

Childhood Cancer Survivor Study Concept Analysis Form

Study Title: Social Adjustment in Adolescent Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study

Working Group and Investigators: Psychosocial Working Group

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Background and Rationale:

The increasing success of therapies to treat childhood cancer and the growing number of adolescent and adult survivors of childhood cancer, necessitates assessment of the issues faced by survivors and development of strategies to minimize the long-term morbidity of cancer and cancer treatment.

The issues faced by adolescents following cancer treatment may be different both in terms of chronology and in the way that cancer survivorship interfaces with the usual transitions of the adolescent period. Age at diagnosis, length of survivorship, and current age and life transitions may all affect the social adjustment of childhood cancer survivors. Physical limitations and the time requirements of cancer therapy and follow-up visits may result in less time spent socializing with friends and participating in school activities or other social activities. This, rather than poor social skills and functioning, may be the underlying etiology of fewer friendship nominations among survivors of more intense chemotherapeutic interventions.

Several studies have focused on the social adjustment of school age children during and immediately following cancer treatment. Reiter-Purtill et al¹ assessed social adjustment in children following completion of cancer treatment. Survivors had a mean age of 13.48 years (range 9-17 years) and were studied an average of 39.8 months after diagnosis and 16.7 months after completion of treatment. They found no significant differences in survivors' social reputation from the perspective of peers. Survivors cast themselves in the "prosocial" role more often than controls. No significant differences in measures of social acceptance were noted. "Children who were treated on more intense protocols were perceived by peers as more social and less aggressive, but as having fewer best friends two years later."

¹ Reiter-Purtill J, Vannatta K, Gerhardt CA, Correll J, Noll RB. A controlled longitudinal study of the social functioning of children who completed treatment of cancer. Journal of Pediatric Hematology/Oncology. 25(6) 2003 467-473

The Child Behavior Checklist ²(CBCL) is a widely used rating scale to measure symptoms of various behavioral and emotional problems. Symptoms are assessed in a variety of areas including somatic complaints, attention problems, anxious/depressed behaviors, social problems and aggressive/delinquent behaviors. These areas are analyzed to assess overall levels of internalizing and externalizing problems. In contrast to rationally-derived scales of behavior, the CBCL was developed empirically.³ The CBCL/4-18 is designed to be completed by parents of children ages 4 to 18 and includes competence items and problems. Parallel standardized forms are available to be filled out by youths and teachers.⁴ In the parent-completed measure, items are rated on a scale of 0-2 (often true, sometimes true, not true) representing the child's behavior over the past 6 months.⁵

A subset of questions from the Child Behavior Checklist (CBCL) as well as some additional questions was asked of parents on the Baseline questionnaire. Utilizing these data, this proposed analysis will examine social adjustment in adolescence, in the years between school age and young adulthood to determine how social adjustment is affected during these critical transitional years. We also hope to better understand the social skills with which teenagers leave adolescence and transition to adulthood.

Specific Aims/Objectives:

- I. To evaluate the social adjustment of teen survivors of childhood cancer through five domains comprised of questions from the CBCL.
- II. To compare the calculated social adjustment scores within subgroups of survivor teens.
- III. To compare the calculated social adjustment scores between teen survivor and teen siblings.

Hypotheses:

- 1. Survivors will be more likely than siblings to exhibit symptoms (behaviors) that indicate limitations across five domains of social adjustment than will siblings.
- 2. Survivors will be noted to have fewer activities with close friends per week
- 3. Survivors of brain tumors will exhibit lower levels of social adjustment compared with survivors of other childhood cancers.
- 4. Survivors who receive cranial radiation will exhibit lower levels of social adjustment compared with survivors without cranial radiation.

² Achenbach, T.M. (1991). Manual for the Child Behavior Checklist/4-18 and 1991 Profile. Burlington: University of Vermont, Department of Psychiatry.

³ Lengua LJ, Sadowski CA, Friedrich WN, Fischer J. Rationally and empirically derived dimensions of children's symptomatology: Expert ratings and confirmatory factor analyses of the CBCL. Journal of Consulting and Clinical Psychology. 69(4); 2001. 683-698

⁴ Achenbach TM, Ruffle TM. The child behavior checklist and related forms for assessing behavioral/emotional problems and competencies. Pediatrics in Review. 21(1);2000. 265-271

⁵ Hart EL, Lahey BB. General Child Behavior Rating Scales. in Shaffer D (Ed); Lucas CP (Ed); et al. (1999) Diagnostic Assessment in Child and Adolescent Psychopathology, xviii, 398pp

Analysis Framework:

For this analysis, data from variables in Section J (questions 16-21) of the < 18 baseline questionnaire will be used. Social adjustment of the 8-17 year olds will be evaluated based on five separate domains of social adjustment and a global social adjustment score.

Principle component analysis will be performed on the 28 social adjustment questions (questions J.19-J.22) answered by the parents who completed the baseline survey for cases and siblings less than age 18. Questions were a subset of the questions on the Child Behavior Checklist (CBCL) (Achenbach), and additional questions from other sources.

The answers to each question on a scale will be summed in this analysis to create a total score for that scale. Standardized sums from each of the five domains will be weighted by their correlation with the total and added to determine the global social adjustment score for each participant or sibling. The mean values of each of the social adjustment domains and the global social adjustment score will be compared between subgroups of survivors, and with siblings. Analysis will be adjusted for age, sex and other potential confounders.

Social competence will be evaluated in a similar manner, by scoring the answers to questions J.16-J.18.

