**The Surrogate Project – Measures**

**Table. Summary of Surrogate Storytelling DCF Elements and Time-points**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **ICU** | **Trial enrollment, time after after patient death** | | |
| **Population (N)** | **Screening** | **Baseline, 2-4 wk** | **FU1, 3 mo** | **FU2, 6 mo** |
| *Surrogates (180) – Screening* |  |  |  |  |
| Study ID | **X** |  |  |  |
| Study ICU | **X** |  |  |  |
| Date of Consent – screening and re-contact | **X** |  |  |  |
| Contact information (address, phone1, phone2, email) | **X** |  |  |  |
| Age | **X** |  |  |  |
| Sex | **X** |  |  |  |
| Ethnicity | **X** |  |  |  |
| Race | **X** |  |  |  |
| Relationship to patient | **X** |  |  |  |
| *Patients (180) - Screening* |  |  |  |  |
| Study ID | **X** |  |  |  |
| Age | **X** |  |  |  |
| Sex | **X** |  |  |  |
| Ethnicity | **X** |  |  |  |
| Race | **X** |  |  |  |
| Karnofsky performance scale | **X** |  |  |  |
| Reason for admission | **X** |  |  |  |
| Regained decision making capacity | **X** |  |  |  |
| Family meeting for discussion re goals of care/LST | **X** |  |  |  |
| Discussion\_date | **X** |  |  |  |
| Limitation of LST | **X** |  |  |  |
| Limitation\_date | **X** |  |  |  |
| Limitation\_types | **X** |  |  |  |
| Vital status | **X** |  |  |  |
| Date of death | **X** |  |  |  |
| Location of death | **X** |  |  |  |
| Date of discharge and disposition, if alive | **X** |  |  |  |
| Time for medical record abstraction, in minutes |  |  |  |  |
| *Surrogate (60) – Trial Enrollment* |  |  |  |  |
| Date of consent – trial enrollment |  | **X** |  |  |
| Dates and method of contact attempts (up to 5) |  | **X** | **X** | **X** |
| Date of completed assessment |  | **X** | **X** | **X** |
| Decedent’s name (for populating CATI questions) |  | **X** |  |  |
| SUDS\_pre |  | **X** |  |  |
| SUDS\_during\_1 – 5 (up to 5 entries) |  | **X** |  |  |
| SUDS\_post |  | **X** |  |  |
| Resilience |  | **X** |  |  |
| Decision making style preference |  | **X** |  |  |
| Personal history of anxiety or depression |  | **X** |  |  |
| Family history of anxiety or depression |  | **X** |  |  |
| Patient had living will or advance directive |  | **X** |  |  |
| Preparedness for death |  | **X** |  |  |
| Impact of Events Scale |  | **X** | **X** | **X** |
| Hospital Anxiety and Depression Scale |  | **X** | **X** | **X** |
| PRIME-MD |  | **X** | **X** | **X** |
| Decision regret scale |  | **X** | **X** | **X** |
| Decision satisfaction |  | **X** | **X** | **X** |
| Self-reported mental health services utilization |  | **X** | **X** | **X** |
| Centrality of events scale |  | **X** | **X** | **X** |
| Visit length, in minutes |  | **X** | **X** | **X** |
| Inventory of Complicated Grief |  |  |  | **X** |
| Feedback\_how\_feel |  |  |  | **X** |
| Feedback\_burden |  |  |  | **X** |
| Feedback\_not\_do |  |  |  | **X** |

**ICU Screening: Initial contact and consent**

**SURROGATE Study ID: P \_\_\_ \_\_\_ \_\_\_ - S**

**Study ICU**

* UPMC Presby MICU
* UPMC St. Margarets MICU
* UPMC Mercy MICU
* UPMC Shadyside MICU

**Age: \_\_\_\_\_\_\_**

**Sex:**

* Man
* Woman

**Ethnicity:**

* Hispanic or Latino
* Not Hispanic or Latino

**Race:**

* American Indian/Alaskan Native
* Asian
* Native Hawaiian or Other Pacific Islander
* Black or African American
* White

**The patient is my:**

* Mother
* Father
* Husband
* Wife
* Partner
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**PATIENT Study ID: P \_\_\_ \_\_\_ \_\_\_ - P**

**Age: \_\_\_\_\_\_\_**

**Sex:**

* Man
* Woman

**Ethnicity:**

* Hispanic or Latino
* Not Hispanic or Latino

**Race:**

* American Indian/Alaskan Native
* Asian
* Native Hawaiian or Other Pacific Islander
* Black or African American
* White

**Karnofsky performance status prior to the illness causing the current hospitalization and ICU admission (proxy-reported)**

* 100 Normal; no complaints; no evidence of disease
* 90 Able to carry out normal activity; minor signs or symptoms of disease
* 80 Normal activity with effort; some signs or symptoms of disease
* 70 Cares for self; unable to carry on normal activity or do active work
* 60 Requires occasional assistance, but is able to care for most of his/her needs
* 50 Requires considerable assistance and frequent medical care
* 40 Disabled; requires special care and assistance
* 30 Severely disabled; hospitalization is indicated although death not imminent
* 20 Very sick; hospitalization necessary, active supportive treatment necessary
* 10 Moribund; fatal processes progressing rapidly
* 0 Dead

**ICU Screening: Medical record review**

**Study ID P \_\_\_ \_\_\_ \_\_\_ - P**

Abstracted by:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date of abstraction: \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_

Total time required for abstraction, in minutes: \_\_\_\_\_\_\_\_\_\_

**ICU admission date:** \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_

**Reason for ICU admission**

* Acute Respiratory Failure
* Coma
* Shock
* Acute renal failure
* Cardiac arrest

**Coexisting conditions**

* Chronic obstructive pulmonary disease
* Chronic heart failure
* Cancer
* Cirrhosis

**APACHE Score** \_\_\_\_\_\_\_\_\_ [pull from APACHE III data collection excel sheet]

**Treatment provided in the ICU**

* Invasive mechanical ventilation
* Vasopressors
* Dialysis
* Sedation

**Regained decision-making capacity and no longer required surrogate to make treatment decisions**

* Yes

If yes, STOP data collection and destroy identifiers

* No

**Documented family meeting involving a discussion about goals of care/limitation of LST**

* Yes

If yes, **first documented family meeting** **date:** \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_

* No

If no, NOT eligible for study; retain study data.

