Collaborative Pediatric Critical Care Research Network (CPCCRN)

CPCCRN Protocol Number 005

Primary Investigator:
Kathleen Meert, MD

Children’s Hospital of Michigan
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annotations key</td>
<td>3</td>
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<td>3</td>
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<td>Survey Scores</td>
<td>17</td>
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</tbody>
</table>
Annotations key:

Table name

Column name followed by # (numeric field) or $ (character field)  
Format (name)  
Code list  

Calculated / Derived variable  

Value not provided  

Table name_Child table name  

Variable in Question Group  

Notes:

SubjectID is a randomly generated ID number that uniquely identifies a child or participating family. It does not contain any identifying information about the original site or participant. Because multiple caregivers within a family could respond to the surveys, SubjectID + PersonSurveyFor will uniquely identify a given survey respondent.

The variable StudyPhase provides the time point at which the survey is completed (i.e., 6 or 18 months). This variable is part of the unique identifier for the two surveys administered at both time points: Inventory of Complicated Grief and Grief Avoidance.

Sensitive and/or identifying information entered in free text fields have been removed from the public use datasets.
Relationship Scales Questionnaire:

Unique ID = SubjectID + PersonSurveyFor

Who is this questionnaire for?

<table>
<thead>
<tr>
<th>PersonSurveyFor #</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value not provided</td>
</tr>
</tbody>
</table>

If Legal guardian, specify who that is

<table>
<thead>
<tr>
<th>DV6608G</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Mother</td>
</tr>
<tr>
<td>2 = Father</td>
</tr>
<tr>
<td>3 = Other guardian – male</td>
</tr>
<tr>
<td>4 = Other guardian - female</td>
</tr>
</tbody>
</table>

Please read each of the following statements and rate the extent to which you believe each statement best describes your feelings about close relationships.

1. I find it difficult to depend on other people.
2. I find it difficult to trust others completely.
3. I find it easy to get emotionally close to others.
4. I want to merge completely with another person.
5. I worry that I will be hurt if I allow myself to become too close to others.
6. I am comfortable without close emotional relationships.
7. I am not sure that I can always depend on others to be there when I need them.
8. I want to be completely emotionally intimate with others.
9. I worry about being alone.
10. I often worry that romantic partners don’t really love me.
11. I find it difficult to trust others completely.
12. I worry about others getting too close to me.
13. I want emotionally close relationships.
14. I am comfortable having other people depend on me.
15. I worry that others don’t value me as much as I value them.
16. People are never there when you need them.
17. My desire to merge completely sometimes scares people away.

DV6497G

<table>
<thead>
<tr>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Not at all like me</td>
</tr>
<tr>
<td>2 = Somewhat like me</td>
</tr>
<tr>
<td>3 = Very much like me</td>
</tr>
<tr>
<td>4 = Not Asked/Not Answered</td>
</tr>
</tbody>
</table>

BPII_Annotated CRF_FINAL_03Jan2013
Relationship Scales Questionnaire:

Unique ID = SubjectID + PersonSurveyFor

19 It is very important to me to feel self-sufficient.
20 I am nervous when anyone gets too close to me.
21 I often worry that romantic partners won't want to stay with me.
22 I prefer not to have other people depend on me.
23 I worry about being abandoned.
24 I am somewhat uncomfortable being close to others.
25 I find that others are reluctant to get as close as I would like.
26 I prefer not to depend on others.
27 I know that others will be there when I need them.
28 I worry about having others not accept me.
29 Romantic partners often want me to be closer than I feel comfortable being.
30 I find it relatively easy to get close to others.

Calculated / derived variables included in the RSQ dataset:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Algorithm / Notes</th>
<th>Format</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>SubjectID</td>
<td>Unique child (family) ID - masked</td>
<td></td>
<td>#</td>
</tr>
</tbody>
</table>
Inventory of Complicated Grief:

Unique ID = SubjectID + PersonSurveyFor + StudyPhase

**Who is this questionnaire for?**

**PersonSurveyFor #**

If Legal guardian, specify who that is:  
Value not provided

**Inventory of Complicated Grief**

Please circle the answer that best describes how you feel right now about your child that died.

