Full Study Protocol

Pediatric Intensive Care Unit Bereavement Study

Version 1.00 – April 21, 2006

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CPCCRN Protocol Number 005

Amendment 1: Version 1.03 – May 22, 2006
Amendment 2: Version 1.04 – May 25, 2007

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Background and Objective

Grief is expected after the death of a loved one. Normal grief is thought to be a dynamic process that consists of overlapping phases including shock, disbelief, confusion, yearning, depression, and eventual acceptance and recovery.[1] Most bereaved persons work through the grief process successfully. Others develop complicated grief, a pattern of extreme or prolonged symptoms that are associated with adverse mental and physical health outcomes.[2,3] Complicated grief is considered by many experts to represent a distinct psychopathological disorder.[4] Complicated grief is triggered by the loss of another person. The major symptoms are those of separation distress and traumatic distress. Separation distress includes intense yearning and longing for the deceased, and an intrusive and distressing preoccupation with thoughts of the deceased. Traumatic distress includes a sense of disbelief regarding the death, anger, numbness, futility and a loss of trust, security and control. Symptoms must persist for at least 6 months to fulfill criteria for complicated grief. A 6-month symptom duration is predictive of long-term adverse outcomes. The phenomenology, potential risk factors, clinical correlates, course and outcomes for complicated grief have been shown to be distinct from those of posttraumatic stress disorder, major depression and adjustment disorder.[4,5]

Complicated grief is estimated to occur in 10-20% of bereaved persons however the prevalence among parents who have lost a child is not well described.[6,7] Risk factors for complicated grief may include a person's *attachment style*.[7-10] The concept of attachment refers to the propensity for individuals to make lasting affectional bonds with others and may account for the emotional responses that occur when these bonds are disrupted or lost. Four prototypical attachment styles have been described based on two underlying dimensions: (1) a person's sense of positivity of self, and (2) a person's sense of positivity of others. "Positivity of self" indicates the degree to which an individual has internalized a sense of his or her own self-worth and expects others to respond to him or her positively. How one views his or herself is associated with the degree of anxiety experienced in close relationships. "Positivity of others" indicates the degree to which an individual expects others to be available and supportive, and is associated with the tendency to seek out or avoid closeness in relationships. The four prototypical attachment styles are conceptualized as (1) secure (low anxiety, low avoidance), (2) dismissing (low anxiety, high avoidance), (3) preoccupied (high anxiety, low avoidance), and (4) fearful (high anxiety, high avoidance). Research suggests that individuals with high attachment anxiety, regardless of their level of attachment avoidance, experience greater intensity of grief during bereavement.[11]

Caregiving style may also be a risk factor for the development of complicated grief, especially among bereaved parents.[7] The concept of caregiving refers to the manner in which individuals attend and respond to a significant other's signals and needs.[12] Four caregiving dimensions have been described between romantic partners: (1) proximity versus distance, (2) sensitivity versus insensitivity, (3) cooperation versus control, and (4) compulsive caregiving. "Proximity versus distance" reflects the degree to which an individual provides a distressed partner with physical and psychological accessibility. "Sensitivity versus insensitivity" reflects the degree to which an individual notices and accurately interprets a partner's needs, feelings, and verbal and nonverbal signals. "Cooperation versus control" reflects the degree to which an individual supports his or her partner's own efforts and attempts to solve problems. "Compulsive caregiving" reflects the degree to which an individual tends to get over involved in his or her partner's problems. Individuals with a compulsive caregiving style may be at greater risk for adverse outcomes after a death. Experts suggest that attachment and caregiving styles are

interrelated and that both are shaped by the relationship a person experiences with his or her own parents during infancy.[8-12]

Deliberate grief avoidance may be a component of complicated grief and may put bereaved individuals at increased risk for poor long-term outcomes.[13,14] Deliberate grief avoidance may include avoidance of places and things that are reminders of the loss (i.e., place where the person died), avoidance of activities that are reminders of the loss (i.e., activities that the deceased frequently did or enjoyed), and avoidance of situations related to illness or death that ordinarily evoke sympathy (i.e., visiting ill people or going to funerals).[13] A recent study conducted with bereaved populations from the U.S. and the People's Republic of China (PRC) demonstrated that deliberate avoidance of thinking about, talking about, and expressing feelings about the deceased results in poorer perceived health among the bereaved in both countries and greater psychological distress among the U.S. population.[14]