**Limitation of LST**

* Yes

If yes, **first documented limitation:** \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_

If yes, **Limitation type** (check all that apply):

* + Withdraw mechanical ventilation
  + Stop pressors or other hemodynamic support
  + Discontinue dialysis
  + Deactivate implantable cardioverter-defibrillator
  + Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No

If no, NOT eligible for study; retain study data.

**Vital Status at Hospital Discharge**

* Dead

If dead, **date of death**: \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_

If dead, **location of death**:

* ICU
* Ward
* Alive

If alive, **date of hospital discharge**: \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_

If alive, **disposition upon hospital discharge**

* Home
* Skilled Nursing Facility
* Other acute care hospital
* Long-term acute care hospital
* Hospice
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Baseline 2-4 week visit**

**ID: P \_\_ \_\_ \_\_ - S**

**Visit ARRIVAL time: \_\_ \_\_:\_\_ \_\_**

Written consent obtained? \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ \_\_ \_\_ by whom: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Subjective Units of Distress Scale (SUDS) – PRE**

Please refer to scale A, the green section, to help answer this question.

Throughout our conversation I will ask you the same question several times to report your distress on a scale of 0 to 100. You can refer to scale A as a guide. Zero is completely calm and 100 is the worst distress that you can imagine.

How do you rate yourself at this moment? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Baseline measures administration START time: \_\_ \_\_:\_\_ \_\_**

**Decedent’s name** (what the surrogate calls them): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

I’m going to ask you several questions about how you’ve been doing since \_\_\_\_\_\_\_\_\_\_’s death. These questions assess anxiety, depression, and PTSD symptoms. There is some duplication in some of the questions. For example, there are several questions about your sleep. So don’t be surprised by that.

**Impact of Events Scale – Revised**

Please refer to Scale B, the yellow section, to answer the following questions.

I’m going to read a list of difficulties people sometimes have after stressful life events, such as your experience with\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_’s death in the ICU. As I read each item, tell me how distressed or bothered during the DURING THE PAST SEVEN DAYS.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| 1. Any reminder brought back feelings about it | 0 | 1 | 2 | 3 | 4 |
| 2. I had trouble staying asleep | 0 | 1 | 2 | 3 | 4 |
| 3. Other things kept making me think about it | 0 | 1 | 2 | 3 | 4 |
| 4. I felt irritable and angry | 0 | 1 | 2 | 3 | 4 |
| 5. I avoided letting myself get upset when I thought about it or was reminded of it | 0 | 1 | 2 | 3 | 4 |
| 6. I thought about it when I didn’t mean to | 0 | 1 | 2 | 3 | 4 |
| 7. I felt as if it hadn’t happened or wasn’t real | 0 | 1 | 2 | 3 | 4 |
| 8. I stayed away from reminders about it | 0 | 1 | 2 | 3 | 4 |
| 9. Pictures about it popped into my mind | 0 | 1 | 2 | 3 | 4 |
| 10. I was jumpy and easily startled | 0 | 1 | 2 | 3 | 4 |
| 11. I tried not to think about it | 0 | 1 | 2 | 3 | 4 |
| 12. I was aware that I still had a lot of feelings about it, but I didn’t deal with them | 0 | 1 | 2 | 3 | 4 |
| 13. My feelings about it were kind of numb | 0 | 1 | 2 | 3 | 4 |
| 14. I found myself acting or feeling as though I was back at that time | 0 | 1 | 2 | 3 | 4 |
| 15. I had trouble falling asleep | 0 | 1 | 2 | 3 | 4 |
| 16. I had waves of strong feelings about it | 0 | 1 | 2 | 3 | 4 |
| 17. I tried to remove it from my memory | 0 | 1 | 2 | 3 | 4 |
| 18. I had trouble concentrating | 0 | 1 | 2 | 3 | 4 |
| 19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart | 0 | 1 | 2 | 3 | 4 |
| 20. I had dreams about it | 0 | 1 | 2 | 3 | 4 |
| 21. I felt watchful or on-guard | 0 | 1 | 2 | 3 | 4 |
| 22. I tried not to talk about it | 0 | 1 | 2 | 3 | 4 |

Scoring:  
Avoidance Subscale = mean of items 5, 7, 8, 11, 12, 13, 17, 22  
Intrusion Subscale = mean of items 1, 2, 3, 6, 9, 14, 16, 20  
Hyperarousal Subscale = mean of items 4, 10, 15, 18, 19, 21

**Hospital Anxiety and Depression Scale**

* Please refer to Scale C to answer these questions.

I’m going to read a statement, followed by four answer choices that will change with each question. Please tell me which answer choice best describes you and HOW YOU’RE FEELING RIGHT NOW.

A) I feel tense or 'wound up':

Most of the time 3

A lot of the time 2

From time to time, occasionally 1

Not at all 0

D) I still enjoy the things I used to enjoy:

Definitely as much 0

Not quite so much 1

Only a little 2

Hardly at all 3

A) I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly 3

Yes, but not too badly 2

A little, but it doesn't worry me 1

Not at all 0

D) I can laugh and see the funny side of things:

As much as I always could 0

Not quite so much now 1

Definitely not so much now 2

Not at all 3

A) Worrying thoughts go through my mind:

A great deal of the time 3

A lot of the time 2

From time to time, but not too often 1

Only occasionally 0

D) I feel cheerful:

Not at all 3

Not often 2

Sometimes 1

Most of the time 0

A) I can sit at ease and feel relaxed:

Definitely 0

Usually 1

Not Often 2

Not at all 3

D) I feel as if I am slowed down:

Nearly all the time 3

Very often 2

Sometimes 1

Not at all 0

A) I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all 0

Occasionally 1

Quite Often 2

Very Often 3

D) I have lost interest in my appearance:

Definitely 3

I don't take as much care as I should 2

I may not take quite as much care 1

I take just as much care as ever 0

A) I feel restless as I have to be on the move:

Very much indeed 3

Quite a lot 2

Not very much 1

Not at all 0

D) I look forward with enjoyment to things:

As much as I ever did 0

Rather less than I used to 1

Definitely less than I used to 2

Hardly at all 3

A) I get sudden feelings of panic:

Very often indeed 3

Quite often 2

Not very often 1

Not at all 0

D) I can enjoy a good book or radio or TV program:

Often 0

Sometimes 1

Not often 2

Very seldom 3

*Scoring (add the As =Anxiety. Add the Ds =Depression). The norms below will give you an idea of the level of Anxiety and Depression.*

*0-7 = Normal*

*8-10 = Borderline abnormal*

*11-21 = Abnormal*

**PRIME-MD (anxiety, depression, and alcohol questions only)**

* Please refer to Scale D, the orange one, to help answer these next questions.

