University of Utah
Data Coordinating Center

ANNOTATED eCRF FOR PUBLIC USE DATASETS

CPCCRN
Pediatric Intensive Care Unit
Bereavement Study

Collaborative Pediatric Critical Care Research Network (CPCCRN)

CPCCRN Protocol Number 005

Primary Investigator:
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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
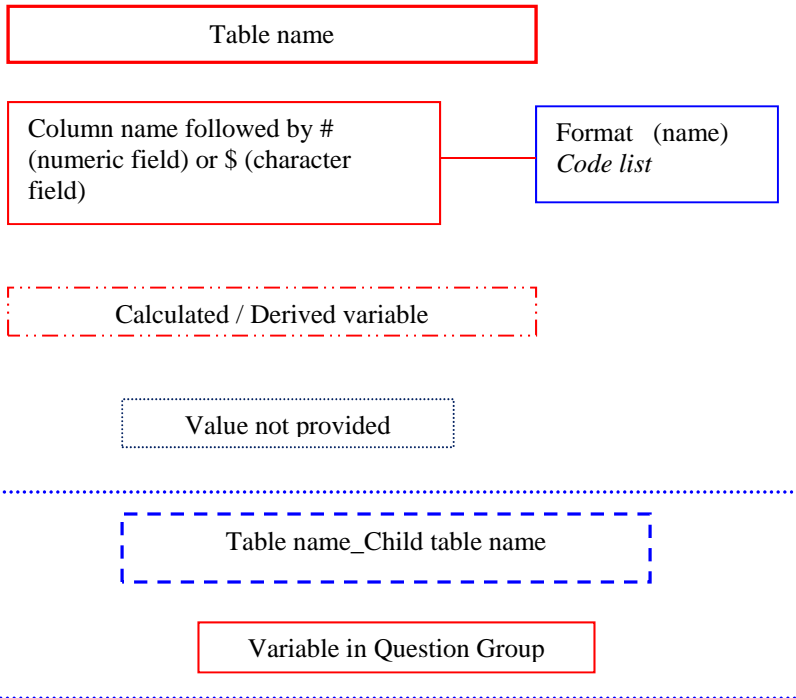
Notes:

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.

RSQ (1 of 2)

Relationship Scales Questionnaire:

SubjectID #

Unique ID = SubjectID + PersonSurveyFor

Who is this questionnaire for?

Who is this questionnaire for?   PersonSurveyFor #

If Legal guardian, specify who that is   Value not provided

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

Relationship Scales Group

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

1 I find it difficult to depend on other people.   RelScalesQ1 #

2 It is very important to me to feel independent.   RelScalesQ2 #

3 I find it easy to get emotionally close to others.   RelScalesQ3 #

4 I want to merge completely with another person.   RelScalesQ4 #

5 I worry that I will be hurt if I allow myself to become too close to others.   RelScalesQ5 #

6 I am comfortable without close emotional relationships.   RelScalesQ6 #

7 I am not sure that I can always depend on others to be there when I need them.   RelScalesQ7 #

8 I want to be completely emotionally intimate with others.   RelScalesQ8 #

9 I worry about being alone.   RelScalesQ9 #

10 I am comfortable depending on other people.   RelScalesQ10 #

11 I often worry that romantic partners don't really love me.   RelScalesQ11 #

12 I find it difficult to trust others completely.   RelScalesQ12 #

13 I worry about others getting too close to me.   RelScalesQ13 #

14 I want emotionally close relationships.   RelScalesQ14 #

15 I am comfortable having other people depend on me.   RelScalesQ15 #

16 I worry that others don't value me as much as I value them.   RelScalesQ16 #

17 People are never there when you need them.   RelScalesQ17 #

18 My desire to merge completely sometimes scares people away.   RelScalesQ18 #

DV6497G
1 = 1 Not at all like me
2 = 2
3 = 3 Somewhat like me
4 = 4
5 = 5 Very much like me
6 = 6 Not Asked/Not Answered

Relationship Scales Questionnaire:

Unique ID = SubjectID + PersonSurveyFor

19 It is very important to me to feel self-sufficient. | RelScalesQ19 #
20 I am nervous when anyone gets too close to me. | RelScalesQ20 #
21 I often worry that romantic partners won't want to stay with me. | RelScalesQ21 #
22 I prefer not to have other people depend on me. | RelScalesQ22 #
23 I worry about being abandoned. | RelScalesQ23 #
24 I am somewhat uncomfortable being close to others. | RelScalesQ24 #
25 I find that others are reluctant to get as close as I would like. | RelScalesQ25 #
26 I prefer not to depend on others. | RelScalesQ26 #
27 I know that others will be there when I need them. | RelScalesQ27 #
28 I worry about having others not accept me. | RelScalesQ28 #
29 Romantic partners often want me to be closer than I feel comfortable being. | RelScalesQ29 #
30 I find it relatively easy to get close to others. | RelScalesQ30 #

