Cancer Control and Intervention Working Group

A Report from the Childhood Cancer Survivor Study

Paul Nathan, on behalf of the working group

CCSS
Childhood Cancer Survivor Study

St. Jude Children's Research Hospital

An NCI-funded Resource

Working Group Membership

CCSS

- Paul Nathan
- Kevin Oeffinger
- Tara Henderson
- Jennifer Ford
- Wendy Leisenring
- Kiri Ness
- Melissa Hudson
- Anne Kirchhoff
- Jackie Casillas

Working Group Progress

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14 Published/In Press Manuscripts (since Investigator Meeting, 6/2017)

3 Currently Submitted Manuscripts

2 Analysis/Manuscript in Process

8 Concepts in development

13 New AOIs

Highlights of Recently Completed Research

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- Effinger: Long-term health and social function in adult survivors of pediatric astrocytoma (EJC)
  - In 1182 astrocytoma survivors, elevated rates of poor general and mental health, functional impairment and activity limitations.
  - Less likely to marry, be employed or graduate college
  - Even non-radiated survivors at elevated risk for chronic conditions, poor health status and poor social outcomes

Highlights of Recently Completed Research

CCSS

- Gini, Hodgson: Cost Effectiveness of Colonoscopy-based Colorectal Cancer Screening in Childhood Cancer Survivors (JNCI)
  - Modified an established CRC screening model for CCS
  - Evaluated 91 colonoscopy screening strategies
  - Optimal strategy in those treated with abdominal/pelvic radiation was 10-yearly colonoscopy starting at age 35 (ICER $92K/life year gained) → 82% of CRC mortality prevented

Highlights of Recently Completed Research

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- Scott: Association of Exercise with Mortality in Adult Survivors of Childhood Cancer (JAMA Oncol)
  - At 15 years, cumulative all-cause mortality was 11.7% for those who exercised 0 MET-h/wk vs. 8.0% for 15 to 21 MET-h/wk
  - Increased exercise over an 8-year period was associated with a 40% reduction in all-cause mortality rate compared with maintenance of low exercise

Highlights of Recently Completed Research

CCSS

- Yan: Adherence to surveillance for second malignant neoplasms and cardiac dysfunction in childhood cancer survivors (submitted Lancet Onc)
  - Despite efforts (care plans, education), adherence to surveillance is poor
  - Breast (12.2%); CRC (37.5%); skin (22.4%); cardiac (41.5%)
  - Survivor receipt of care plan (26.9%) impacts breast, skin and cardiac screening
  - PCP receipt of a care plan (19.8%) only impacts skin cancer screening

Intervention Studies

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Prior studies:

- Smoking cessation (Emmons): JCO (2005); JCO (2009)
- Tobacco quit line (Klesges): Nicotine & Tobacco Research (2015)
- ECHOS (Hudson): JCO (2014)
- EMPOWER (Oeffinger): JCO (In press)
- ASK (Geller): Trials (2015); J Invest Dermatol (2019)

Intervention Studies

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In progress:

- EQUAL (Tonorezos)
- CHIIP (Chow)
- EMPOWER2 (Oeffinger)
- Health Insurance Navigation Program (Park)
- Shut-I (Brinkman)
- EASE - pain (Alberts)

Intervention Studies

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Submitted for funding:

- Telegenetics (Henderson)
- Reproductive health education (Su)
- ECHOS2 (Ehrhardt)

Pipeline:

- CRC surveillance (Henderson/Nathan)
- PRO on mobile platform (I-Chan Huang)
- ASK2 (Geller)
- Physical activity (Ness/Gibson)