1. Over the LAST 2 WEEKS, how often have you been bothered by any of the following problems?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Not at all** | **Several days** | **More than half the days** | **Nearly every day** |
| 1. Little interest or pleasure in doing things |  |  |  |  |
| 1. Feeling down, depressed, or hopeless |  |  |  |  |
| 1. Trouble falling or staying asleep, or sleeping too much |  |  |  |  |
| 1. Feeling tired or having little energy |  |  |  |  |
| 1. Poor appetite or overeating |  |  |  |  |
| 1. Feeling bad about yourself – or that you are a failure or have let yourself or your family down |  |  |  |  |
| 1. Trouble concentrating on things, such as reading the newspaper or watching television |  |  |  |  |
| 1. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual |  |  |  |  |
| 1. **Thoughts that you would be better off dead or of hurting yourself in some way** |  |  |  |  |

1. Questions about anxiety.

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. In the last 4 weeks, have you had an anxiety attack – suddenly feeling fear or panic?  * **If you checked “NO”, go to question #4** |  |  |
| 1. Has this ever happened before? |  |  |
| 1. Do some of these attacks come suddenly out of the blue – that is, in situations where you don’t expect to be nervous or uncomfortable? |  |  |
| 1. Do these attacks bother you a lot or are you worried about having another attack? |  |  |

1. Think about your last bad anxiety attack.

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. Were you short of breath? |  |  |
| 1. Did your heart race, pound, or skip? |  |  |
| 1. Did you have chest pain or pressure? |  |  |
| 1. Did you sweat? |  |  |
| 1. Did you feel as if you were choking? |  |  |
| 1. Did you have hot flashes or chills? |  |  |
| 1. Did you have nausea or an upset stomach, or the feeling that you were going to have diarrhea? |  |  |
| 1. Did you feel dizzy, unsteady, or faint? |  |  |
| 1. Did you have tingling or numbness in parts of your body? |  |  |
| 1. Did you tremble or shake? |  |  |
| 1. Were you afraid you were dying? |  |  |

Please refer to Scale E, the light red one, to help answer this next set of questions.

1. Over the LAST 4 WEEKS, how often have you been bothered by any of the following problems?

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Not at all** | **Several days** | **More than half the days** |
| 1. Feeling nervous, anxious, on edge, or worrying about a lot of different things.  * **If you checked “Not at all”, go to question #5.** |  |  |  |
| 1. Feeling restless so that it is hard to sit still. |  |  |  |
| 1. Getting tired very easily. |  |  |  |
| 1. Muscle tension, aches, or soreness. |  |  |  |
| 1. Trouble falling asleep or staying asleep. |  |  |  |
| 1. Trouble concentrating on things, such as reading a book or watching TV. |  |  |  |
| 1. Becoming easily annoyed or irritable. |  |  |  |

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. Do you ever drink alcohol (including beer or wine)?  * **If you checked “NO” go to question #7.** |  |  |

1. Have any of the following happened to you MORE THAN ONCE IN THE LAST 6 MONTHS?

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. You drank alcohol even though a doctor suggested that you stop drinking because of a problem with your health. |  |  |
| 1. You drank alcohol, were high from alcohol, or hung over while you were working, going to school, or taking care of children or other responsibilities. |  |  |
| 1. You missed or were late for work, school, or other activities because you were drinking or hung over. |  |  |
| 1. You had a problem getting along with other people while you were drinking. |  |  |
| 1. You drove a car after having several drinks or after drinking too much. |  |  |

Please refer to Scale F, the lavender one, for this next question.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Not difficult at all** | **Somewhat difficult** | **Very difficult** | **Extremely difficult** |
| 1. Regarding the problems on this questionnaire that you’ve reported having, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? |  |  |  |  |

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**History of anxiety or depression**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **NO** | **YES** | **Don’t know / Not sure** | Prefer not to answer |
| Has a doctor or other health professional ever told you that you have…..  depression  anxiety  post-traumatic stress disorder (PTSD)? |  | | | |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
| Are you now taking medicine or receiving treatment from a doctor or other health professional for any type of mental health condition or emotional problem? |  |  |  |  |

**Family History of anxiety or depression**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **NO** | **YES** | **Don’t know / Not sure** | Prefer not to answer |
| Do any of your first-degree relatives (parents, siblings, or children) have a history of depression? |  |  |  |  |
| Do any of your first-degree relatives (parents, siblings, or children) have a history of anxiety? |  |  |  |  |

**Mental Health Services/Help Seeking Self-Report Measure**

For these next few questions, please consider if you’ve done these things SINCE \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_[name] DIED.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **NO** | **YES** | **Details** |
| Have you consulted with any kind of mental health specialist? |  |  |  |
| Have you received any counseling for your nerves, mood, or sleep? |  |  |  |
| Have you taken any medication for your nerves, mood, or sleep? |  |  |  |
| Have you consulted with a clergy member? |  |  |  |
| Have you participated in a grief support group? |  |  |  |
| Are there any other services or activities you’ve participated in that have been helpful? |  |  |  |

**Living will/advance directive**

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| Before the admission to the ICU, had you and \_\_\_\_\_\_\_\_\_\_\_\_\_[name] ever discussed the treatments he/she would want (or would not want) if he/she were too sick to speak for him/herself? |  |  |
| Did \_\_\_\_\_\_\_\_\_\_\_\_\_[name] have a living will or advance directive indicating what treatments he/she would want (or would not want) if he/she were too sick to speak for him/herself? |  |  |

**Decision Making Style Preference**

* Please refer to Scale H to answer this question.

Which ONE of the following best describes how you wanted to make decisions about life-support for \_\_\_\_\_\_[name] when he/she was in the ICU?