Other personal, relational and situational factors may increase risk for complicated grief. Such potential risk factors may include the bereaved person's sex, race, education level, the trajectory of the death (i.e., sudden versus after chronic illness), violence-related death (i.e., homicide, suicide), the quality of the death (i.e., bereaved person's perceptions of suffering and duration of dying process), and the social supports perceived to be available or actually received after the death.[15-19] For parents, the number of remaining children may affect the development of complicated grief.[20] Most studies of complicated grief have been conducted in elderly widows and widowers, therefore risk factors among bereaved parents have been inadequately defined. Our *long-term goal* is to develop preventive interventions that can reduce adverse mental and physical health outcomes for parents whose child has died in the Pediatric Intensive Care Unit (PICU). To accomplish our long-term goal, we first need to describe the prevalence and risk factors for complicated grief in parents. This information will help us to identify parents most in need of preventive interventions and estimate the sample size required to test the effectiveness of such interventions.

Objective: To estimate the prevalence and describe risk factors for complicated grief in parents who have experienced the death of their child in the PICU.

Methods

Study design: A multicenter, prospective survey is planned.

Participants: Bereaved parents (i.e., biological parents and/or legal guardians) will be eligible for the study 6 months after their child's death in a PICU. All children will have died in a PICU that is part of the Collaborative Pediatric Critical Care Research Network (CPCCRN). One or both parents of the deceased child will be eligible to participate. Eligible parents must be English or Spanish speaking.

Participant identification: Each CPCCRN site will review its PICU logbook or electronic database on a monthly basis to identify children who died 6 months earlier. Medical records will be reviewed to retrieve parents' names, addresses, telephone numbers and primary language. This information will be used to recruit parents into the study (see participant recruitment, below). This process will be ongoing until the required sample size has been achieved (see sample size below). The HIPAA Privacy Rule allows covered entities that have pre-established clinical relationships with subjects (i.e., CPCCRN PIs) to use protected health information (i.e., medical records) for purposes preparatory to research such as to aid in subject recruitment (obtaining consent).[21]

Participant recruitment and data collection: Eligible parents will receive a letter and two identical sets of questionnaires in the mail (one for the mother and one for the father). The letter will explain to the parents that they are being asked to participate in a research study. The letter will contain the essential elements of informed consent and will serve as an information sheet. The letter will ask parents to complete the questionnaires and return them by mail to the site investigator. The site investigator's telephone number will be included in the letter and parents will be invited to call for more information.

Completed questionnaires will be returned to the site investigator using enclosed, addressed, stamped envelopes (one for the mother and one for the father). If the questionnaires are not returned within one month, the site investigator will contact the parents by telephone and ask whether either parent is willing to participate. If so, the parent will be given the option of completing and returning the questionnaires by mail, or completing the questionnaires verbally with the investigator by telephone. If the parent prefers to complete the questionnaires by telephone, they can be completed at that time, or at a later scheduled date. A thank-you card will be sent to the parent once the site investigator receives the completed questionnaires.

Consent: Consent is implied for parents who complete the questionnaires in writing and return them by mail to the site investigator. Consent may be implied because if a parent does not want to participate, he or she can simply discard the mailed questionnaires. Verbal consent will be obtained for parents who complete the questionnaires by telephone. Verbal consent will be documented by the investigator in the research record. Verbal consent will be obtained because the investigator will not be physically present with the parent, and a parent who does not want to participate can tell the investigator such when the investigator calls.

Survey instruments: Five survey instruments will be used: (1) The Inventory of Complicated Grief (ICG), (2) The Relationship Scales Questionnaire (RSQ), (3) The Caregiving Questionnaire (CG), (4) The Grief Avoidance Questionnaire (GAQ), and (5) The Social Support Questionnaire (SSQ) - Short Form. Parents will also provide brief demographic and clinical information.

The ICG is a 19-item self-report instrument assessing the extent of complicated grief.[22] Respondents report the frequency with which they currently experience the emotional, cognitive and behavioral states described in each item. Responses are reported on a 5-point scale ranging from "never" to "always." Item responses are summed to obtain a total scale score. The ICG takes 3-5 minutes to complete. The ICG has high internal consistency and test-retest reliability. For the total ICG scale, reported Cronbach's alpha is 0.94 and test-retest reliability correlation is 0.8. Validity has been assessed in relation to other scales measuring related constructs. ICG scores greater than or equal to 30 have been shown to be associated with impaired general health, mental health, physical health, social functioning and bodily pain measures. The ICG has been used in many studies that affirm its validity as a measure of complicated grief.

