



Pediatric Cancer

Insights, Challenges, Strategies and Resources



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Initial Steps – early into diagnosis*

- Contact with patient & family – **Who is this person?***
 - Lay of the land academic & social relations to school
- Contact with school
 - School's concerns & interests
 - The needs of the learner
 - What information to share
 - Expectations
- Setting up home & hospital instruction
 - Rights, laws & regulations (local, state, & federal)

*** If your institution has a hospital-school liaison or point person, these are the steps to follow. If not, the family needs to employ other resources.**



Intermediate Steps – during treatment

- Monitoring Progress – common concerns
 - Hospital point person update school on short & long term effects
 - Discuss the learner's academic progress
 - » Progressing to the next grade
 - » Creation of a formal or informal educational plan
 - » Academic adjustments
 - » Keeping peer relations
 - Discuss academic program
 - » Quality & quantity of home & hospital instruction
 - » Scheduling
 - » Communication between family, school, & hospital



APHOES Practice Recommendations, 2011

Returning to the classroom

- School intervention programming in schools
 - Staff professional development
 - Classroom presentations
 - Content discussed
- Goal is to demystify and clear up any mis-information
 - Medical
 - Physical
 - Educational



APHOES Practice Recommendations, 2011

Intermediate Steps – during treatment

- Need for Neuropsychological testing
 - Academic
 - Intelligence
 - Memory – Executive Functioning



APHOES Practice Recommendations, 2011

Late Effects: The Emerging Priority

- Children's Oncology Group Late Effects Committee: COG Late Effects Guidelines
 - www-survivorshipguidelines.org



Late Effects

- Late Effects – Testing
 - Neurocognitive Testing
 - School Documentation (Intelligence, academic, therapies, etc.)
 - Annual Follow ups
- Late Effects Physical
 - Referrals for Speech, Physical or Occupational Therapy
 - Referrals for vision or hearing
 - Referrals for assistive/augmentative technology
 - Notes for P.E.
- Late Effects Psychosocial
 - Monitor for anxiety, social problems, depression
 - Helpful to have a "safe" person or space



APHOES Practice Recommendations, 2011

What Are Neurodevelopmental Problems?

- Neurodevelopmental problems are problems with a child's ability to learn, remember, and perform because of
 - Damage to the brain and blood vessels in the brain and/or
 - Interruption in the development of the brain and the way it works (e.g., chemistry, metabolism, oxygen availability)



How the brain can be damaged

- Genetics
- Structural damage
- Vascular injury: Large vessel, Microvascular
- Neurotransmitter abnormalities (acute and chronic)
- Metabolic abnormalities
- Neuroendocrine abnormalities
- Disruptions in development of
 - Myelin formation
 - Neural connections
- Environmental and Learning Factors

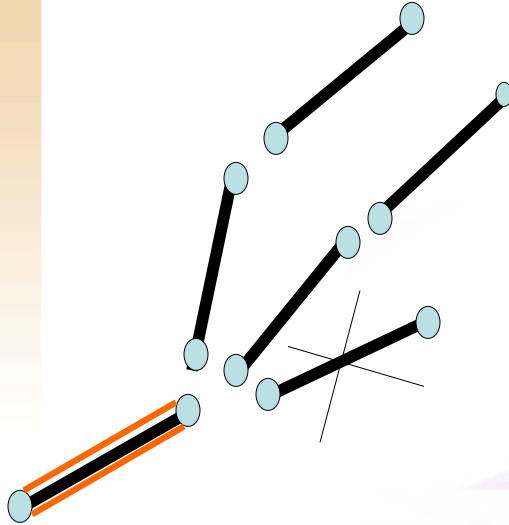


Things related to Late Effects

- Tumor: Size & Location
- Surgery and consequences of surgery
- Radiation Therapy to the head
- Chemotherapy
- Other Considerations
 - Genetics and family history
 - Injury unrelated to cancer
 - Limited learning experiences



Brain Development



Factors Associated with Cognitive Outcome

- Age at time of treatment
- Gender
- Radiation Therapy
- Some Chemotherapy medications
- Surgical Factors
- Shunt, Seizures
- CNS Infection