* I preferred to make the decisions .
* I preferred to make the final decisions after seriously considering the doctor's opinion.
* I preferred that the doctor and I share responsibility for the decisions.
* I preferred that my the doctor make the final decisions after seriously considering my opinion
* I preferred to leave all decisions to the doctor.

**Decisional Regret Scale / Decision Satisfaction**

* Please refer to Scale G, the blue section, to help answer these questions.

Please reflect on decision to remove life-support for \_\_\_\_\_\_\_\_\_\_\_\_\_[name].

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Decision regret scale** | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
| It was the right decision | 1 | 2 | 3 | 4 | 5 |
| I regret the choice that was made | 1 | 2 | 3 | 4 | 5 |
| I would go for the same choice if I had to do it over | 1 | 2 | 3 | 4 | 5 |
| The choice did me a lot of harm | 1 | 2 | 3 | 4 | 5 |
| The decision was a wise one | 1 | 2 | 3 | 4 | 5 |
| **Decision satisfaction** |  |  |  |  |  |
| I am satisfied with the decision. | 1 | 2 | 3 | 4 | 5 |

**Centrality of Events Scale**

* Still referring to Scale G, the blue section, to help answer these questions.

Please think back upon \_\_\_\_\_\_\_\_\_\_’s death in the ICU

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
| 1. I feel the event has become part of my identity | 1 | 2 | 3 | 4 | 5 |
| 2. This event has become a reference point for the way I understand myself and the world. | 1 | 2 | 3 | 4 | 5 |
| 3. I feel that this event has become a central part of my life story. | 1 | 2 | 3 | 4 | 5 |
| 4. This event has colored the way I think and feel about other experiences. | 1 | 2 | 3 | 4 | 5 |
| 5. This event permanently changed my life. | 1 | 2 | 3 | 4 | 5 |
| 6. I often think about the effects this event will have on my future. | 1 | 2 | 3 | 4 | 5 |
| 7. This event was a turning point in my life | 1 | 2 | 3 | 4 | 5 |

**Resilience**

* Please refer to Scale G, the blue section, to help answer these questions.

Please indicate the extent to which you agree with each of the following statements.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
| 1. I tend to bounce back quickly after hard times | 1 | 2 | 3 | 4 | 5 |
| 2. I have a hard time making it through stressful events (R) | 1 | 2 | 3 | 4 | 5 |
| 3. It does not take me long to recover from a stressful event | 1 | 2 | 3 | 4 | 5 |
| 4. It is hard for me to snap back when something bad happens (R) | 1 | 2 | 3 | 4 | 5 |
| 5. I usually come through difficult times with little trouble | 1 | 2 | 3 | 4 | 5 |
| 6. I tend to take a long time to get over set-backs in my life (R) | 1 | 2 | 3 | 4 | 5 |

*Reference: Smith, B.W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P. and Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. International Journal of Behavioural Medicine, 15, 194-200. Accessed at* [*http://homepages.uwp.edu/crooker/745-Resile/articles/Smith-etal-2008-BRS-indiv.pdf*](http://homepages.uwp.edu/crooker/745-Resile/articles/Smith-etal-2008-BRS-indiv.pdf)

**Preparedness**

Please refer to Scale H, the dark green section, to help answer these questions.

How prepared did you feel for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_’s [name] death?

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Well prepared |  |  | Somewhat prepared |  |  | Totally unprepared |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

*Reference: Barry LC. Kasl SV. Prigerson HG. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. Am J Geriatr Psychiatry. 10(4):447-57, 2002 Jul-Aug.*

* **Baseline measures administration END time: \_\_ \_\_:\_\_ \_\_**

**Subjective Units of Distress Scale (SUDS) – During1**

Please refer back to scale A, the first, light green section, to help answer this question.

“On that scale of distress do you rate yourself at this moment?” \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Subjective Units of Distress Scale (SUDS) – During2**

Please refer back to scale A, the first, light green section, to help answer this question.

“On that scale of distress do you rate yourself at this moment?” \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Subjective Units of Distress Scale (SUDS) – During3**

Please refer back to scale A, the first, light green section, to help answer this question.

“On that scale of distress do you rate yourself at this moment?” \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Subjective Units of Distress Scale (SUDS) – During4**

Please refer back to scale A, the first, light green section, to help answer this question.

“On that scale of distress do you rate yourself at this moment?” \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Interview START time: \_\_ \_\_:\_\_ \_\_**

**Subjective Units of Distress Scale (SUDS) – POST INTERVIEW**

Please refer to scale A, the green section, to help answer this question.

“On that scale of distress do you rate yourself at this moment?” \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Interview END time: \_\_ \_\_:\_\_ \_\_**

**DEPARTURE time: \_\_ \_\_:\_\_ \_\_**

**VISIT time, in minutes \_\_\_\_\_\_\_\_\_\_\_\_\_**

**3-month follow-up telephone visit**

**ID: P \_\_ \_\_ \_\_ - S**

I’m going to ask you several questions about how you’ve been doing since \_\_\_\_\_\_\_\_\_\_’s death. These questions assess anxiety, depression, and PTSD symptoms. There is some duplication in some of the questions. For example, there are several questions about your sleep. So don’t be surprised by that.

