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# **Psychological/Neuropsychological Working Group**

## **CCSS Meeting**

### **June 2008**

## Psych/Neuropsych WG: previous topics

- Development and Validation of the CCSS-NCQ and the BSI-18 in a survivors/sibling sample
- Psych outcomes within leukemia/lymphoma, solid tumor, and brain tumor groups
- QOL in survivors of Neuroblast/Wilms; survivors of lower extremity bone tumors
- Overall psych, HRQOL, and Life Satisfaction in survivors vs sibs; risk factors within survivors

## Psych/Neuropsych WG: previous topics

- Sleep and fatigue in survivors/siblings
- Social Adjustment in adolescent survivors
- Impact of limitations in physical, executive and emotional function on HRQOL
- CAM use in survivors vs sibs
- Characterization of drinking patterns in survivors

## Results of 3 major papers:

- 1. Development and Validation of the BSI-18 in a survivors/sibling sample**
- 2. Development and Validation of the CCSS-NCQ**
- 3. Overall psych, HRQOL, and Life Satisfaction in survivors vs sibs; risk factors within survivors**

# Factor Structure of the Brief Symptom Inventory-18 (BSI-18)

- The BSI-18 is a new measure popular in oncology but with limited validation
- Confirmatory factor analysis validated the BSI-18 scales in adult survivors of pediatric cancer
- Standardized approach to the analysis of mental health items included in CCSS

# CCSS-Neurocognitive Questionnaire

- Four factors representing broad neurocognitive functions, including:
  - Task Efficiency, Emotional Regulation, Organization, Memory
- Good internal consistency and agreement with established measures (BPI, BSI)
- Sensitivity w factor scores good for two factors.
- Sensitivity using frequency of maximum rating (i.e. “Often a Problem”) good for all four factors.
- Specificity still to be determined.

# Psych Outcomes & HRQOL

- **Psych** (BSI-18), **HRQOL** (SF-36), **life satisfaction** (Cantril LOL)
  - 7,147 survivors & 388 siblings
- **Global Distress:**
  - Survivors (49.17 ±.12) > Sibs (46.64±.51);  
but distress in both < popul norms:  
**surv/sibs psych healthy**
- **Physical Health:**
  - Surv<Sibs 51.3 vs 55.0; P<0.001
- **Emotional Health:** Surv < Sibs;
  - small effect sizes, other than in vitality

# Psych Outcomes & HRQOL

- **Life Satisfaction:**
  - Survivors positive LS in present ( $7.3 \pm .02$ ) & future ( $8.6 \pm .02$ )
- **Risk Factors for psychol distress & poor HRQOL**
  - Female gender, low education, unmarried, low SES, unemployed, no med insurance, major med cond, RX cranial radiation.
- **Surv/Sibs good psych health, HRQOL, Life Satisfaction**
- **Targeted surv subgroups for intervention**



## Psych/Neuropsych WG: under discussion

- Buchbinder: Psychosocial, HRQOL, Health behavior outcomes in Siblings vs population norms
- Okcu: free radical scavenging polymorph & NCQ
- Ellenberg: Cognitive Outcomes in brain tumor survivors
- Lu: Pain Outcomes in survivors vs siblings
- Lu: Longitudinal analysis of predictors of pain in survivors: dx, Rx, demo, psych, PTS

## Psych/Neuropsych WG: under discussion

- Kadan-Lottick: Cognitive outcomes in leukemia survivors: treatment effects
- Stuber: Predictors of PTS in survivors
- Zebrack: Predictors of PTG in survivors
- Stuber/Zebrack: Relationship between PTS and PTG: implications for resiliency
- Bornstein: Mental retardation/learning disability in survivors of cancer diagnosed during infancy
- Recklitis: Suicide ideation after childhood cancer

## Psych/Neuropsych WG: Gaps

- Interventions for targeted subgroups of survivors at risk for pain, suicide ideation, psychological distress, poor HRQOL
- Relationship between genetics and behavior (polymorphisms associated with pain, psych distress, cognitive outcomes)
- Pathways of outcomes related to maladaptive behaviors, psychological distress, pain, and poor HRQOL
- Pathways to resilience

## Analysis concepts: Existing data

- Status of survivors whose questionnaires have been completed by proxy
- Symptom clusters
- Predictors of maladaptive health risk behaviors
- Role of child development in psychological, cognitive, and health behavior outcomes

## Analysis concepts: Future data

- Psychological distress, HRQOL, and life satisfaction in the new cohort
- Pain and symptom clusters in the new cohort: predictors and pathways
- Newer treatments for brain tumors: cognitive and functional outcomes

## Ancillary Studies

### Non-intervention research

- **Assessment of cognitive function, emotional regulation, and physical function in low grade astrocytomas**
- **Association between polymorphisms related to increased pain in cancer populations (e.g. COMT) and to increased stress and pain, psychological, and HRQOL outcomes**

## **Ancillary Studies**

### Intervention research

- **Interventions targeted at subgroups with pain, high psychological distress, poor HRQOL, suicidal ideation**
- **Enhancing self-advocacy for seeking help for above**
- **Benefit-finding in survivors**

## Ancillary Studies

### Intervention research

- Pilot the development of a telephoned intervention that could help survivors with emotional distress gain better medical and psychosocial care
- Validation study of the BSI-18 as a screening tool compared to psychiatric diagnostic interview administered by phone.



# **Psychological/Neuropsychological Working Group RFA's**

- **Targeted evaluations and interventions for subgroups of survivors with cognitive deficits and neurologic/chronic health condition co-morbidities; including identification of the subgroup who still have proxy informers (novel proxy interventions)**

# **Psychological/Neuropsychological Working Group RFA's**

- **Interventions using newer technology (internet and/or cell phones) targeting subgroups of survivors with the greatest psychological distress and poor HRQOL morbidity**

# **Psychological/Neuropsychological Working Group RFA's**

- **Plans for longitudinal studies that can take advantage of the multiple time points in the data to examine psychological and HRQOL outcomes.**
  - **For example, studies of how changes in chronic conditions are tied to changes in depression and anxiety**

# Understanding HRQOL and Well Being

## APPROACHES

**Working from the  
data downward  
and from direct  
contact with  
patients upward**



# THINK ABOUT HEALTH-PROMOTING INTERVENTIONS