DV6497G
1 = 1 Not at all like me
2 = 2
3 = 3 Somewhat like me
4 = 4
5 = 5 Very much like me
6 = 6 Not Asked/Not Answered

Calculated / derived variables included in the RSQ dataset:

Variable	Algorithm / Notes	Format	Type
SubjectID	Unique child (family) ID - masked		#

ICG (1 of 2)

Inventory of Complicated Grief:

SubjectID #   StudyPhase #

PHASE
1 = 6 Months
2 = 18 Months

Unique ID = SubjectID + PersonSurveyFor + StudyPhase

Who is this questionnaire for?

Who is this questionnaire for?   PersonSurveyFor #

If Legal guardian, specify who that is   Value not provided

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

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   InvCompGrfQ1 #

2 Memories of the person who died upset me   InvCompGrfQ 2 #

3 I feel I cannot accept the death of the person who died   InvCompGrfQ3 #

4 I feel myself longing for the person who died   InvCompGrfQ4 #

5 I feel drawn to places and things associated with the person who died   InvCompGrfQ5 #

6 I can't help feeling angry about his/her death   InvCompGrfQ 6 #

7 I feel disbelief over what happened   InvCompGrfQ7 #

8 I feel stunned or dazed over what happened   InvCompGrfQ8 #

9 Ever since he/she died it is hard for me to trust people   InvCompGrfQ9 #

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

ICG (2 of 2)

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   InvCompGrfQ 10 #

11 I have pain in the same area of my body or have some of the same symptoms as the person who died   InvCompGrfQ11 #

12 I go out of my way to avoid reminders of the person who died   InvCompGrfQ 12 #

13 I feel that life is empty without the person who died   InvCompGrfQ 13 #

14 I hear the voice of the person who died speak to me   InvCompGrfQ14 #

15 I see the person who died stand before me   InvCompGrfQ 15 #

16 I feel that it is unfair that I should live when this person died   InvCompGrfQ16 #

17 I feel bitter over this person's death   InvCompGrfQ17 #

18 I feel envious of others who have not lost someone close   InvCompGrfQ18 #

19 I feel lonely a great deal of the time ever since he/she died   InvCompGrfQ19 #

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

Calculated / derived variables included in the ICG dataset:

Variable	Algorithm / Notes	Format	Type
SubjectID	Unique child (family) ID - masked		#
StudyPhase	Follow-up time point	PHASE	#

GRIEFAVOID (1 of 1)

PHASE
1 = 6 Months
2 = 18 Months

Grief Related Avoidance Questionnaire:

SubjectID #   StudyPhase #

Unique ID = SubjectID + PersonSurveyForm + StudyPhase

Who is this questionnaire for?

Who is this questionnaire for?   PersonSurveyFor #

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

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.

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

1 …avoid thinking about your deceased child?   GrfRelAvoidQ1 #

2 ◇avoid talking about your deceased child?   GrfRelAvoidQ2 #

3 ◇avoid showing your feelings about your deceased child?   GrfRelAvoidO3 #

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

4 …avoid thinking about your deceased child?   GrfRelAvoidQ4 #

5 ◇avoid talking about your deceased child?   GrfRelAvoidQ5 #

6 ◇avoid showing your feelings about your deceased child?   GrfRelAvoidQ6 #

DV6499G
1 = 1 Almost never
2 = 2 Sometimes
3 = 3 Moderately often
4 = 4 Very often
5 = 5 Almost constantly
6 = 6 Not Asked/Not Answered

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

7 …avoid thinking about your deceased child?   GrfRelAvoidQ7 #

Calculated / derived variables included in the GRIEFAVOID dataset:

Variable	Algorithm / Notes	Format	Type
SubjectID	Unique child (family) ID - masked		#
StudyPhase	Follow-up time point	PHASE	#

CAREGIVING (1 of 2)

The Caregiving Questionnaire:

Unique ID = SubjectID + PersonSurveyFor   SubjectID #

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

Who is this questionnaire for?