**Impact of Events Scale – Revised**

I’m going to read a list of difficulties people sometimes have after stressful life events, such as your experience with\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_’s death in the ICU. As I read each item, tell me how distressed or bothered during the DURING THE PAST SEVEN DAYS (not at all, a little bit, moderately, quite a bit, extremely)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| 1. Any reminder brought back feelings about it | 0 | 1 | 2 | 3 | 4 |
| 2. I had trouble staying asleep | 0 | 1 | 2 | 3 | 4 |
| 3. Other things kept making me think about it | 0 | 1 | 2 | 3 | 4 |
| 4. I felt irritable and angry | 0 | 1 | 2 | 3 | 4 |
| 5. I avoided letting myself get upset when I thought about it or was reminded of it | 0 | 1 | 2 | 3 | 4 |
| 6. I thought about it when I didn’t mean to | 0 | 1 | 2 | 3 | 4 |
| 7. I felt as if it hadn’t happened or wasn’t real | 0 | 1 | 2 | 3 | 4 |
| 8. I stayed away from reminders about it | 0 | 1 | 2 | 3 | 4 |
| 9. Pictures about it popped into my mind | 0 | 1 | 2 | 3 | 4 |
| 10. I was jumpy and easily startled | 0 | 1 | 2 | 3 | 4 |
| 11. I tried not to think about it | 0 | 1 | 2 | 3 | 4 |
| 12. I was aware that I still had a lot of feelings about it, but I didn’t deal with them | 0 | 1 | 2 | 3 | 4 |
| 13. My feelings about it were kind of numb | 0 | 1 | 2 | 3 | 4 |
| 14. I found myself acting or feeling as though I was back at that time | 0 | 1 | 2 | 3 | 4 |
| 15. I had trouble falling asleep | 0 | 1 | 2 | 3 | 4 |
| 16. I had waves of strong feelings about it | 0 | 1 | 2 | 3 | 4 |
| 17. I tried to remove it from my memory | 0 | 1 | 2 | 3 | 4 |
| 18. I had trouble concentrating | 0 | 1 | 2 | 3 | 4 |
| 19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart | 0 | 1 | 2 | 3 | 4 |
| 20. I had dreams about it | 0 | 1 | 2 | 3 | 4 |
| 21. I felt watchful or on-guard | 0 | 1 | 2 | 3 | 4 |
| 22. I tried not to talk about it | 0 | 1 | 2 | 3 | 4 |

Scoring:  
Avoidance Subscale = mean of items 5, 7, 8, 11, 12, 13, 17, 22  
Intrusion Subscale = mean of items 1, 2, 3, 6, 9, 14, 16, 20  
Hyperarousal Subscale = mean of items 4, 10, 15, 18, 19, 21

**Hospital Anxiety and Depression Scale**

I’m going to read a statement, followed by four answer choices that will change with each question. Please tell me which answer choice best describes you and HOW YOU’RE FEELING RIGHT NOW.

A) I feel tense or 'wound up':

Most of the time 3

A lot of the time 2

From time to time, occasionally 1

Not at all 0

D) I still enjoy the things I used to enjoy:

Definitely as much 0

Not quite so much 1

Only a little 2

Hardly at all 3

A) I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly 3

Yes, but not too badly 2

A little, but it doesn't worry me 1

Not at all 0

D) I can laugh and see the funny side of things:

As much as I always could 0

Not quite so much now 1

Definitely not so much now 2

Not at all 3

A) Worrying thoughts go through my mind:

A great deal of the time 3

A lot of the time 2

From time to time, but not too often 1

Only occasionally 0

D) I feel cheerful:

Not at all 3

Not often 2

Sometimes 1

Most of the time 0

A) I can sit at ease and feel relaxed:

Definitely 0

Usually 1

Not Often 2

Not at all 3

D) I feel as if I am slowed down:

Nearly all the time 3

Very often 2

Sometimes 1

Not at all 0

A) I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all 0

Occasionally 1

Quite Often 2

Very Often 3

D) I have lost interest in my appearance:

Definitely 3

I don't take as much care as I should 2

I may not take quite as much care 1

I take just as much care as ever 0

A) I feel restless as I have to be on the move:

Very much indeed 3

Quite a lot 2

Not very much 1

Not at all 0

D) I look forward with enjoyment to things:

As much as I ever did 0

Rather less than I used to 1

Definitely less than I used to 2

Hardly at all 3

A) I get sudden feelings of panic:

Very often indeed 3

Quite often 2

Not very often 1

Not at all 0

D) I can enjoy a good book or radio or TV program:

Often 0

Sometimes 1

Not often 2

Very seldom 3

*Scoring (add the As =Anxiety. Add the Ds =Depression). The norms below will give you an idea of the level of Anxiety and Depression.*

*0-7 = Normal*

*8-10 = Borderline abnormal*

*11-21 = Abnormal*

**PRIME-MD (anxiety, depression, and alcohol questions only)**

1. Over the LAST 2 WEEKS, how often have you been bothered by any of the following problems?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Not at all** | **Several days** | **More than half the days** | **Nearly every day** |
| 1. Little interest or pleasure in doing things |  |  |  |  |
| 1. Feeling down, depressed, or hopeless |  |  |  |  |
| 1. Trouble falling or staying asleep, or sleeping too much |  |  |  |  |
| 1. Feeling tired or having little energy |  |  |  |  |
| 1. Poor appetite or overeating |  |  |  |  |
| 1. Feeling bad about yourself – or that you are a failure or have let yourself or your family down |  |  |  |  |
| 1. Trouble concentrating on things, such as reading the newspaper or watching television |  |  |  |  |
| 1. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual |  |  |  |  |
| 1. **Thoughts that you would be better off dead or of hurting yourself in some way** |  |  |  |  |

1. Questions about anxiety.

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. In the last 4 weeks, have you had an anxiety attack – suddenly feeling fear or panic?  * **If you checked “NO”, go to question #4** |  |  |
| 1. Has this ever happened before? |  |  |
| 1. Do some of these attacks come suddenly out of the blue – that is, in situations where you don’t expect to be nervous or uncomfortable? |  |  |
| 1. Do these attacks bother you a lot or are you worried about having another attack? |  |  |

1. Think about your last bad anxiety attack.

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. Were you short of breath? |  |  |
| 1. Did your heart race, pound, or skip? |  |  |
| 1. Did you have chest pain or pressure? |  |  |
| 1. Did you sweat? |  |  |
| 1. Did you feel as if you were choking? |  |  |
| 1. Did you have hot flashes or chills? |  |  |
| 1. Did you have nausea or an upset stomach, or the feeling that you were going to have diarrhea? |  |  |
| 1. Did you feel dizzy, unsteady, or faint? |  |  |
| 1. Did you have tingling or numbness in parts of your body? |  |  |
| 1. Did you tremble or shake? |  |  |
| 1. Were you afraid you were dying? |  |  |

1. Over the LAST 4 WEEKS, how often have you been bothered by any of the following problems?

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Not at all** | **Several days** | **More than half the days** |
| 1. Feeling nervous, anxious, on edge, or worrying about a lot of different things.  * **If you checked “Not at all”, go to question #5.** |  |  |  |
| 1. Feeling restless so that it is hard to sit still. |  |  |  |
| 1. Getting tired very easily. |  |  |  |
| 1. Muscle tension, aches, or soreness. |  |  |  |
| 1. Trouble falling asleep or staying asleep. |  |  |  |
| 1. Trouble concentrating on things, such as reading a book or watching TV. |  |  |  |
| 1. Becoming easily annoyed or irritable. |  |  |  |