The RSQ is a 30-item self report measure of adult attachment style.[9,23] Using a 5-point scale, participants rate the extent to which each item best describes his or her characteristic style in close relationships. The RSQ was designed to obtain scores for each of four attachment patterns: (1) secure, (2) dismissing, (3) preoccupied, and (4) fearful. Alternatively, the RSQ can be used to obtain scores for the two underlying dimensions: (1) anxious attachment, and (2) avoidant attachment.[24] The psychometric properties of the RSQ have been described.[23] The

RSQ scores show good convergent validity when correlated with interview ratings of attachment style. The RSQ takes 5-8 minutes to complete.

The CQ is a 32-item self-report measure designed to assess four caregiving dimensions: (1) proximity versus distance, (2) sensitivity versus insensitivity, (3) cooperation versus control, and (4) compulsive caregiving.[12] Respondents indicate how well each item describes their feelings and behavior using a 6-point scale. Item responses are summed to obtain subscale and total scale scores. The CQ has high internal consistency and test-retest reliability. Cronbach's alphas for each of the four subscales are 0.83, 0.83, 0.87 and 0.80, respectively, and test-retest reliability correlations are 0.77, 0.78, 0.88 and 0.81, respectively. The CQ takes 5-8 minutes to complete.

The GAQ is a 7-item measure assessing three grief avoidance behaviors (i.e., avoidance of thinking about, talking about and expressing feelings about the deceased) in two contexts (with close family members and with close friends).[14] The avoidance of thinking about the deceased is also phrased for respondents being alone. Respondents report the frequency with which they had experienced each behavior during the past month. Responses are reported on a 5-point scale ranging from "almost never" to "almost constantly." Item responses are summed to obtain a total scale score. The GAQ has been used in bereaved populations from both the U.S. and People's Republic of China. The GAQ has shown high internal consistency with Cronbach's alphas of 0.83 (U.S.) and 0.94 (PRC). The GAQ takes 3 minutes to complete.

The SSQ-Short Form is a 6-item abbreviated version of the full scale 27-item Social Support Questionnaire.[25,26] The SSQ is designed to measure two components of social support: (1) the perceived availability of social supports, and (2) the degree of satisfaction with social supports. For each item, the respondent lists the people whom he or she can count on for help or support in the manner described, and ranks his or her degree of satisfaction with that support. Item responses are summed to obtain subscale scores (i.e., availability and satisfaction). The SSQ-Short Form has high internal consistency and test-retest reliability. Chronbach's alpha ranges from 0.9-0.93. The SSQ-Short form takes 3-5 minutes to complete.

Demographic information will be self-reported by the parent completing the questionnaires and will include the parent's age, sex, race, ethnicity, marital status, education, number of other living children, relationship to the deceased child (i.e., biological mother, biological father, other legal guardian), and the child's age at time of death, sex and cause of death.

Categories of non-participants: Based on previous research, we realize that there are many ways bereaved parents may refuse to participate and the importance of remaining sensitive to passive refusals.[27] Parents will be categorized as a "refusal to participate" if (1) the parent tells the investigator that he or she does not want to participate, (2) the parent agrees to complete the questionnaires and return them by mail but the investigator never receives them, or (3) the parent makes an appointment to complete the questionnaires by telephone but is unavailable at the time of the appointment without prior cancellation and without returning the investigator's call. Parents will be categorized as "unable to locate" if (1) the initial contact letter is returned and no forwarding address is available, and (2) the parent cannot be reached by telephone.

Data management: The Data Coordinating Center for the CPCCRN (University of Utah) supports a secure Web-based collaborative workspace called *eRoom™* to safely and securely collect, store, manage and distribute sensitive information between CPCCRN Clinical Centers and the Data Coordinating Center. The *eRoom™* facility is password secured and Internet communications are via 128-bit encrypted SSL connection. All CPCCRN investigators have

been trained in the use of *eRoom™*. This system is used to transfer large chunks of data such as computer files. TrialDB is a clinical trials database system developed at Yale University, and used by the Data Coordinating Center for all CPCCRN studies. This system is password secured and Internet communications are via 128-bit encrypted SSL connection. All CPCCRN investigators have been trained in the use of TrialDB, and have signed confidentiality agreements with the Data Coordinating Center. Data collected from parent questionnaires (without personal identifiers) will be entered electronically into TrialDB by site investigators.

