of religion was assessed using the following questions: (*How important is religion in your daily life?*) from (1) *not at all* to (4) *extremely* and religious service attendance (*How frequently do you attend religious services?*). History of anxiety and depression were assessed (e.g., *Do you have a personal history of anxiety?*), and whether they had ever received treatment by a physician or mental health provider.

This study requires the use of the following information:

- ICU Patient information (the only PHI required is the hospital ID number used to collect the non-PHI demographics and outcome information)
 - Age (if the patient’s age is greater than 89, it will be recorded as 89)
 - Sex
 - Race
 - Ethnicity
 - Primary ICU diagnosis
 - APACHE II score at admission
 - Prior ICU admissions in the last 5 years (per report from participant)
 - Mortality at 3 months (i.e., living or deceased per report from participant)
 - Hospital and ICU length of stay
 - Presence of mechanical ventilation
 - Baseline terminal illness (congestive heart failure, ESRD, liver failure, cancer)
- Study Participant information:
 - Age
 - Sex
 - Race
 - Ethnicity
 - Religion (importance, affiliation, and degree of importance)
 - Employment status
 - Number of hours weekly spent with the patient (averaged over the last month) and whether the participant lives with the patient,
 - Highest level of education.
 - Limited medical history: diagnosed depression, anxiety, sleep disorder, obesity. ^{30,31}
 - Psychiatric history of depression or anxiety
 - History of substance and alcohol abuse

The informed consent form describes the elements of PHI that will be used as a part of this study. All identifiable study information that is collected will be kept on computers owned and secured by Intermountain Healthcare. Any PHI collected for this study will be de-identified prior to disclosure to study collaborators outside of Intermountain Healthcare and only under authorization of current, valid data use agreements. The code used to de-identify these subjects will be retained by the Intermountain Healthcare Principal Investigator to allow re-identification of the subject should clarification of information be required. Identifiers of study participants will be maintained securely in order to report study results to participants, e.g., via newsletters.

We will randomize family members to receive either the PTG intervention and or non-intervention control group (control writing condition). The intervention group will participate in a brief expressive writing intervention. The control group will receive a control writing condition (fact-based writing) and complete the other study measures.

Descriptive statistics will be calculated for all demographic variables as well as all instruments (both at baseline and 4 month follow up). PTGI at 4 months (along with the secondary outcomes) will be compared between the intervention and control arms using Wilcoxon Rank Sum tests. Further, we will use linear regression to assess the relationship between expressive writing and PTGI at 4 months, adjusting for other relevant factors (i.e., participant demographics, (including age), patient demographics, illness severity of the patient, social support of the participant, caregiver burden, etc.).

Sample Size:

Studies of post-traumatic growth using the PTGI have sample means ranging from 45-77^{51 52-55}. We hypothesize that participants in the intervention arm will have a higher PTGI at 4 months compared to those in the control arm. Based on previous studies, we assumed a mean (SD) PTGI at 4 months of 45¹⁸ in the control arm and 56²¹ in the intervention arm^{23,52,53}. A power analysis based on the Wilcoxon Rank Sum test determined 102 patients are necessary to identify a significant difference (alpha=0.05) between the arms. To account for potential dropout, we will seek to enroll 130 patients total, 65 in each arm.

Funding:

We have applied for an IRMF grant.

Copying Data Already Collected:

Some of the questionnaires for this study are the same as the questionnaires for the study Family Presence (IRB #1050086). To avoid asking subjects the same questions multiple times in a short time period, if subjects have consented to this study and were previously consented and enrolled in the other study, responses to the same questionnaires in the other study will be copied into the data for this study.

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Appendixes:

Include survey tools, data collection forms, etc.

Appendix 1. (IESR, HADS, and Brief Cope)

Appendix 2. Post Traumatic Growth Inventory

Appendix 3. Essay Evaluation Measure

Appendix 4. Groningen Activity Restriction Scale (GARS)

Appendix 5. Physical Symptoms Scale

Appendix 6. Social Support Index

Appendix 7. Writing Instructions for ICU Experience Study Participants

Appendix 1. Impact of Event Scale Revised (IES-R)

Permission from Dr. Weiss by Samuel Brown, MD MS pending.