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. Do you ever drink alcohol (including beer or wine)?  * **If you checked “NO” go to question #7.** |  |  |

1. Have any of the following happened to you MORE THAN ONCE IN THE LAST 6 MONTHS?

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. You drank alcohol even though a doctor suggested that you stop drinking because of a problem with your health. |  |  |
| 1. You drank alcohol, were high from alcohol, or hung over while you were working, going to school, or taking care of children or other responsibilities. |  |  |
| 1. You missed or were late for work, school, or other activities because you were drinking or hung over. |  |  |
| 1. You had a problem getting along with other people while you were drinking. |  |  |
| 1. You drove a car after having several drinks or after drinking too much. |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Not difficult at all** | **Somewhat difficult** | **Very difficult** | **Extremely difficult** |
| 1. Regarding the problems on this questionnaire that you’ve reported having, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? |  |  |  |  |

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**Mental Health Services/Help Seeking Self-Report Measure**

For these next few questions, please consider if you’ve done these things SINCE \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_[name] DIED.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **NO** | **YES** | **Details** |
| Have you consulted with any kind of mental health specialist? |  |  |  |
| Have you received any counseling for your nerves, mood, or sleep? |  |  |  |
| Have you taken any medication for your nerves, mood, or sleep? |  |  |  |
| Have you consulted with a clergy member? |  |  |  |
| Have you participated in a grief support group? |  |  |  |
| Are there any other services or activities you’ve participated in that have been helpful? |  |  |  |

**Decisional Regret Scale / Decision Satisfaction**

Please reflect on decision to remove life-support for \_\_\_\_\_\_\_\_\_\_\_\_\_[name]. I’ll read each statement and you tell me if you strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree with the statement.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Decision regret scale** | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
| It was the right decision | 1 | 2 | 3 | 4 | 5 |
| I regret the choice that was made | 1 | 2 | 3 | 4 | 5 |
| I would go for the same choice if I had to do it over | 1 | 2 | 3 | 4 | 5 |
| The choice did me a lot of harm | 1 | 2 | 3 | 4 | 5 |
| The decision was a wise one | 1 | 2 | 3 | 4 | 5 |
| **Decision satisfaction** |  |  |  |  |  |
| I am satisfied with the decision. | 1 | 2 | 3 | 4 | 5 |

**Centrality of Events Scale**

Please think back upon \_\_\_\_\_\_\_\_\_\_’s death in the ICU. I’ll read each statement and you tell me if you strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree with the statement.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
| 1. I feel the event has become part of my identity | 1 | 2 | 3 | 4 | 5 |
| 2. This event has become a reference point for the way I understand myself and the world. | 1 | 2 | 3 | 4 | 5 |
| 3. I feel that this event has become a central part of my life story. | 1 | 2 | 3 | 4 | 5 |
| 4. This event has colored the way I think and feel about other experiences. | 1 | 2 | 3 | 4 | 5 |
| 5. This event permanently changed my life. | 1 | 2 | 3 | 4 | 5 |
| 6. I often think about the effects this event will have on my future. | 1 | 2 | 3 | 4 | 5 |
| 7. This event was a turning point in my life | 1 | 2 | 3 | 4 | 5 |

*Reference: Smith, B.W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P. and Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. International Journal of Behavioural Medicine, 15, 194-200. Accessed at* [*http://homepages.uwp.edu/crooker/745-Resile/articles/Smith-etal-2008-BRS-indiv.pdf*](http://homepages.uwp.edu/crooker/745-Resile/articles/Smith-etal-2008-BRS-indiv.pdf)

**VISIT time, in minutes \_\_\_\_\_\_\_\_\_\_\_\_\_**

**6-month follow-up telephone visit**

**ID: P \_\_ \_\_ \_\_ - S**

I’m going to ask you several questions about how you’ve been doing since \_\_\_\_\_\_\_\_\_\_’s death. These questions assess anxiety, depression, and PTSD symptoms. There is some duplication in some of the questions. For example, there are several questions about your sleep. So don’t be surprised by that.

**Impact of Events Scale – Revised**

I’m going to read a list of difficulties people sometimes have after stressful life events, such as your experience with\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_’s death in the ICU. As I read each item, tell me how distressed or bothered during the DURING THE PAST SEVEN DAYS (not at all, a little bit, moderately, quite a bit, extremely)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| 1. Any reminder brought back feelings about it | 0 | 1 | 2 | 3 | 4 |
| 2. I had trouble staying asleep | 0 | 1 | 2 | 3 | 4 |
| 3. Other things kept making me think about it | 0 | 1 | 2 | 3 | 4 |
| 4. I felt irritable and angry | 0 | 1 | 2 | 3 | 4 |
| 5. I avoided letting myself get upset when I thought about it or was reminded of it | 0 | 1 | 2 | 3 | 4 |
| 6. I thought about it when I didn’t mean to | 0 | 1 | 2 | 3 | 4 |
| 7. I felt as if it hadn’t happened or wasn’t real | 0 | 1 | 2 | 3 | 4 |
| 8. I stayed away from reminders about it | 0 | 1 | 2 | 3 | 4 |
| 9. Pictures about it popped into my mind | 0 | 1 | 2 | 3 | 4 |
| 10. I was jumpy and easily startled | 0 | 1 | 2 | 3 | 4 |
| 11. I tried not to think about it | 0 | 1 | 2 | 3 | 4 |
| 12. I was aware that I still had a lot of feelings about it, but I didn’t deal with them | 0 | 1 | 2 | 3 | 4 |
| 13. My feelings about it were kind of numb | 0 | 1 | 2 | 3 | 4 |
| 14. I found myself acting or feeling as though I was back at that time | 0 | 1 | 2 | 3 | 4 |
| 15. I had trouble falling asleep | 0 | 1 | 2 | 3 | 4 |
| 16. I had waves of strong feelings about it | 0 | 1 | 2 | 3 | 4 |
| 17. I tried to remove it from my memory | 0 | 1 | 2 | 3 | 4 |
| 18. I had trouble concentrating | 0 | 1 | 2 | 3 | 4 |
| 19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart | 0 | 1 | 2 | 3 | 4 |
| 20. I had dreams about it | 0 | 1 | 2 | 3 | 4 |
| 21. I felt watchful or on-guard | 0 | 1 | 2 | 3 | 4 |
| 22. I tried not to talk about it | 0 | 1 | 2 | 3 | 4 |

Scoring:  
Avoidance Subscale = mean of items 5, 7, 8, 11, 12, 13, 17, 22  
Intrusion Subscale = mean of items 1, 2, 3, 6, 9, 14, 16, 20  
Hyperarousal Subscale = mean of items 4, 10, 15, 18, 19, 21

**Hospital Anxiety and Depression Scale**

I’m going to read a statement, followed by four answer choices that will change with each question. Please tell me which answer choice best describes you and HOW YOU’RE FEELING RIGHT NOW.