1 I think about this person so much that it's hard for me to do the things I normally do
2 Memories of the person who died upset me
3 I feel I cannot accept the death of the person who died
4 I feel myself longing for the person who died
5 I feel drawn to places and things associated with the person who died
6 I can't help feeling angry about his/her death
7 I feel disbelief over what happened
8 I feel stunned or dazed over what happened
9 Ever since he/she died it is hard for me to trust people

**DV6491G**
0 = Never
1 = Rarely
2 = Sometimes
3 = Often
4 = Always
5 = Not Asked/Not Answered

**DV6608G**
1 = Mother
2 = Father
3 = Other guardian – male
4 = Other guardian - female

**PHASE**
1 = 6 Months
2 = 18 Months
Inventory of Complicated Grief:

Unique ID = SubjectID + PersonSurveyFor + StudyPhase

10 Ever since he/she died I feel like I have lost the ability to care about other people or I feel distant from people I care about
11 I have pain in the same area of my body or have some of the same symptoms as the person who died
12 I go out of my way to avoid reminders of the person who died
13 I feel that life is empty without the person who died
14 I hear the voice of the person who died speak to me
15 I see the person who died stand before me
16 I feel that it is unfair that I should live when this person died
17 I feel bitter over this person’s death
18 I feel envious of others who have not lost someone close
19 I feel lonely a great deal of the time ever since he/she died

Calculated / derived variables included in the ICG dataset:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Algorithm / Notes</th>
<th>Format</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>SubjectID</td>
<td>Unique child (family) ID - masked</td>
<td>#</td>
<td></td>
</tr>
<tr>
<td>StudyPhase</td>
<td>Follow-up time point</td>
<td>PHASE</td>
<td>#</td>
</tr>
</tbody>
</table>

DV6491G
0 = Never
1 = Rarely
2 = Sometimes
3 = Often
4 = Always
5 = Not Asked/Not Answered
Grief Related Avoidance Questionnaire:

Unique ID = SubjectID + PersonSurveyForm + StudyPhase

Who is this questionnaire for?

If Legal guardian, specify who that is

Value not provided

Grief Related Avoidance Questionnaire

The questions below ask about your thoughts, feelings, and behavior during the past month in relation to the death of your child. Please choose one answer for each question.

1...avoid thinking about your deceased child?

2...avoid talking about your deceased child?

3...avoid showing your feelings about your deceased child?

When you were with close family members during the past month, how often did you?

4...avoid thinking about your deceased child?

5...avoid talking about your deceased child?

6...avoid showing your feelings about your deceased child?

When you were with close friends during the past month, how often did you?

7...avoid thinking about your deceased child?

When you were alone during the past month, how often did you?

Calculated / derived variables included in the GRIEFAVOID dataset:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Algorithm / Notes</th>
<th>Format</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>SubjectID</td>
<td>Unique child (family) ID - masked</td>
<td>#</td>
<td></td>
</tr>
<tr>
<td>StudyPhase</td>
<td>Follow-up time point</td>
<td>PHASE</td>
<td>#</td>
</tr>
</tbody>
</table>
The Caregiving Questionnaire:

Unique ID = SubjectID + PersonSurveyFor

Who is this questionnaire for?

Who is this questionnaire for?

If Legal guardian, specify who that is

Value not provided

For each statement, circle the number that indicates how descriptive the statement is to you.

1. I sometimes push my partner away when s/he reaches out for a needed hug or kiss.
2. I can always tell when my partner needs comforting, even when s/he doesn't ask for it.
3. I always respect my partner's ability to make his/her own decisions and solve his/her own problems.
4. When my partner cries or is distressed, my first impulse is to hold or touch him/her.
5. I help my partner without becoming overinvolved in his/her problems.
6. Too often, I don't realize when my partner is upset or worried about something.
7. When my partner is troubled or upset, I move closer to provide support and comfort.
8. I'm good at knowing when my partner needs my help or support and when s/he would rather handle things alone.
9. I feel comfortable holding my partner when s/he needs physical signs of support and reassurance.
10. I'm not very good at 'tuning in' to my partner's needs and feelings.
11. I tend to get overinvolved in my partner's problems and difficulties.
12. I don't like it when my partner is needy and clings to me.
13. I often end up telling my partner what to do when s/he is trying to make a decision.
14. I sometimes miss the subtle signs that show how my partner is feeling.
15. When necessary I can say 'no' to my partner's requests for help without feeling guilty.
16. I tend to be too domineering when trying to help my partner.
17. When it's important, I take care of my own needs before I try to take of my partner's.
18. I am very attentive to my partner's nonverbal signals for help and support.
The Caregiving Questionnaire:

Unique ID = SubjectID + PersonSurveyFor

19 I can easily keep myself from becoming overly concerned about or overly protective of my partner.
20 I'm very good about recognizing my partner's needs and feelings, even when they're different from my own.
21 I can help my partner work out his/her problems without 'taking control'.
22 I sometimes draw away from my partner's attempts to get a reassuring hug from me.
23 I am always supportive of my partner's own efforts to solve his/her problems.
24 I tend to take on my partner's problems - and then feel burdened by them.
25 When my partner seems to want or need a hug, I'm glad to provide it.
26 When I help my partner with something, I tend to want to do things 'my way'.
27 I frequently get too 'wrapped up' in my partner's problems and needs.
28 I sometimes 'miss' or 'misread' my partner's signals for help and understanding?
29 When my partner is crying or emotionally upset, I sometimes feel like withdrawing.
30 When my partner tells me a problem, I sometimes go too far in criticizing his/her own attempts to deal with it.
31 I create problems by taking on my partner's troubles as if they were my own.
32 When helping my partner solve a problem, I am much more 'cooperative' than 'controlling'.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Algorithm / Notes</th>
<th>Format</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>SubjectID</td>
<td>Unique child (family) ID - masked</td>
<td>#</td>
<td></td>
</tr>
</tbody>
</table>

Calculated / derived variables included in the CAREGIVING dataset:

DV6498G
1 = 1 Not at all like me
2 = 2
3 = 3
4 = 4
5 = 5
6 = 6 Very much like me
7 = 7 Not Asked/Not Answered
Social Support Questionnaire:

**SUPPORT**: Unique ID = SubjectID + PersonSurveyFor

**SUPPORTCONTACTS**: Unique ID = SubjectID+PersonSurveyFor+Question+Repeat_Instance

<table>
<thead>
<tr>
<th>SubjectID</th>
<th>Question</th>
<th>Repeat_Instance</th>
</tr>
</thead>
</table>

Please note: For entries with no relationship specified in the SUPPORTCONTACTS dataset, only the initials were provided in the original entry.

Who is this questionnaire for?

If Legal guardian, specify who that is

Value not provided

The Social Support Questionnaire (Short Form)

The following questions ask about people in your environment who provide you with help and support. Each question has two parts. For the first part, list all people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons' initials, their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how satisfied you are with the overall support you have.

If you have had no support for a question, check the words "No one", but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the questions as best as you can. All your responses will be kept confidential.

1a. Whom can you really count on to be dependable when you need help?

If there is someone, please list them all below:

<table>
<thead>
<tr>
<th>Initials</th>
<th>Relationship</th>
<th>SSQRelation $</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value not provided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How satisfied?

1b. How satisfied?

2a. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

If there is someone, please list them all below:

<table>
<thead>
<tr>
<th>Initials</th>
<th>Relationship</th>
<th>SSQRelation $</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value not provided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

...
Social Support Questionnaire:

SUPPORT: Unique ID = SubjectID + PersonSurveyFor

SUPPORTCONTACTS: Unique ID = SubjectID+PersonSurveyFor+Question+Repeat_Instance

How satisfied?

2b. How satisfied? SocSupportQ2b #

Question Three

3a. Who accepts you totally, including both your worst and best points? SocSupportQ3a #

If there is someone, please list them below:

<table>
<thead>
<tr>
<th>Initials</th>
<th>Relationship</th>
<th>SSQRelation $</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value not provided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Add record Delete record

How satisfied?