(Read the following statement to the *participant*): I really appreciate your help with these surveys. I want to ask about something else now. The following is a list of difficulties people sometimes have after stressful life events. I will read each item, and then ask you to indicate how distressing each difficulty has been for you during the past 7 days with respect to your experience with your loved one's ICU stay. How much were you distressed or bothered by these difficulties? In the questions, the word "it" refers to your experience with your loved one's ICU stay.

1. Any reminder brought back feelings about it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
2. I had trouble staying asleep.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
3. Other things kept making me think about it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
4. I felt irritable and angry.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
5. I avoided letting myself get upset when I thought about it or was reminded of it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
6. I thought about it when I didn't mean to.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
7. I felt as if it hadn't happened or wasn't real.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely

8. I stayed away from reminders of it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
9. Pictures about it popped into my mind.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
10. I was jumpy and easily startled.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
11. I tried not to think about it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
13. My feelings about it were kind of numb.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
14. I found myself acting or feeling like I was back at that time.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
15. I had trouble falling asleep.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
16. I had waves of strong feelings about it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
17. I tried to remove it from my memory.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely

18. I had trouble concentrating.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
20. I had dreams about it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
21. I felt watchful and on guard.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely
22. I tried not to talk about it.	<input type="checkbox"/> 1 Not at all <input type="checkbox"/> 2 A little Bit <input type="checkbox"/> 3 Moderately <input type="checkbox"/> 4 Quite a bit <input type="checkbox"/> 5 Extremely

Hospital Anxiety and Depression Scale (HADS) License from GL Assessment pending.

Record responses directly on licensed copy of instrument from Nfer Nelson, UK & include with CRF

(Read the following introduction to the participant): I am now going to ask some different questions. Doctors are aware that emotions play an important part in most illnesses. This questionnaire is designed to help us to know how you feel. I will read each item with the possible responses. Please respond with the reply that comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long, thought out response.

1. I feel tense or 'wound up'	<input type="checkbox"/> ₁ Most of the time <input type="checkbox"/> ₂ A lot of the time <input type="checkbox"/> ₃ From time to time, occasionally <input type="checkbox"/> ₄ Not at all
2. I still enjoy the things I used to enjoy	<input type="checkbox"/> ₁ Definitely as much <input type="checkbox"/> ₂ Not quite so much <input type="checkbox"/> ₃ Only a little <input type="checkbox"/> ₄ Hardly at all
3. I get a sort of frightened feeling as if something awful is about to happen	<input type="checkbox"/> ₁ Very definitely and quite badly <input type="checkbox"/> ₂ Yes, but not too badly <input type="checkbox"/> ₃ A little, but it doesn't worry me <input type="checkbox"/> ₄ Not at all
4. I can laugh and see the funny side of things	<input type="checkbox"/> ₁ As much as I always could <input type="checkbox"/> ₂ Not quite so much now <input type="checkbox"/> ₃ Definitely not so much now <input type="checkbox"/> ₄ Not at all
5. Worrying thoughts go through my mind	<input type="checkbox"/> ₁ A great deal of the time <input type="checkbox"/> ₂ A lot of the time <input type="checkbox"/> ₃ From time to time but not too often <input type="checkbox"/> ₄ Only occasionally
6. I feel cheerful	<input type="checkbox"/> ₁ Not at all <input type="checkbox"/> ₂ Not often <input type="checkbox"/> ₃ Sometimes <input type="checkbox"/> ₄ Most of the time