A) I feel tense or 'wound up':

Most of the time 3

A lot of the time 2

From time to time, occasionally 1

Not at all 0

D) I still enjoy the things I used to enjoy:

Definitely as much 0

Not quite so much 1

Only a little 2

Hardly at all 3

A) I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly 3

Yes, but not too badly 2

A little, but it doesn't worry me 1

Not at all 0

D) I can laugh and see the funny side of things:

As much as I always could 0

Not quite so much now 1

Definitely not so much now 2

Not at all 3

A) Worrying thoughts go through my mind:

A great deal of the time 3

A lot of the time 2

From time to time, but not too often 1

Only occasionally 0

D) I feel cheerful:

Not at all 3

Not often 2

Sometimes 1

Most of the time 0

A) I can sit at ease and feel relaxed:

Definitely 0

Usually 1

Not Often 2

Not at all 3

D) I feel as if I am slowed down:

Nearly all the time 3

Very often 2

Sometimes 1

Not at all 0

A) I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all 0

Occasionally 1

Quite Often 2

Very Often 3

D) I have lost interest in my appearance:

Definitely 3

I don't take as much care as I should 2

I may not take quite as much care 1

I take just as much care as ever 0

A) I feel restless as I have to be on the move:

Very much indeed 3

Quite a lot 2

Not very much 1

Not at all 0

D) I look forward with enjoyment to things:

As much as I ever did 0

Rather less than I used to 1

Definitely less than I used to 2

Hardly at all 3

A) I get sudden feelings of panic:

Very often indeed 3

Quite often 2

Not very often 1

Not at all 0

D) I can enjoy a good book or radio or TV program:

Often 0

Sometimes 1

Not often 2

Very seldom 3

*Scoring (add the As =Anxiety. Add the Ds =Depression). The norms below will give you an idea of the level of Anxiety and Depression.*

*0-7 = Normal*

*8-10 = Borderline abnormal*

*11-21 = Abnormal*

**PRIME-MD (anxiety, depression, and alcohol questions only)**

1. Over the LAST 2 WEEKS, how often have you been bothered by any of the following problems?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Not at all** | **Several days** | **More than half the days** | **Nearly every day** |
| 1. Little interest or pleasure in doing things |  |  |  |  |
| 1. Feeling down, depressed, or hopeless |  |  |  |  |
| 1. Trouble falling or staying asleep, or sleeping too much |  |  |  |  |
| 1. Feeling tired or having little energy |  |  |  |  |
| 1. Poor appetite or overeating |  |  |  |  |
| 1. Feeling bad about yourself – or that you are a failure or have let yourself or your family down |  |  |  |  |
| 1. Trouble concentrating on things, such as reading the newspaper or watching television |  |  |  |  |
| 1. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual |  |  |  |  |
| 1. **Thoughts that you would be better off dead or of hurting yourself in some way** |  |  |  |  |

1. Questions about anxiety.

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. In the last 4 weeks, have you had an anxiety attack – suddenly feeling fear or panic?  * **If you checked “NO”, go to question #4** |  |  |
| 1. Has this ever happened before? |  |  |
| 1. Do some of these attacks come suddenly out of the blue – that is, in situations where you don’t expect to be nervous or uncomfortable? |  |  |
| 1. Do these attacks bother you a lot or are you worried about having another attack? |  |  |

1. Think about your last bad anxiety attack.

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. Were you short of breath? |  |  |
| 1. Did your heart race, pound, or skip? |  |  |
| 1. Did you have chest pain or pressure? |  |  |
| 1. Did you sweat? |  |  |
| 1. Did you feel as if you were choking? |  |  |
| 1. Did you have hot flashes or chills? |  |  |
| 1. Did you have nausea or an upset stomach, or the feeling that you were going to have diarrhea? |  |  |
| 1. Did you feel dizzy, unsteady, or faint? |  |  |
| 1. Did you have tingling or numbness in parts of your body? |  |  |
| 1. Did you tremble or shake? |  |  |
| 1. Were you afraid you were dying? |  |  |

1. Over the LAST 4 WEEKS, how often have you been bothered by any of the following problems?

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Not at all** | **Several days** | **More than half the days** |
| 1. Feeling nervous, anxious, on edge, or worrying about a lot of different things.  * **If you checked “Not at all”, go to question #5.** |  |  |  |
| 1. Feeling restless so that it is hard to sit still. |  |  |  |
| 1. Getting tired very easily. |  |  |  |
| 1. Muscle tension, aches, or soreness. |  |  |  |
| 1. Trouble falling asleep or staying asleep. |  |  |  |
| 1. Trouble concentrating on things, such as reading a book or watching TV. |  |  |  |
| 1. Becoming easily annoyed or irritable. |  |  |  |

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. Do you ever drink alcohol (including beer or wine)?  * **If you checked “NO” go to question #7.** |  |  |

1. Have any of the following happened to you MORE THAN ONCE IN THE LAST 6 MONTHS?

|  |  |  |
| --- | --- | --- |
|  | **NO** | **YES** |
| 1. You drank alcohol even though a doctor suggested that you stop drinking because of a problem with your health. |  |  |
| 1. You drank alcohol, were high from alcohol, or hung over while you were working, going to school, or taking care of children or other responsibilities. |  |  |
| 1. You missed or were late for work, school, or other activities because you were drinking or hung over. |  |  |
| 1. You had a problem getting along with other people while you were drinking. |  |  |
| 1. You drove a car after having several drinks or after drinking too much. |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Not difficult at all** | **Somewhat difficult** | **Very difficult** | **Extremely difficult** |
| 1. Regarding the problems on this questionnaire that you’ve reported having, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? |  |  |  |  |