Who is this questionnaire for?   PersonSurveyFor #

If Legal guardian, specify who that is   Value not provided

The Caregiving Questionnaire

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.   CareGivingQ1 #

2 I can always tell when my partner needs comforting, even when s/he doesn't ask for it.   CareGivingQ2 #

3 I always respect my partner's ability to make his/her own decisions and solve his/her own problems.   CareGivingQ3 #

4 When my partner cries or is distressed, my first impulse is to hold or touch him/her.   CareGivingQ4 #

5 I help my partner without becoming overinvolved in his/her problems.   CareGivingQ5 #

6 Too often, I don◆t realize when my partner is upset or worried about something.   CareGivingQ6 #

7 When my partner is troubled or upset, I move closer to provide support and comfort.   CareGivingQ7 #

8 I'm good at knowing when my partner needs my help or support and when s/he would rather handle things alone.   CareGivingQ8 #

9 I feel comfortable holding my partner when s/he needs physical signs of support and reassurance.   CareGivingQ9 #

10 I'm not very good at 'tuning in' to my partner's needs and feelings.   CareGivingQ10 #

11 I tend to get overinvolved in my partner's problems and difficulties.   CareGivingQ11 #

12 I don't like it when my partner is needy and clings to me.   CareGivingQ12 #

13 I often end up telling my partner what to do when s/he is trying to make a decision.   CareGivingQ13 #

14 I sometimes miss the subtle signs that show how my partner is feeling.   CareGivingQ14 #

15 When necessary I can say 'no' to my partner's requests for help without feeling guilty.   CareGivingQ15 #

16 I tend to be too domineering when trying to help my partner.   CareGivingQ16 #

17 When it's important, I take care of my own needs before I try to take of my partner's.   CareGivingQ17 #

18 I am very attentive to my partner's nonverbal signals for help and support.   CareGivingQ18 #
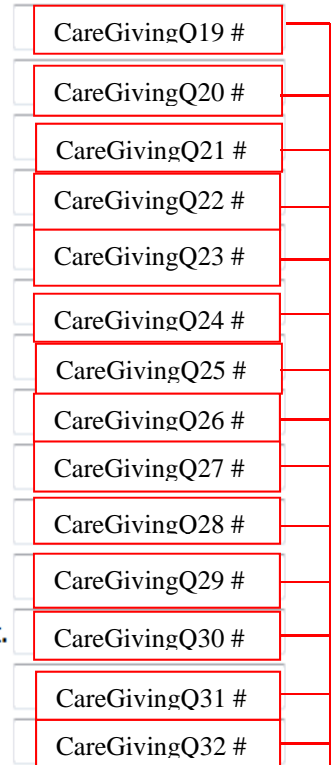
DV6498G
1 = 1 Not at all like me
2 = 2
3 = 3
4 = 4
5 = 5
6 = 6 Very much like me
7 = 7 Not Asked/Not Answered

<div style="border: 1px solid red; text-align: center;">CAREGIVING (2 of 2)</div>

The Caregiving Questionnaire:

Unique ID = SubjectID + PersonSurveyFor

19 I can easily keep myself from becoming overly concerned about or overly protective of my partner. CareGivingQ19 #

20 I'm very good about recognizing my partner's needs and feelings, even when they're different from my own. CareGivingQ20 #

21 I can help my partner work out his/her problems without 'taking control'. CareGivingQ21 #

22 I sometimes draw away from my partner's attempts to get a reassuring hug from me. CareGivingQ22 #

23 I am always supportive of my partner's own efforts to solve his/her problems. CareGivingQ23 #

24 I tend to take on my partner's problems - and then feel burdened by them. CareGivingQ24 #

25 When my partner seems to want or need a hug, I'm glad to provide it. CareGivingQ25 #

26 When I help my partner with something, I tend to want to do things 'my way'. CareGivingQ26 #

27 I frequently get too 'wrapped up' in my partner's problems and needs. CareGivingQ27 #

28 I sometimes 'miss' or 'misread' my partner's signals for help and understanding? CareGivingQ28 #

29 When my partner is crying or emotionally upset, I sometimes feel like withdrawing. CareGivingQ29 #

30 When my partner tells me about a problem, I sometimes go too far in criticizing his/her own attempts to deal with it. CareGivingQ30 #

31 I create problems by taking on my partner's troubles as if they were my own. CareGivingQ31 #

32 When helping my partner solve a problem, I am much more 'cooperative' than 'controlling'. CareGivingQ32 #

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

Calculated / derived variables included in the CAREGIVING dataset:

Variable	Algorithm / Notes	Format	Type
SubjectID	Unique child (family) ID - masked		#

SUPPORT (1 of 3)

Social Support Questionnaire:

SUPPORT: Unique ID = SubjectID + PersonSurveyFor

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

SubjectID #   Question #   Repeat_Instance #

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?