7. I can sit at ease and feel relaxed	<input type="checkbox"/> ₁ Not at all <input type="checkbox"/> ₂ Not often <input type="checkbox"/> ₃ Sometimes <input type="checkbox"/> ₄ Most of the time
8. I feel as if I am slowed down	<input type="checkbox"/> ₁ Nearly all the time <input type="checkbox"/> ₂ Very often <input type="checkbox"/> ₃ Sometimes <input type="checkbox"/> ₄ Not at all
9. I get a sort of frightened feeling like 'butterflies' in the stomach	<input type="checkbox"/> ₁ Not at all <input type="checkbox"/> ₂ Occasionally <input type="checkbox"/> ₃ Quite often <input type="checkbox"/> ₄ Very often
10. I have lost interest in my appearance	<input type="checkbox"/> ₁ Definitely <input type="checkbox"/> ₂ I don't take so much care as I should <input type="checkbox"/> ₃ I may not take quite as much care <input type="checkbox"/> ₄ I take just as much care as ever
11. I feel restless, as if I have to be on the move	<input type="checkbox"/> ₁ Very much indeed <input type="checkbox"/> ₂ Quite a lot <input type="checkbox"/> ₃ Not very much <input type="checkbox"/> ₄ Not at all
12. I look forward with enjoyment to things	<input type="checkbox"/> ₁ As much as I ever did <input type="checkbox"/> ₂ Rather less than I used to <input type="checkbox"/> ₃ Definitely less than I used to <input type="checkbox"/> ₄ Hardly at all
13. I get sudden feelings of panic	<input type="checkbox"/> ₁ Very often indeed <input type="checkbox"/> ₂ Quite often <input type="checkbox"/> ₃ Not very often <input type="checkbox"/> ₄ Not at all
14. I can enjoy a good book or radio or TV program	<input type="checkbox"/> ₁ Often <input type="checkbox"/> ₂ Sometimes <input type="checkbox"/> ₃ Not often <input type="checkbox"/> ₄ Very Seldom

Coping with Stress (Brief COPE)

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off of things	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real."	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10. I've been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4

20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating	1	2	3	4
28. I've been making fun of the situation	1	2	3	4

Appendix 2. Post Traumatic Growth Inventory

Instructions: Please indicate for each of the statements below the degree to which this change occurred in your life as a result of your crisis, using the following scale.

	I did not experience this change as a result of my crisis	I experienced this change to a very small degree as a result of my crisis	I experienced this change to a small degree as a result of my crisis	I experienced this change to a moderate degree as a result of my crisis	I experienced this change to a great degree as a result of my crisis	I experienced this change to a very great degree as a result of my crisis
My priorities about what is important in life	0	1	2	3	4	5
An appreciation for the value of my own life	0	1	2	3	4	5
I developed new interests	0	1	2	3	4	5
A feeling of self-reliance	0	1	2	3	4	5
A better understanding of spiritual matters	0	1	2	3	4	5
Knowing that I can count on people in times of trouble	0	1	2	3	4	5
I established a new path for my life	0	1	2	3	4	5
A sense of closeness with others	0	1	2	3	4	5
A willingness to express my emotions	0	1	2	3	4	5
Knowing I can handle difficulties	0	1	2	3	4	5
I'm able to do better things with my life	0	1	2	3	4	5

	I did not experience this change as a result of my crisis	I experienced this change to a very small degree as a result of my crisis	I experienced this change to a small degree as a result of my crisis	I experienced this change to a moderate degree as a result of my crisis	I experienced this change to a great degree as a result of my crisis	I experienced this change to a very great degree as a result of my crisis
Being able to accept the way things work out	0	1	2	3	4	5
Appreciating each day	0	1	2	3	4	5
New opportunities are available which wouldn't have been	0	1	2	3	4	5
Having compassion for others	0	1	2	3	4	5
Putting effort into my relationships	0	1	2	3	4	5
I'm more likely to try to change things which need changing	0	1	2	3	4	5
I have a stronger religious faith	0	1	2	3	4	5
I discovered that I'm stronger than I thought I was	0	1	2	3	4	5
I learned a great deal about how wonderful people are	0	1	2	3	4	5
I accept needing others	0	1	2	3	4	5

Appendix 3. Essay Evaluation Measure

Instructions: Please answer the following questions about your essay using the scale provided.

	Not at All	Low	Slightly	Neutral	Moderately	Very	A Great Deal
How personal was the essay that you wrote today?	0	1	2	3	4	5	6
How much did you reveal your emotions in what you wrote today?	0	1	2	3	4	5	6
Have much of what you wrote today have you shared with/told others?	0	1	2	3	4	5	6

Appendix 4.

Groningen Activity Restriction Scale (GARS)

The following questions refer to daily activities which should be performed frequently. In each question it is asked whether you *are able to perform* the activity at this moment. It is not intended to assess whether you are actually performing the activities, but if you can do them if necessary.