Sample size estimation: As an initial step, we plan to estimate a single proportion of bereaved parents who have complicated grief (ICG score $\geq$30). If L denotes the margin of error within which we wish to estimate the proportion, the required sample size is given by $n = Z^2p(1-p)/L^2$, where Z is the standard error associated with a confidence interval (Z =1.96 at the 95% confidence interval).[28] According to previous studies, complicated grief was estimated to occur in about 20% (p) of bereaved persons.[6,7] We further assume that L = 0.05. Based on these parameters, the estimated sample size is 246. Provided that a sample size of this magnitude is used, there is a 95% probability that the estimate (20%) obtained will be within 0.05 of the population value.

As the next step, we plan to explore risk factors for complicated grief. Furukawa et al [29] reported that the mean of the Social Support Questionnaire (SSQ-Short Form) was 3.2 in psychiatric patients with a standard deviation (SD) of 1.96. In normal controls, the mean was 4.43 with a SD of 1.83. We used a sample size calculation developed by DuPont et al[30] to estimate the sample sized needed to test the difference of 1.23 (4.43-3.2) in population means with the power of 95% and type I error probability α = 0.05 (2-sided) and a ratio of subjects without complicated grief/subjects with complicated grief equal to 4 (20% with complicated grief). The estimated sample size is 195 (39 subjects with complicated grief and 156 subjects without). The sample size estimated in the initial step is large enough to test this difference (246 subjects, 20% of whom have complicated grief).

The means and SDs of the Relationship Scales Questionnaire (RSQ) in a population of bereaved subjects were reported to be 3.0$\pm$1.03 for the anxiety dimension and 3.79$\pm$0.72 for the avoidance dimension.[11] However, we could not find studies reporting means and SDs for the RSQ in bereaved subjects with and without complicated grief. Likewise, we could not find studies reporting means and SDs for the Caregiving Questionnaire (CG) or the Grief Avoidance Questionnaire (GAQ) for subjects with and without complicated grief. Therefore, the following operational method[30] was used to assure that the sample size of 246 was large enough to test a meaningful difference in population means. Given (1) the sample size of 246; (2) a ratio of subjects without complicated grief/subjects with complicated grief equal to 4; (3) a power of 95% and α=0.05 (2 sided), and (4) the assuming the range of the within group SD to be between 1.5-3, the sample size of 246 generates a power of 95% to detect a range of difference between 0.87-1.74 in the population means.

Statistical plan:
(1) Descriptive analysis: Descriptive statistics (i.e., distributions, frequencies, means, and proportions) will be performed to describe the study population. We will describe the distributions of demographics, attachment scores, caregiving scores, grief avoidance scores and social support scores in the two groups (subjects with and without complicated grief).

(2) Reliability analysis of psychometric measures: In an effort to assess scale validity, item structure of scales will be assessed using Cronbach's alpha and factor analysis and compared

to published scale psychometrics in similar or comparable populations. We will perform data analyses for reliability and potential factorial structures in SAS using *proc corr, factor and calis*.[31]

(3) Analysis of the associations between the risk factors and complicated grief: A binary analysis will be performed to test the difference of attachment scores, caregiving scores, grief avoidance scores, social support scores and other potential factors between the two groups (subjects with and without complicated grief), using a t-test or χ^2 test, depending on the nature of the variables. In order to control for other potential confounders, either multiple linear regression models for continuous dependent variables or multiple logistic regression models for binary or ordinal dependent variables will be used to estimate the associations between complicated grief and risk factors. Before modeling, we will check the assumptions relevant to these models including linearity, multicollinearity, outliers and normal distribution of the dependent variables. Normalization of dependent variables will be performed if needed. For the ordinal logistic regression analysis, if the common slope assumption of the cumulative logistic model with proportional odds is not reasonable, we will use *proc catmod* in SAS to fit a model with separate slope parameters.[32]

Potential for parent follow-up: Parents who complete the questionnaires will be asked to indicate whether or not they are willing for the investigators to contact them for research participation in the future. This will be the last question included in the questionnaire set. If the parent agrees to future contact by the investigators for research participation, the parent will be sent the ICG and GAQ questionnaires at 18 months after his or her child's death. The questions regarding demographic and clinical information and the RSQ, CG and SSQ will not be included in the follow-up questionnaires. The same consent process will be used for the follow-up questionnaires. This will allow us to evaluate change in complicated grief symptoms and risk factors over time in a subgroup of parents without unnecessarily contacting those who do not want to participate further.