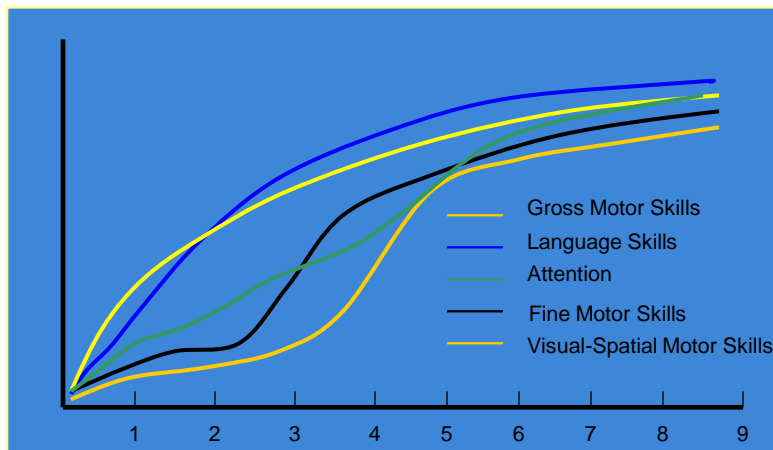


Neurodevelopmental Model

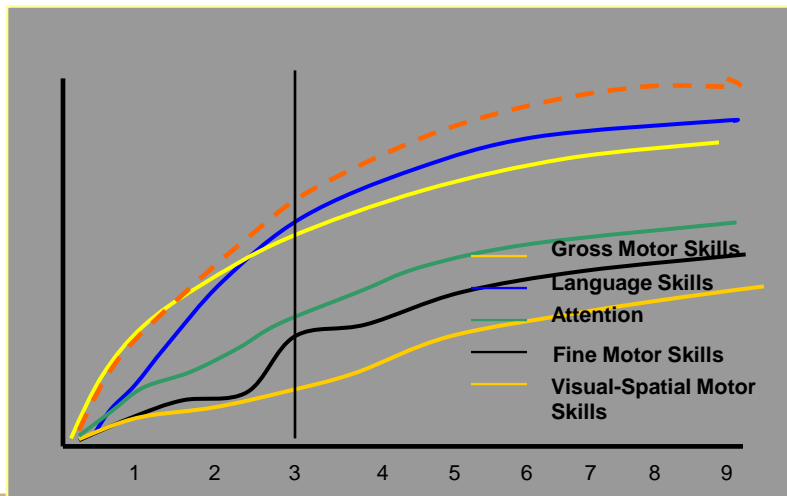
- Treatment seems to have its greatest effect on the part of the brain that develops after treatment. The parts of the brain that have developed before treatment seem to be relatively safe.



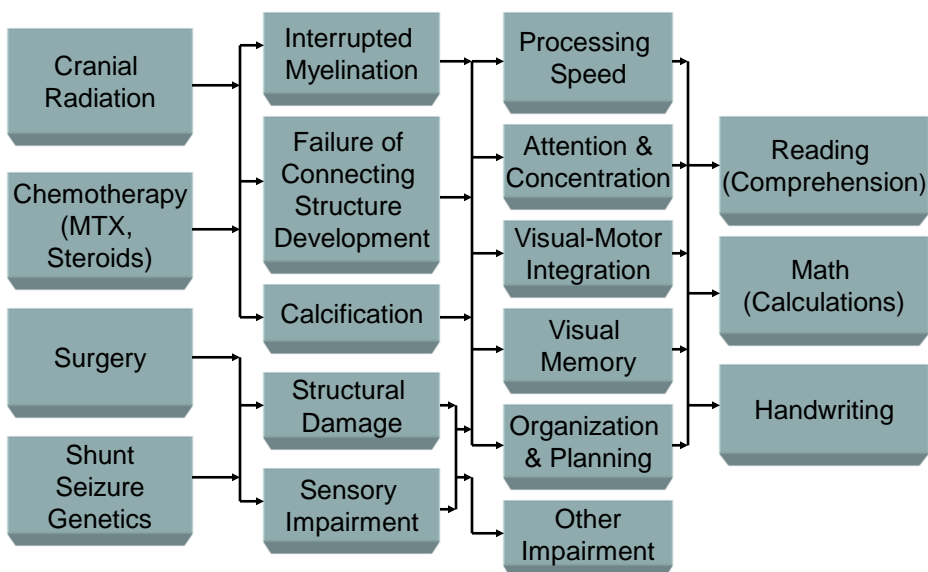
Emerging Cognitive Deficits: Developmental Patterns