Response categories for each item

1. Yes, I can do it fully independently without any difficulty
2. Yes, I can do it fully independently but with some difficulty
3. Yes, I can do it fully independently but with great difficulty
4. No, I cannot do it fully independently, I can only do it with someone's help

GARS items

1. Can you, fully independently, dress yourself?
2. Can you, fully independently, get in and out of bed?
3. Can you, fully independently, stand up from sitting in a chair?
4. Can you, fully independently, wash your face and hands?
5. Can you, fully independently, wash and dry your whole body?
6. Can you, fully independently, get on and off the toilet?
7. Can you, fully independently, feed yourself?
8. Can you, fully independently, get around in the house (if necessary with a cane or walker)?
9. Can you, fully independently, go up and down the stairs?
10. Can you, fully independently, walk outdoors (if necessary with a cane or walker)?
11. Can you, fully independently, take care of your feet and toenails?
12. Can you, fully independently, prepare breakfast or lunch?
13. Can you, fully independently, prepare dinner?
14. Can you, fully independently, do "light" household activities (for example, dusting and tidying up)?
15. Can you, fully independently, do "heavy" household activities (for example mopping, cleaning the windows, and vacuuming)?
16. Can you, fully independently, wash and iron your clothes?
17. Can you, fully independently, make the beds?
18. Can you, fully independently, do the shopping?

Activity Restriction Scale (ARS)

"Please tell me how much you have restricted your activities in each of the following areas due to the care you are providing to your loved one:	
1. Care of yourself?	<input type="checkbox"/> ₁ Not restricted at all <input type="checkbox"/> ₂ Slightly restricted <input type="checkbox"/> ₃ Moderately restricted <input type="checkbox"/> ₄ Greatly restricted
2. Caring for others?	<input type="checkbox"/> ₁ Not restricted at all <input type="checkbox"/> ₂ Slightly restricted <input type="checkbox"/> ₃ Moderately restricted <input type="checkbox"/> ₄ Greatly restricted

3. Eating habits?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
4. Sleeping habits?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
5. Doing household chores?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
6. Going shopping for him/herself	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
7. Visiting friends?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
8. Working on hobbies?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
9. Sports and recreation?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
10. Going to work?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted
11. Maintaining friendship?	<input type="checkbox"/> 1 Not restricted at all <input type="checkbox"/> 2 Slightly restricted <input type="checkbox"/> 3 Moderately restricted <input type="checkbox"/> 4 Greatly restricted

Appendix 5. Physical Symptoms Scale

Instructions: On how many of the past 30 days have you experienced each of the following symptoms?

	Number of Days
	0-30
Headache	
Stomach Ache/Pain/Upset	
Chest Pain	
Runny/Congested Nose	
Coughing/Sore Throat	
Faintness/Dizziness	
Shortness of Breath	
Racing/Pounding Heart	
Stiff/Sore Muscles	

Instructions: In the past 30 days, have you seen a doctor/health care professional for treatment for any of these symptoms?

	Yes	No
Headache		
Stomach Ache/Pain/Upset		
Chest Pain		
Runny/Congested Nose		
Coughing/Sore Throat		
Faintness/Dizziness		
Shortness of Breath		
Racing/Pounding Heart		
Stiff/Sore Muscles		

Appendix 6. Social Support

Instructions: When we need support such as advice, understanding or a favor, our relationship with other people (for example, parents, spouses, friends), may or may not have both helpful and upsetting aspects. For the person **most important** to you, please complete the following.

- Specify the relationship to you (such as a spouse, sister, co-worker, or friend) and the gender of the person
- Provide an estimate of the length of time you have known this person, and the average number of times per week you have contact with this person
- When you need support such as advice, understanding or a favor, rate this person on:
 - How generally helpful this person is to you (using the scale titled “HOW HELPFUL?”)
 - How generally upsetting this person is to you (using the scale titled “HOW UPSETTING?”)

(Note: When asked to rate the extent the individual is HELPFUL, you should ignore any upsetting aspects of the relationship. When asked to rate the extent the individual is UPSETTING, you should ignore any helpful aspects of the relationship.)
- For the final rating, indicate how unpredictable the person is when you need support such as advice, understanding or a favor.