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**Mental Health Services/Help Seeking Self-Report Measure**

For these next few questions, please consider if you’ve done these things SINCE \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_[name] DIED.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **NO** | **YES** | **Details** |
| Have you consulted with any kind of mental health specialist? |  |  |  |
| Have you received any counseling for your nerves, mood, or sleep? |  |  |  |
| Have you taken any medication for your nerves, mood, or sleep? |  |  |  |
| Have you consulted with a clergy member? |  |  |  |
| Have you participated in a grief support group? |  |  |  |
| Are there any other services or activities you’ve participated in that have been helpful? |  |  |  |

**Decisional Regret Scale / Decision Satisfaction**

Please reflect on decision to remove life-support for \_\_\_\_\_\_\_\_\_\_\_\_\_[name]. I’ll read each statement and you tell me if you strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree with the statement.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Decision regret scale** | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
| It was the right decision | 1 | 2 | 3 | 4 | 5 |
| I regret the choice that was made | 1 | 2 | 3 | 4 | 5 |
| I would go for the same choice if I had to do it over | 1 | 2 | 3 | 4 | 5 |
| The choice did me a lot of harm | 1 | 2 | 3 | 4 | 5 |
| The decision was a wise one | 1 | 2 | 3 | 4 | 5 |
| **Decision satisfaction** |  |  |  |  |  |
| I am satisfied with the decision. | 1 | 2 | 3 | 4 | 5 |

**Centrality of Events Scale**

Please think back upon \_\_\_\_\_\_\_\_\_\_’s death in the ICU. I’ll read each statement and you tell me if you strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree with the statement.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
| 1. I feel the event has become part of my identity | 1 | 2 | 3 | 4 | 5 |
| 2. This event has become a reference point for the way I understand myself and the world. | 1 | 2 | 3 | 4 | 5 |
| 3. I feel that this event has become a central part of my life story. | 1 | 2 | 3 | 4 | 5 |
| 4. This event has colored the way I think and feel about other experiences. | 1 | 2 | 3 | 4 | 5 |
| 5. This event permanently changed my life. | 1 | 2 | 3 | 4 | 5 |
| 6. I often think about the effects this event will have on my future. | 1 | 2 | 3 | 4 | 5 |
| 7. This event was a turning point in my life | 1 | 2 | 3 | 4 | 5 |

*Reference: Smith, B.W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P. and Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. International Journal of Behavioural Medicine, 15, 194-200. Accessed at* [*http://homepages.uwp.edu/crooker/745-Resile/articles/Smith-etal-2008-BRS-indiv.pdf*](http://homepages.uwp.edu/crooker/745-Resile/articles/Smith-etal-2008-BRS-indiv.pdf)

**Inventory of complicated grief**

Listen to the following statements and tell me how much they apply to you…never, rarely, sometimes, often, always.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Never | Rarely | Sometimes | Often | Always |
| 1. I think about this person so much that it’s hard for me to do the things I normally do. | 0 | 1 | 2 | 3 | 4 |
| 2. Memories of the person who died upset me. | 0 | 1 | 2 | 3 | 4 |
| 3. I feel I cannot accept the death of the person who died. | 0 | 1 | 2 | 3 | 4 |
| 4. I feel myself longing for the person who died. | 0 | 1 | 2 | 3 | 4 |
| 5. I feel drawn to places and things associated with the person who died. | 0 | 1 | 2 | 3 | 4 |
| 6. I cannot help feeling angry about his/her death. | 0 | 1 | 2 | 3 | 4 |
| 7. I feel disbelief over what happened. | 0 | 1 | 2 | 3 | 4 |
| 8. I feel stunned or dazed over what happened. | 0 | 1 | 2 | 3 | 4 |
| 9. Ever since s/he died it is hard for me to trust people. | 0 | 1 | 2 | 3 | 4 |
| 10. Ever since s/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about. | 0 | 1 | 2 | 3 | 4 |
| 11. I have pain in the same area of my body or have some of the same symptoms as the person who died. | 0 | 1 | 2 | 3 | 4 |
| 12. I go out of my way to avoid reminders of the person who died. | 0 | 1 | 2 | 3 | 4 |
| 13. I feel that life is empty without the person who died. | 0 | 1 | 2 | 3 | 4 |
| 14. I hear the voice of the person who died speak to me. | 0 | 1 | 2 | 3 | 4 |
| 15. I see the person who died stand before me. | 0 | 1 | 2 | 3 | 4 |
| 16. I feel that it is unfair that I should live when this person died. | 0 | 1 | 2 | 3 | 4 |
| 17. I feel bitter over this person’s death. | 0 | 1 | 2 | 3 | 4 |
| 18. I feel envious of others who have not lost someone close. | 0 | 1 | 2 | 3 | 4 |
| 19. I feel lonely a great deal of the time ever since s/he died. | 0 | 1 | 2 | 3 | 4 |

**Visit time, in minutes: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**End-of-study feedback**

Now that your participation in the study is over, we’d like to ask you some questions about the experience of participation. We’d like you to be as honest as possible. Your feedback can help us to improve the study before we expand it to a larger group of surrogate decision makers.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Much Better | Better | Neither Better or Worse | Worse | Much Worse |
| 1. How did participation in this study make you feel? | 1 | 2 | 3 | 4 | 5 |
| * 1. Tell me more about why you feel that way. | [*Open text box*] | | | | |

For the next 2 questions, I’m going to read you several statements and I want you to tell me whether you agree strongly, agree, neither agree or disagree, disagree, disagree strongly with the statement.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Agree Strongly | Agree | Neither Agree nor Disagree | Disagree | Disagree Strongly |
| 1. Participating in this study was burdensome. | 1 | 2 | 3 | 4 | 5 |
| * 1. Tell me more about why you feel that way. |  | | | | |
| 1. I wish I hadn’t agreed to participate in the study. | 1 | 2 | 3 | 4 | 5 |
| 1. Tell me more about why you feel that way. |  | | | | |
| 1. Is there anything else you’d like us to know about your experience of participating in this study? |  | | | | |