3b. How satisfied? SocSupportQ3b #

Question 4

4a. Whom can you count on to really care about you, regardless of what is really happening to you? SocSupportQ4a #

If there is someone, please list them below:

<table>
<thead>
<tr>
<th>Initials</th>
<th>Relationship</th>
<th>SSQRelation $</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value not provided</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Add record Delete record

How satisfied?

4b. How satisfied? SocSupportQ4b #

DV6495G
1 = No one
2 = There is someone
3 = Not Asked/Not Answered

DV6494G
1 = 6 very satisfied
2 = 5 fairly satisfied
3 = 4 a little satisfied
4 = 3 a little dissatisfied
5 = 2 fairly dissatisfied
6 = 1 very dissatisfied
7 = 0 Not Asked/Not Answered
Social Support Questionnaire:

**SUPPORT: Unique ID = SubjectID + PersonSurveyFor**

**SUPPORTCONTACTS: Unique ID = SubjectID+PersonSurveyFor+Question+Repeat_Instance**

### Question 5

5a. Whom can you really count on to help you feel better when you are feeling generally down-in-the dumps?  

If there is someone, please list them below:

<table>
<thead>
<tr>
<th>Initials</th>
<th>Relationship</th>
<th>SSQRelation $</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How satisfied?

5b. How satisfied?  

DV6495G  
1 = No one  
2 = There is someone  
3 = Not Asked/Not Answered

### Question 6

6a. Whom can you really count on to console you when you are upset?  

If there is someone, please list them below:

<table>
<thead>
<tr>
<th>Initials</th>
<th>Relationship</th>
<th>SSQRelation $</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How satisfied?

6b. How satisfied?  

DV6494G  
1 = 6 very satisfied  
2 = 5 fairly satisfied  
3 = 4 a little satisfied  
4 = 3 a little dissatisfied  
5 = 2 fairly dissatisfied  
6 = 1 very dissatisfied  
7 = 0 Not Asked/Not Answered

**Calculated / derived variables included in the SUPPORT and SUPPORTCONTACTS datasets:**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Algorithm / Notes</th>
<th>Format</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>SubjectID</td>
<td>Unique child (family) ID - masked</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>Question</td>
<td>Question Number (1-6)</td>
<td></td>
<td>#</td>
</tr>
</tbody>
</table>
Parent Information & Child Information:

Unique ID = SubjectID + PersonSurveyFor

**Parent Information**

Please answer the following questions about yourself by choosing the best answer or filling in the space provided.

1. Did parent provide their age?
2. How old are you (in years)?
3. What is your gender?
4. What race describes you best?
5. Ethnicity of patient

**DV3005G**
- 1 = Male
- 2 = Female
- 3 = Not Asked/Not Answered

**DV6484G**
- -1 = Hispanic or Latino
- 0 = Not Hispanic or Latino
- 1 = Unknown

**DV6483G**
- 0 = Black or African American
- 1 = White or Caucasian
- 2 = American Indian / Alaska Native *
- 3 = Asian
- 4 = Native Hawaiian or Other Pacific Islander
- 5 = Not Asked/Not Answered

* Combined with 5 = Not Asked/Not Answered

6. What is your marital status?
7. If other marital status, please describe:

**DV743G**
- 1 = Married
- 2 = Widowed
- 3 = Separated
- 4 = Divorced
- 5 = Never married
- 6 = Other
- 7 = Not Asked/Not Answered
Bereavement Phase II Annotated PUDS eCRF

Parent Information & Child Information:

Unique ID = SubjectID + PersonSurveyFor

8. What is the highest education you received?
9. If other education, please describe:
10. What best describes your relationship to the child that died?
11. If other relationship, please describe:
12. How many other children do you have besides the child that died?

DV6485G
1 = Elementary School or none at all*
2 = High school
3 = Apprenticeship
4 = Some college or junior college
5 = College Education
6 = Postgraduate degree
7 = Other
8 = Not Asked/Not Answered

*Combined responses for Elementary school and none at all

DV6489G
1 = Biological mother
2 = Biological father
3 = Other

DV6490G
1 = None
2 = One
3 = Two
4 = Three or more
5 = Not Asked/Not Answered

Parent Information & Child Information:

Unique ID = SubjectID + PersonSurveyFor

8. What is the highest education you received?
9. If other education, please describe:
10. What best describes your relationship to the child that died?
11. If other relationship, please describe:
12. How many other children do you have besides the child that died?

