Psychosocial Issues in Pediatric Cancer

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Psychosocial Impact of Cancer Diagnosis

Immediate
- Emotional
  - Grief, fear, anger in parents, child, extended family, friends
- Practical
  - Management of other responsibilities (jobs, sports teams, church/PTA/etc.)
- Financial
  - One parent often stops working due to treatment demands
  - Medical bills, medication co-pays
- Lifestyle changes
  - Patient misses school, isolated from friends, changes in appearance
  - Adjustment to medical processes/procedures and hospitalization
  - Disruptions in daily routine/schedule

Long-term
- Worry about physical effects of cancer treatment
  - Risk secondary malignancies, cardiovascular toxicity, organ impairment
- Risks of infertility
  - Sperm banking feasible for many males
  - Preservation options for females - less affordable, often not feasible
- Emotional problems
  - PTS symptoms can develop for patients and/or parents
  - Brain tumor patients at greater risk for social difficulties, academic problems, mood disturbances
  - AYA’s with cancer (compared to peers) - less likely to marry, have children, have medical insurance, or be employed full-time

Psychosocial Impact of Cancer Diagnosis

Neurocognitive Late Effects in Pediatric Cancer

Neurocognitive deficits (long-term)
- >40% of pediatric cancer survivors show impairment
  - Children with brain tumors and leukemia at greatest risk
- Other risk factors
  - Tumor type/location (e.g. medulloblastoma, craniopharyngioma)
  - Treatment regimen
    - Cranial radiation
    - Intrathecal chemotherapy
  - Younger age at diagnosis
  - Female sex (mixed results in literature)

Neurocognitive Late Effects in Pediatric Cancer

- Domains most likely affected
  - Global intellectual functioning (full scale IQ)
  - Attention and working memory
  - Processing speed
  - Executive functioning – set of skills related to planning/organization, time management, flexible thinking
  - Historically difficult to collect data in large, multi-site studies (i.e. clinical trials)
- But... Ability to track functioning of patients over time may help us determine when deficits begin to emerge and whether early intervention can prevent or ameliorate these tx-related effects

Clinical Research: Neurocognitive Late Effects

- Embry – Chair of COG protocol ALT07C1
  - Developed to streamline and standardize efforts to collect neurocognitive outcomes data across clinical trials within COG
  - Abbreviated assessment battery
    - Requires 1 - 2 hours administration time with child
    - Parent-report questionnaires
    - Administered at 3 discrete time points: 9, 30, & 60 months post-dx
  - Assesses domains known to be most affected by cancer therapy
    - Companion study for 7 separate clinical trials (medulloblastoma, ependymoma, CNS germ cell tumors, ALL, AML)
  - Currently 713 patients enrolled across 165 COG institutions
Clinical Research: Neurocognitive Late Effects

- COG protocol ALTE07C1
  - At the cooperative group level - Outcomes used in development of next generation of clinical trials
    - e.g., survival rates are similar between treatment arms but neurocognitive decline is greater for one treatment vs another
  - At the patient level - Outcomes used to advocate for appropriate educational services
  - Implications of neurocognitive impairment:
    - Need for special education services
    - Problems seeking and completing college education
    - Potentially limits employment opportunities

Hem/Onc Psychosocial Services - What do we do?

- Robust psychosocial team
  - Psychologist, social workers, nurse case manager/care coordinator, child life specialist
  - Trained to talk with families about emotional and physical needs, and to find support services and resources
- Services provided to every newly diagnosed pt/ family
  - Initial assessment of insurance status, employment/financial status, family functioning, mental health history, school issues
  - Psychoeducation and procedural preparation
  - Liaison with school – need for homebound services, special ed, etc
  - Monitor treatment adherence and barriers
  - Provide emotional support, encourage self-care

Hem/Onc Psychosocial Services
What do we do?

- Interventions for developing behavioral and mental health problems
  - Problems taking oral medications
  - Parenting issues – lack of discipline or limit setting
  - Needle phobias and other anxieties
  - Acting out behaviors
  - Adjustment to new routines and expectations
  - Conflicts within family (e.g., parents and teens)
  - Intensive support for AYAs
  - Preparation for upcoming procedures (e.g., amputation, NG-tube)
  - Depression, anxiety, disruptive behaviors, etc.
  - Advocacy within school setting