- (a) Outcome of interest: Composite scores from 5 domains: Depression, Social Deviance, Attention Problems, Interpersonal Problems, Behavior Problems, and a Total score using the questions from the CBCL. A Social Competence score will also be calculated using questions asked, that are not from the CBCL.
- (b) Study subjects: Cases and siblings who were alive and < 18 years of age at the time of the baseline questionnaire which was completed by a parent. (Questionnaires completed by a proxy other than a parent will be deleted from this analysis.)
- (c) Possible explanatory variables: sex, race/ethnicity, age at interview, age at diagnosis, diagnosis, treatment (chemotherapy Y/N, radiation Y/N, cranial radiation Y/N), use of anti-depressants or other mood disorders drugs, scarring/disfigurement (question B.9), presence of other major medical condition (previously created for psychosocial analysis) Y/N.
- (d) Examples of specific tables: Table 1 shows the number of cases and siblings eligible for this analysis.

Table 1. Characteristics of the study participants

| | | cipants :3451) | Siblings (N=813) | | | |
|-----------------------------|------|-------------------|---------------------|---------|--|--|
| | N | (%) | N | (%) | | |
| Sex | | | | , , | | |
| Female | 1640 | (47.52) | 395 | (48.59) | | |
| Male | 1811 | (52.48) | 418 | (51.41) | | |
| Race/Ethnicity | | | | | | |
| White | 2895 | (83.89) | 674 | (82.90) | | |
| Black | 212 | (6.14) | 31 | (3.81) | | |
| Hispanic | 184 | (5.33) | 40 | (4.92) | | |
| Other . | 160 | (4.64) | 68 | (8.36) | | |
| Age at interview | | . , | | ` , | | |
| <12 years | 472 | (13.68) | 164 | (20.17) | | |
| 12-14 years | 1270 | (36.80) | 268 | (32.96) | | |
| 15-17 years | 1709 | (49.52) | 381 | (46.86) | | |
| Age at diagnosis | | , | | , | | |
| <2 years | 1201 | (34.80) | NA | NA | | |
| 2-4 years | 1716 | (49.72) | NA | NA | | |
| 5-9 years | 534 | (15.47) | NA | NA | | |
| Diagnosis | | , | | | | |
| Leukemia | | | , | | | |
| CNS | | | | | | |
| HD | | | | | | |
| HNL | | | | | | |
| Wilms' tumor | | | | | | |
| Neuroblastoma | | | | | | |
| Soft tissue sarcoma | | | | | | |
| Bone cancer | | | | | | |
| Treatment | | | | | | |
| Surgery only | | | | | | |
| Chemotherapy | | | | | | |
| Radiation | | | | | | |
| Chemotherapy & radiation | | | | | | |
| Cranial radiation | | | | | | |
| Yes | | | | | | |
| No | | | | | | |
| Medication (Antidepressant) | | | | | | |
| Yes | | | | | | |
| No | | | | | | |
| Unknown | | | | | | |
| Disfigurement | | | | | | |

Head/Neck/Scalp/Eye

Limb

Chest or Abdomen

| Other major medical condition | |
|-------------------------------|--|
| Yes | |
| No | |

Table 2. Means and standard deviations for each of five social domains and total social adjustment score, comparing participants to siblings

| | Depression | | Social Deviance | | Attention Problems | | | | Behavior Problems | | Total | | Social Competence | |
|------------------|------------|----|--------------------|--|-----------------------|----------|----------|---------|----------------------|----|-------|--|----------------------|----|
| | Mean | SD | Mean | SD | | SD | Mean | | Mean | SD | Mean | SD | | SD |
| PARTICIPANTS | | | | | | | | | | | | | | |
| Sex | | | | 1 | | | | | | | | | | |
| Female | | | | † | | | | ļ | | | | | | |
| Male | | | | | | | | | | | | | | |
| Race/Ethnicity | | | | † | | | | | | | . • | | | |
| White | | | | | | | | | | | | | | |
| Black | | | | † | | | | | - | | | | | |
| Hispanic | | | | | | | | | | | | | | |
| Other | <u> </u> | | | | | | | | | | | - | | |
| Age at interview | | | | | | | | | | | | | | |
| <12 years | | 1 | | | | | | | | | | | | |
| 12-14 years | | | | | | | | | | | | | | |
| 15-17 years | | | | | | | | | | | | | | |
| Total | | | | | | | | | | | | | | |
| SIBLINGS | | | | | | | | | | | | | | |
| Sex | | 1 | | | | | | | | | | | | |
| Female | | | | | | | | | | | | | | |
| Male | | ļ | | | | | | | | | | | | |
| Race/Ethnicity | | | | | | | | | | | | | | |
| White | | | | | | | | | | | | | | |
| Black | | | | | 1 | | | | | | | | | |
| Hispanic | | | | | | | | | | | | | | |
| Other | | | | | | | | | | | | | | |
| Age at interview | | | | 1 | | | | | | | | | | |
| <12 years | | | | | <u> </u> | | <u> </u> | | | | | | | |
| 12-14 years | | | | | | | | | | | | - | | |
| 15-17 years | | | | | | | | | | | | | | |
| Total | | | | | | | | | | | | | | |

Special Consideration:

This project will fulfill scholarly requirements for pediatric residency completion at the University of Minnesota for Kris Ann Schultz. Ann Mertens and Lonnie Zeltzer will oversee the manuscript development. Kiri Ness will perform the analysis at the University of Minnesota, with oversight from John Whitton and the Statistical Center.