					HOW HELPFUL is this person to you?	HOW UPSETTING is this person to you?	HOW UNPREDICTABLE is this person to you?
Initials of person most Important to you.	Relationship to you.	Gender of person.	Appropriate length of time you have known the person (years or months).	Average number of times per week you have contact with the person.	1 = Not at all helpful 2 = A little helpful 3 = Somewhat helpful 4 = Moderately helpful 5 = Very helpful 6 = Extremely helpful (Circle one number)	1 = Not at all upsetting 2 = A little upsetting 3 = Somewhat upsetting 4 = Moderately upsetting 5 = Very upsetting 6 = Extremely upsetting (Circle one number)	1 = Not at all unpredictable 2 = A little unpredictable 3 = Somewhat unpredictable 4 = Moderately unpredictable 5 = Very unpredictable 6 = Extremely unpredictable (Circle one number)
					1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6

Appendix 7. Writing Instructions for ICU Experience Study Participants

Writing Instructions for Study Participants (A)

Thank you for agreeing to complete the writing part of this study at home. Below are instructions for the writing session.

1. You have been assigned a unique identifier to use instead of your name. For example, your identifier could be **193JAO**.
2. Writing session: You will write for 20 minutes on your computer, take a 10 to 15-minute break and then write for 20 minutes. After the second writing sessions take a 10 to 15-minute break and write for 20 minutes (third writing session).
3. Save each writing session to your computer, please save your writing. Title the document as the unique identifier (193JAO) we sent you and ICU Experience. Example: 193JAO ICU Experience. Save the writing to your computer.
4. Label each writing session. The first one should be writing 1. The second writing as writing 2 and the third as writing 3. All three writing sessions can be saved in one document, but please label each one so we know which session is which (session 1, session 2, or session 3).
5. Prior to starting each writing session, please read the instructions below.

Writing Instructions

"What I would like you to write about for these three sessions are your deepest thoughts and feelings about your experience with your family member in the Intensive Care Unit (ICU). I realize that people with a loved one in the ICU experience a full range of emotions and thoughts, and I want you to focus on any and all of them. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You might think about all the various feelings and changes that you experienced before your loved one was hospitalized in the ICU, after the diagnosis that led them to the ICU, during treatment, and now. Whatever you choose to write, it is critical that you really focus on your deepest thoughts and feelings. Ideally, I would like you to focus on feelings, thoughts, or changes that you have not discussed in great detail with others- private feelings. You might also tie your thoughts and feelings about your experiences with having your loved one in the ICU to other parts of your life, i.e., your childhood, people you love (this loved one and others), who you are, or who you want to be. Again, the most important part of your writing is that you really focus on your deepest emotions and thoughts. The only rule we have is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. Don't worry about grammar, spelling, or sentence structure. Don't worry about erasing or crossing things out. Just write."

6. Once you have completed your writing, email your writing to Mardee Merrill at Mardee.Merrill@imail.org or to Ramona Hopkins, PhD at Mona.Hopkins@imail.org. In the subject line put your identifier, in this example 193JAO.

Please contact Mardee Merrill if you have any questions at 801-507-4608 or Mardee.Merril@imail.org.

Writing Instructions for Study Participants (B)

Thank you for agreeing to complete the writing part of this study at home. Below are instructions for the writing session.

1. You have been assigned a unique identifier to use instead of your name. For example, your identifier could be **193JAO**.
2. Writing session: You will write for 20 minutes, take a 10 to 15-minute break and then write for 20 minutes. After the second writing sessions take a 10 to 15-minute break and write for 20 minutes (third writing session).
3. Save each writing session to your computer, please save your writing. Title the document as the unique identifier (193JAO) we sent you and ICU Experience. Example: 193JAO ICU Experience. Save the writing to your computer.
4. Label each writing session The first one should be writing 1. The second writing as writing 2 and the third as writing 3. All three writing sessions can be saved in one document, but please label each one so we know which session is which (session 1, session 2, or session 3).
5. Prior to starting each writing session, please read the instructions below.

“What I would like you to write about for these three sessions are all the facts about your experience with your family member in the Intensive Care Unit (ICU). We are not interested in your thoughts and emotions. Please do not include them. We are interested in all the facts about how your loved one came to the ICU and the facts about your experiences in the ICU with your loved one. The only rule we have is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. Don’t worry about grammar, spelling, or sentence structure. Don’t worry about erasing or crossing things out. Just write.”