Financial toxicity data

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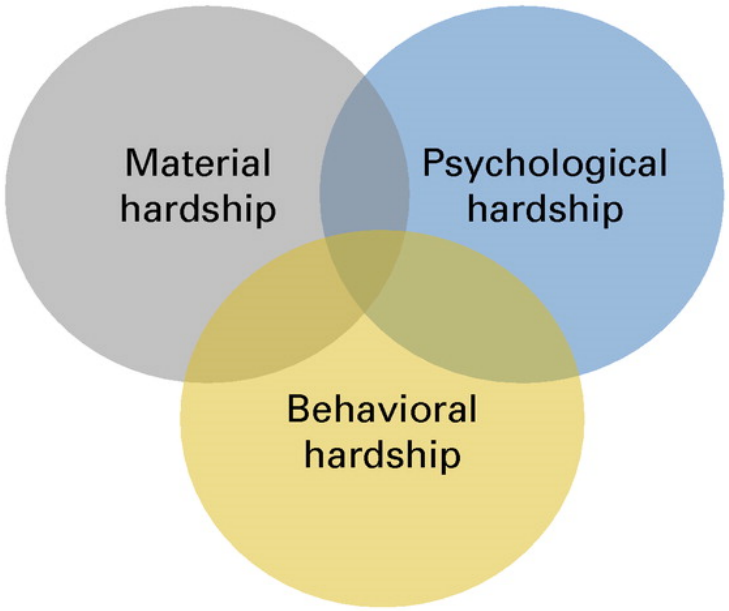

Material Hardship

High out-of-pocket medical costs that impact household income and assets
Inability to pay for medical care or deferral of needed care or testing
Asset depletion, general/medical debt, or declaration of bankruptcy
Housing and food insecurity
Inability to actively engage in productive work for pay as a result of the lasting effects of cancer that lead to unemployment or underemployment
Job lock, or the inability of individuals to freely engage in extra work activities to earn a promotion, reduce work hours to attend to household needs, or leave a job to pursue other activities because doing so will result in the loss of employee benefits, most notably health insurance

Psychological Hardship

Elevated stress, distress, or worry about current/future financial situation

Behavioral Hardship

A delaying or forgoing of medical care because of costs
Nonadherence to medications, as prescribed, including skipping medication doses, taking less medication, or not filling a prescription because of cost

Nathan et al. JCO (2018)

Financial toxicity

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- Household income
- Home ownership → value, mortgages and loans
- Debts (credit card, car loans, medical debts etc.)
- Collections and bankruptcy
- Work
  - Time off
  - Change to less demanding job or schedule
  - Avoided promotion
  - Job lock

Financial toxicity

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- Health insurance
- Medical bills
  - Unable/difficulty paying
  - Paying off over time
- Avoided medical care due to cost
- Financial sacrifices due to medical debt (e.g. reduced spending on basics or luxury goods, made a change to living arrangement)
- Out of pocket medical expenses
- Worry about being able to pay bills if get sick

Five Year Plan: Progress Update

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- Study whether survivors treated on contemporary protocols in more recent eras are less likely to experience adverse health status and social outcomes than those treated in prior eras
- Explore whether survivors treated in more recent eras adhere more closely to recommended risk-based medical care and surveillance
- Translate previous findings into interventions aimed at reducing risk and increasing compliance with guideline-based surveillance and care
- Use of mHealth technology … will determine whether behavior change is associated with improvements in objective measures of health outcomes
- Develop and validate other risk prediction models…focusing on pulmonary dysfunction, premature menopause, and neurocognitive dysfunction

Discussion: Opportunities and Threats

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Major Threat or Challenge:

- Saturation of health status studies
- Intervention studies:
  - Participant fatigue
  - Cross contamination of interventions studies
  - Finite resource
  - Sustainable external funding

Major Opportunity:

- Eureka
- Interventions beyond behavior change: exercise, medication etc.
- Moving beyond CCSS…dissemination and implementation in survivors outside of cohort

Current Top Priorities

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- Continued development, funding and launch of intervention studies - leveraging Eureka platform when appropriate

- Financial toxicity: awaiting data from f/u #6

Future Top Priorities

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- Transition from observation to intervention
  - Have a constantly rotating set of intervention studies using Eureka (or other platforms)
  - Remote measurement technology

- Implementation and sustainability
  - >450,000 survivors are not in CCSS
  - How can we scale successful intervention studies to the broader world of survivors?

Immediate Opportunities for Investigators

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- Financial toxicity

- Intervention studies
  - Collaborate with external experts
  - Will need external funding
  - Incorporate implementation science → spread and scale