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Inventory of Complicated Grief

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

	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 can't 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 he/she died it is hard for me to trust people…	0	1	2	3	4
(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...	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 he/she died…	0	1	2	3	4

Relationship Scales Questionnaire

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

	Not at all like me		Somewhat like me		Very much like me
(1) I find it difficult to depend on other people.	1	2	3	4	5
(2) It is very important to me to feel independent.	1	2	3	4	5
(3) I find it easy to get emotionally close to others.	1	2	3	4	5
(4) I want to merge completely with another person.	1	2	3	4	5
(5) I worry that I will be hurt if I allow myself to become too close to others.	1	2	3	4	5
(6) I am comfortable without close emotional relationships.	1	2	3	4	5
(7) I am not sure that I can always depend on others to be there when I need them.	1	2	3	4	5
(8) I want to be completely emotionally intimate with others.	1	2	3	4	5
(9) I worry about being alone.	1	2	3	4	5
(10) I am comfortable depending on other people.	1	2	3	4	5
(11) I often worry that romantic partners don't really love me.	1	2	3	4	5
(12) I find it difficult to trust others completely.	1	2	3	4	5
(13) I worry about others getting too close to me.	1	2	3	4	5
(14) I want emotionally close relationships.	1	2	3	4	5
(15) I am comfortable having other people depend on me.	1	2	3	4	5
(16) I worry that others don't value me as much as I value them.	1	2	3	4	5

	Not at all like me		Somewhat like me		Very much like me
(17) People are never there when you need them.	1	2	3	4	5
(18) My desire to merge completely sometimes scares people away.	1	2	3	4	5
(19) It is very important to me to feel self-sufficient.	1	2	3	4	5
(20) I am nervous when anyone gets too close to me.	1	2	3	4	5
(21) I often worry that romantic partners won't want to stay with me.	1	2	3	4	5
(22) I prefer not to have other people depend on me.	1	2	3	4	5
(23) I worry about being abandoned.	1	2	3	4	5
(24) I am somewhat uncomfortable being close to others.	1	2	3	4	5
(25) I find that others are reluctant to get as close as I would like.	1	2	3	4	5
(26) I prefer not to depend on others.	1	2	3	4	5
(27) I know that others will be there when I need them.	1	2	3	4	5
(28) I worry about having others not accept me.	1	2	3	4	5
(29) Romantic partners often want me to be closer than I feel comfortable being.	1	2	3	4	5
(30) I find it relatively easy to get close to others.	1	2	3	4	5

The Caregiving Questionnaire

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

	Not at all descriptive of me					Very descriptive of me
(1) I sometimes push my partner away when s/he reaches out for a needed hug or kiss.	1	2	3	4	5	6
(2) I can always tell when my partner needs comforting, even when s/he doesn't ask for it.	1	2	3	4	5	6
(3) I always respect my partner's ability to make his/her own decisions and solve his/her own problems.	1	2	3	4	5	6
(4) When my partner cries or is distressed, my first impulse is to hold or touch him/her.	1	2	3	4	5	6
(5) I help my partner without becoming overinvolved in his/her problems.	1	2	3	4	5	6
(6) Too often, I don't realize when my partner is upset or worried about something.	1	2	3	4	5	6
(7) When my partner is troubled or upset, I move closer to provide support and comfort.	1	2	3	4	5	6
(8) I'm good at knowing when my partner needs my help or support and when s/he would rather handle things alone.	1	2	3	4	5	6
(9) I feel comfortable holding my partner when s/he needs physical signs of support and reassurance.	1	2	3	4	5	6
(10) I'm not very good at 'tuning in' to my partner's needs and feelings.	1	2	3	4	5	6
(11) I tend to get overinvolved in my partner's problems and difficulties.	1	2	3	4	5	6
(12) I don't like it when my partner is needy and clings to me.	1	2	3	4	5	6
(13) I often end up telling my partner what to do when s/he is trying to make a decision.	1	2	3	4	5	6