6. Once you have completed your writing, email your writing to Mardee Merrill at Mardee.Merrill@imail.org or to Ramona Hopkins, PhD at Mona.Hopkins@imail.org. In the subject line put your identifier, in this example 193JAO.

Please contact Mardee Merrill if you have any questions at 801-507-4608 or Mardee.Merril@imail.org.

Writing Instructions for Study Participants who do not have a Computer (C)

Thank you for agreeing to complete the writing part of this study at home. Below are instructions for the writing session.

1. You have been assigned a unique identifier to use instead of your name. For example, your identifier could be **193JAO**.

2. Writing session: You will write for 20 minutes long-hand, take a 10 to 15-minute break and then write for 20 minutes. After the second writing sessions take a 10 to 15-minute break and write for 20 minutes (third writing session).
3. Title the document as the unique identifier (193JAO) we sent you and staple together if possible.
4. Label each writing session. The first one should be writing 1. The second writing as writing 2 and the third as writing 3. All three can be in one document, but please label each writing session so we can tell which is which.
5. Prior to starting each writing session, please read the instructions below.

Writing Instructions

“What I would like you to write about for these three sessions are your deepest thoughts and feelings about your experience with your family member in the Intensive Care Unit (ICU). I realize that people with a loved one in the ICU experience a full range of emotions and thoughts, and I want you to focus on any and all of them. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You might think about all the various feelings and changes that you experienced before your loved one was hospitalized in the ICU, after the diagnosis that led them to the ICU, during treatment, and now. Whatever you choose to write, it is critical that you really focus on your deepest thoughts and feelings. Ideally, I would like you to focus on feelings, thoughts, or changes that you have not discussed in great detail with others-private feelings. You might also tie your thoughts and feelings about your experiences with having your loved one in the ICU to other parts of your life, i.e., your childhood, people you love (this loved one and others), who you are, or who you want to be. Again, the most important part of your writing is that you really focus on your deepest emotions and thoughts. The only rule we have is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. Don’t worry about grammar, spelling, or sentence structure. Don’t worry about erasing or crossing things out. Just write.”

6. Once you have completed your writing, you will be provided with a self-addressed stamped envelope. Please your writing sample inside and mail to:

Mardee Merrill
Pulmonary Research
Sorenson Heart-Lung Center, 6th floor
5121 S. Cottonwood Street
Murray , Utah 84107

Please contact Mardee Merrill if you have any questions at 801-507-4608 or Mardee.Merril@imail.org.

Writing Instructions for Study Participants who do not have a Computer (D)

Thank you for agreeing to complete the writing part of this study at home. Below are instructions for the writing session.

1. You have been assigned a unique identifier to use instead of your name. For example, your identifier could be **193JAO**.
2. Writing session: You will write for 20 minutes long-hand, take a 10 to 15-minute break and then write for 20 minutes. After the second writing sessions take a 10 to 15-minute break and write for 20 minutes (third writing session).
3. Title the document as the unique identifier (193JAO) we sent you and staple together if possible.
4. Label each writing session. The first one should be writing 1. The second writing as writing 2 and the third as writing 3. All three can be in one document, but please label each writing session so we can tell which is which.
5. Prior to starting each writing session, please read the instructions below.

Writing Instructions

“What I would like you to write about for these three sessions are all the facts about your experience with your family member in the Intensive Care Unit (ICU). We are not interested in your thoughts and emotions. Please do not include them. We are interested in all the facts about how your loved one came to the ICU and the facts about your experiences in the ICU with your loved one. The only rule we have is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. Don’t worry about grammar, spelling, or sentence structure. Don’t worry about erasing or crossing things out. Just write.”

6. Once you have completed your writing, you will be provided with a self-addressed stamped envelope. Please place your writing sample inside and mail to:

Mardee Merrill
Pulmonary Research
Sorenson Heart-Lung Center, 6th floor
5121 S. Cottonwood Street
Murray , Utah 84107

Please contact Mardee Merrill if you have any questions at 801-507-4608 or Mardee.Merril@imail.org.