DV6485G
1 = Elementary School or none at all*
2 = High school
3 = Apprenticeship
4 = Some college or junior college
5 = College Education
6 = Postgraduate degree
7 = Other
8 = Not Asked/Not Answered

*Combined responses for Elementary school and none at all

DV6489G
1 = Biological mother
2 = Biological father
3 = Other

DV6490G
1 = None
2 = One
3 = Two
4 = Three or more
5 = Not Asked/Not Answered

Child Information

Please answer the following questions about your child that died by choosing the best answer or filling in the space provided.

13. What was the gender of your child that died?
14. How old was your child at the time of his or her death?
15. Days/months/years?
16. What was the cause of your child’s death?
17. Date of Death

DV3005G
1 = Male
2 = Female
3 = Not Asked/Not Answered

date
1 = Cardiac
2 = Malignancy
3 = Multiple organ failure/sepsis
4 = Neurologic
5 = Respiratory failure
6 = Trauma
7 = Other
8 = Unknown
Parent Information & Child Information:

Unique ID = SubjectID + PersonSurveyFor

May we contact you again?

18. May we contact you again for research participation in the future? [MayWeContactYou #]

Calculated / derived variables included in the PARENT dataset:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Algorithm / Notes</th>
<th>Format</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>SubjectID</td>
<td>Unique child (family) ID - masked</td>
<td>#</td>
<td></td>
</tr>
<tr>
<td>TimeToInitialSurvey</td>
<td>Time from child death to 6 month survey completed (days)</td>
<td>#</td>
<td></td>
</tr>
<tr>
<td>Timeto18MonthSurvey</td>
<td>Time from child death to 18 month survey completed (days)</td>
<td>#</td>
<td></td>
</tr>
<tr>
<td>PersonSurveyFor</td>
<td>Individual completing survey</td>
<td>DV6608G</td>
<td>#</td>
</tr>
<tr>
<td>CauseOfDeath</td>
<td>Cause of death (PI review)</td>
<td>death</td>
<td>#</td>
</tr>
</tbody>
</table>
Survey Scores:

*Please note: Algorithms for each of the survey scores are available in separate documentation*

Unique ID = SubjectID + PersonSurveyFor

**Calculated / derived variables included in the SURVEYSCORES dataset for 6 and 18 month Survey Responses:**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Algorithm / Notes</th>
<th>Format</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>SubjectID</td>
<td>Unique child (family) ID - masked</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>PersonSurveyFor</td>
<td>Individual completing survey</td>
<td>DV6608G</td>
<td>#</td>
</tr>
<tr>
<td>ICGScore</td>
<td>Inventory of Complicated Grief Score</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>GAScore</td>
<td>Grief Avoidance Score</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>RSQSecure</td>
<td>RSQ Secure</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>RSQFearful</td>
<td>RSQ Fearful</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>RSQPreoccupied</td>
<td>RSQ Preoccupied</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>RSQDismissing</td>
<td>RSQ Dismissing</td>
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<td>#</td>
</tr>
<tr>
<td>CGproximity</td>
<td>Proximity vs. Distance</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>CGSensitivity</td>
<td>Sensitivity vs. Insensitivity</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>CGcooperation</td>
<td>Cooperation vs. Control</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>CGcompulsive</td>
<td>Compulsive Caregiving</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>CGresponsive</td>
<td>Responsive Caregiving (combine 3 subscales)</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>SSQNavg</td>
<td>Social Support Number Average</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>SSQavg</td>
<td>Social Support Satisfaction Average</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>ICGScore18</td>
<td>Inventory of Complicated Grief Score (18 months)</td>
<td></td>
<td>#</td>
</tr>
<tr>
<td>GAScore18</td>
<td>Grief Avoidance Score (18 months)</td>
<td></td>
<td>#</td>
</tr>
</tbody>
</table>

DV6608G
1 = Mother
2 = Father
3 = Other guardian – male
4 = Other guardian - female