	Not at all descriptive of me					Very descriptive of me
(14) I sometimes miss the subtle signs that show how my partner is feeling.	1	2	3	4	5	6
(15) When necessary I can say ‘no’ to my partner’s requests for help without feeling guilty.	1	2	3	4	5	6
(16) I tend to be too domineering when trying to help my partner.	1	2	3	4	5	6
(17) When it’s important, I take care of my own needs before I try to take care of my partner’s.	1	2	3	4	5	6
(18) I am very attentive to my partner’s nonverbal signals for help and support.	1	2	3	4	5	6
(19) I can easily keep myself from becoming overly concerned about or overly protective of my partner.	1	2	3	4	5	6
(20) I’m very good about recognizing my partner’s needs and feelings, even when they’re different from my own.	1	2	3	4	5	6
(21) I can help my partner work out his/her problems without ‘taking control’.	1	2	3	4	5	6
(22) I sometimes draw away from my partner’s attempts to get a reassuring hug from me.	1	2	3	4	5	6
(23) I am always supportive of my partner’s *own efforts* to solve his/her problems.	1	2	3	4	5	6
(24) I tend to take on my partner’s problems – and then feel burdened by them.	1	2	3	4	5	6
(25) When my partner seems to want or need a hug, I’m glad to provide it.	1	2	3	4	5	6
(26) When I help my partner with something, I tend to want to do things ‘my way’.	1	2	3	4	5	6
(27) I frequently get too “wrapped up” in my partner’s problems and needs.	1	2	3	4	5	6
(28) I sometimes ‘miss’ or ‘misread’ my partner’s signals for help and understanding.	1	2	3	4	5	6

	Not at all descriptive of me					Very descriptive of me
(29) When my partner is crying or emotionally upset, I sometimes feel like withdrawing.	1	2	3	4	5	6
(30) When my partner tells me about a problem, I sometimes go too far in criticizing his/her own attempts to deal with it.	1	2	3	4	5	6
(31) I create problems by taking on my partner's troubles as if they were my own.	1	2	3	4	5	6
(32) When helping my partner solve a problem, I am much more 'cooperative' than 'controlling'.	1	2	3	4	5	6

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 circle one number for each question.

When you were with close family members during the past month, how often did you...	almost never	sometimes	moderately often	very often	almost constantly
(1)...avoid thinking about your deceased child?	1	2	3	4	5
(2)...avoid talking about your deceased child?	1	2	3	4	5
(3)...avoid showing your feelings about your deceased child?	1	2	3	4	5

When you were with close friends during the past month, how often did you...	almost never	sometimes	moderately often	very often	almost constantly
(4)...avoid thinking about your deceased child?	1	2	3	4	5
(5)...avoid talking about your deceased child?	1	2	3	4	5
(6)...avoid showing your feelings about your deceased child?	1	2	3	4	5

When you were alone during the past month, how often did you...	almost never	sometimes	moderately often	very often	almost constantly
(7)...avoid thinking about your deceased child?	1	2	3	4	5

The Social Support Questionnaire (Short Form)

The following questions ask about people in your environment who provide you with help or 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 you can. All your responses will be kept confidential.

Example:

Who do you know whom you can trust with information that could get you in trouble?

No One	1) T.N. (brother)	4) T.N. (father)	7)
	2) L.M. (friend)	5) L.M. (employer)	8)
	3) R.S. (friend)	6)	9)

How satisfied?

6- very satisfied	5- fairly satisfied	(4- a little satisfied)	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

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

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

1b. How satisfied?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

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

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

2b. How satisfied?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

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

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

3b. How satisfied?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

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

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

4b. How satisfied?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

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

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

5b. How satisfied?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

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

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

6b. How satisfied?

6- very satisfied	5- fairly satisfied	4- a little satisfied	3- a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

Parent Information

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

1. How old are you? _____ years

2. What is your gender?
    a. Male
    b. Female

3. What race describes you best?
    a. Black or African American
    b. White or Caucasian
    c. American Indian/ Alaskan Native
    d. Asian
    e. Native Hawaiian or Other Pacific Islander

4. What ethnicity describes you best?
    a. Hispanic
    b. Non-Hispanic

5. What is your marital status?
    a. Married
    b. Widowed
    c. Separated
    d. Divorced
    e. Never married
    f. Other
        i. If other, please describe:_____

6. What is the highest education you received?
    a. None at all
    b. Elementary school
    c. High school
    d. Apprenticeship or vocational training
    e. Some college or junior college
    f. College Degree
    g. Postgraduate degree
    h. Other
        i. If other, please describe:_____

7. What best describes your relationship to the child that died?
    a. Biological mother
    b. Biological father
    c. Other
        i. If other, please describe:_____

8. How many other children do you have besides the child that died?
    a. None
    b. One
    c. Two
    d. Three or more

Child Information

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

1. What was the gender of your child that died?
   a. Male
   b. Female

2. How old was your child at the time of his or her death? _____ days/ months / years
   (please circle one)

3. What was the cause of your child's death? _____

May we contact you again for research participation in the future? (If you respond yes to this question, we will send you the same set of questionnaires to complete again approximately one year from now).

a. Yes
b. No