Emerging Cognitive Deficits: Developmental Patterns



The Neurodevelopmental Model Treatment-Academic Linkages



Common Late and Emerging Effects



- Slow Processing Speed
- Attention Difficulties
- Memory Difficulties
- Fine Motor Coordination and Speed
- Planning, Organization, Executive Function Difficulties
- Visual-Spatial-Motor Integration Difficulties
- Mathematics Difficulties (calculation, not application)
- Reading Difficulties (comprehension)
- Social Difficulties



What diseases result in the greatest risk?

- All malignant brain tumors
- ALL treated with intrathecal chemo +/- RT, higher dose MTX during consolidation
- ALL followed by BMT using TBI
- Any child with RT to the head or face
- Some neuroblastoma
- Very young children with prolonged hospitalizations



Strategies for Intervention



- Context of Intervention
 - School Re-entry
 - Teacher, Parent, Peer, Child Education
- Rehabilitative Approaches
- Medical Approaches
- Compensatory Assistive Technology



Does Medication Help?

- Studies show methylphenidate has a beneficial effect on learning impaired survivors of brain tumors and ALL. (Meyers et al., 1998; Thompson et al., 2001)
- FDA warnings and cautions
 - All anti-depressants
 - All stimulant medications
 - increased risk for depression or anxiety,
 - risk of sudden heart failure.



Cognitive Rehabilitation

- Strategies based on mass practice and repetition (exercising the brain)
- In one study, many sessions of multi-component cognitive therapy resulted in
 - limited change in overall intelligence
 - improvement in sustained attention
 - Some improvement in academic achievement



Individualized School Plans

- **Individual Educational Plan (IEP) or 504 Plan. Availability may depend on whether school:**
 - is public or private
 - receives federal funding and has regulatory requirements
- **Accommodations may include**
 - Extended time to complete assignments
 - Reduced homework so that reinforcement of learning occurs, but time involved in completing the work doesn't deter learning and cause other problems



Testing Accommodations

- **Accommodations for standardized testing** and consideration of standardized scores for college admissions (eg. SAT, GRE, MCAT, LSAT)
 - Requires neuropsychological evaluation completed within 3 years of request
 - Requires letter from professional involved in case
- **Anticipate new areas of difficulty**
 - Repeated evaluations may be needed into young adulthood.



Teaching/Organizational Strategies

- Shift from "Read-Write" to "Listen-Speak" learning
 - Books on tape/disk
 - Text to Speech and Speech to Text
 - Use of Voice recognition software on computer
 - Use of text capture/scanning
 - Use of calculator
 - Oral rather than written testing
 - Use of support devices when oral not possible/allowed
- Use organizational strategies
 - Separate trapper-keepers for each subject
 - PDA calendars with alarm reminders



Outcomes of Compensatory Intervention Model: Case Series

- Outcomes
 - All 10 graduated high school, all but one with regular diploma
 - 5 of 10 are or have been Florida ACS College Scholarship Recipients, B-average GPA
 - All have accommodations in place in college



Parents as Advocates

- While school personnel may seem like they are enemies, they are often just not informed
 - Take time to provide education- teachers, special education personnel, administrators
 - Take time to learn what resources are and are not available
 - Brainstorm with the educational team about ways to address your child's needs- sometimes the best solution is the one that you and your child's educators creatively develop



Parents as Litigators

- As a last resort, become aware of your rights- federal and state- and seek legal counsel. This step is only recommended when all collaborative methods are exhausted
 - Legal remedies are expensive, both in time and \$
 - Legal remedies are seldom quick
 - Legal remedies often produce long-term resentment that can affect your child
 - However, legal remedies are part of your rights as a parent



College & Post Secondary Search Process

- Choosing the right college or post secondary program
 - Major
 - Geography
 - Location (urban, suburban, rural)
 - Cost
 - Disability or illness specific needs & supports