Who is this questionnaire for?   PersonSurveyFor #

If Legal guardian, specify who that is [   ]   Value not provided

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

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?   SocSupportQ1a #

If there is someone, please list them all below:

Initials   Relationship   SSQRelation $

Value not provided

[Add record] [Delete record]   SUPPORTCONTACTS

How satisfied?

1b. How satisfied?   SocSupportQ1b #

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

Question two

2a. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?   SocSupportQ2a #

If there is someone, please list them below:

Initials   Relationship   SSQRelation $

Value not provided

[Add record] [Delete record]   SUPPORTCONTACTS

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

SUPPORT (2 of 3)

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:

Initials	Relationship
	SSQRelation $
Value not provided	

Add record   Delete record

SUPPORTCONTACTS

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

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:

Initials	Relationship
	SSQRelation $
Value not provided	

Add record   Delete record

SUPPORTCONTACTS

How satisfied?

4b. How satisfied?   SocSupportQ4b # ▼

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

SUPPORT (3 of 3)

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? | SocSupportQ5a #

If there is someone, please list them below:

| Initials | Relationship | SSQRelation $ |
| Value not provided | |

Add record | Delete record

SUPPORTCONTACTS

How satisfied?

5b. How satisfied? | SocSupportQ5b #

Question 6

6a. Whom can you really count on to console you when you are upset? | SocSupportQ6a #

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

If there is someone, please list them below:

| Initials | Relationship | SSQRelation $ |
| Value not provided | |

Add record | Delete record

SUPPORTCONTACTS

How satisfied?

6b. How satisfied? | SocSupportQ6b #

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:

Variable	Algorithm / Notes	Format	Type
SubjectID	Unique child (family) ID - masked		#
Question	Question Number (1-6)		#

PARENT (1 of 3)

Parent Information & Child Information:

SubjectID #   PersonSurveyFor #

Unique ID = SubjectID + PersonSurveyFor

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

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?   Value not provided

2. How old are you (in years)?   Age #

3. What is your gender?   Qgender #

4. What race describes you best?   Qrace #

5. Ethnicity of patient   Ethnicity #

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?   MaritalStatus #

7. If other marital status, please describe: MaritalOther $

DV743G
1 = Married
2 = Widowed
3 = Separated
4 = Divorced
5 = Never married
6 = Other
7 = Not Asked/Not Answered

PARENT (2 of 3)

Parent Information & Child Information:

Unique ID = SubjectID + PersonSurveyFor

8. What is the highest education you received?   Education #   [▼]

   Value not provided

9. If other education, please describe:

10. What best describes your relationship to the child that died?   RelationToChild #

11. If other relationship, please describe: RelationOther $

12. How many other children do you have besides the child that died?   HowManyChildren #

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?   GenderChild #   [▼]

14. How old was your child at the time of his or her death?   15. Days/months/years?   AgeUnit #   [▼]

   AgeAtDeathChild #

16. What was the cause of your child's death?   CauseOfDeath #

17. Date of Death   TimeToInitialSurvey #   Timeto18MonthSurvey #

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

death
1 = Cardiac
2 = Malignancy
3 = Multiple organ failure/sepsis
4 = Neurologic
5 = Respiratory failure
6 = Trauma
7 = Other
8 = Unknown

DV6496G
1 = Days
2 = Months
3 = Years
4 = Not Asked/Not Answered

PARENT (3 of 3)

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 # ▼

DV256G
1 = Yes
2 = No
3 = Not Asked/Not Answered

Calculated / derived variables included in the PARENT dataset:

Variable	Algorithm / Notes	Format	Type
SubjectID	Unique child (family) ID - masked		#
TimeToInitialSurvey	Time from child death to 6 month survey completed (days)		#
Timeto18MonthSurvey	Time from child death to 18 month survey completed (days)		#
PersonSurveyFor	Individual completing survey	DV6608G	#
CauseOfDeath	Cause of death (PI review)	death	#

SURVEYSCORES (1 of 1)

Survey Scores:

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

Unique ID = SubjectID + PersonSurveyFor   SubjectID #   PersonSurveyFor #

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

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

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