

PSYCHOSOCIAL OUTCOMES OF PEDIATRIC BRAIN TUMORS

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CONFLICTS OF INTEREST

Nothing to declare



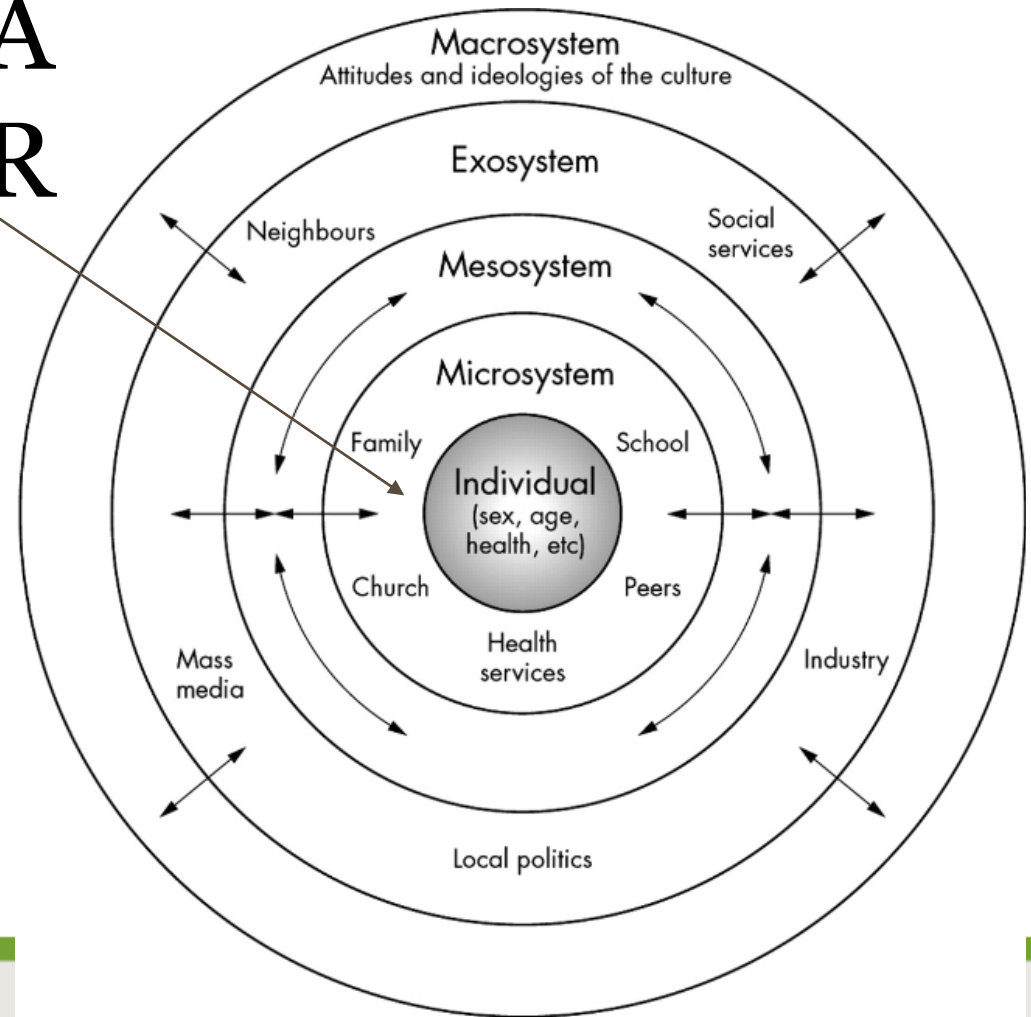
OBJECTIVES

- Describe Psychosocial Outcomes in Pediatric (Pituitary) Brain Tumors
 - Standards for Psychosocial Care for Children with Cancer and their Families
 - Emotional/Quality of Life
 - Cognitive
 - Social
- Recommendations/tips to promote better quality of life

SYSTEMS PERSPECTIVE

CHILD WITH A BRAIN TUMOR

- Child experiences affect family
- Family coping & management of illness affect child
 - For better or worse



IMPACTS OF TUMOR & TREATMENT

Short-term Physical Consequences

- Pain, weakness
- Endocrine dysfunction

Related Short-term Psychosocial Consequences:

- Fear, sadness, withdrawal, trauma
- Separation from family
- Social isolation
- Acute distress in parents

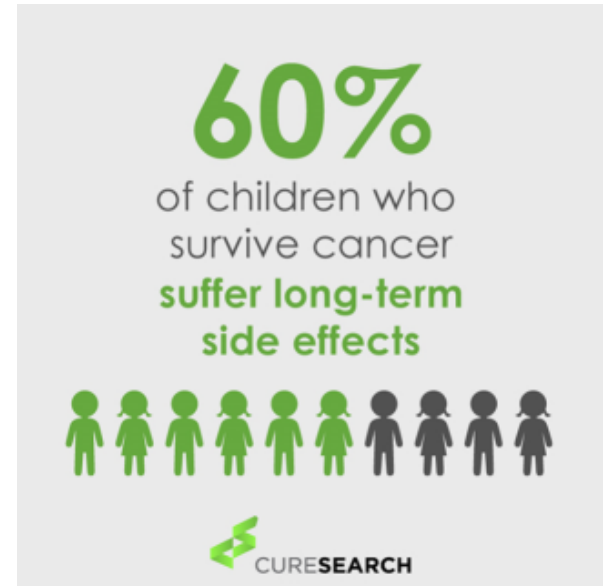


Such psychosocial challenges can become chronic

IMPACTS OF TREATMENT

Long-term physical consequences

- Multiple organ systems can be affected depending on disease and treatments
 - E.g., Endocrine, neurodevelopmental, sensory
- Chronic fatigue & sleep disturbance
- Secondary cancers (w/ radiation)



SUCH CONSEQUENCES INCREASE RISK FOR PSYCHOSOCIAL PROBLEMS

MEDICAL LATE EFFECTS OF PITUITARY BRAIN TUMORS

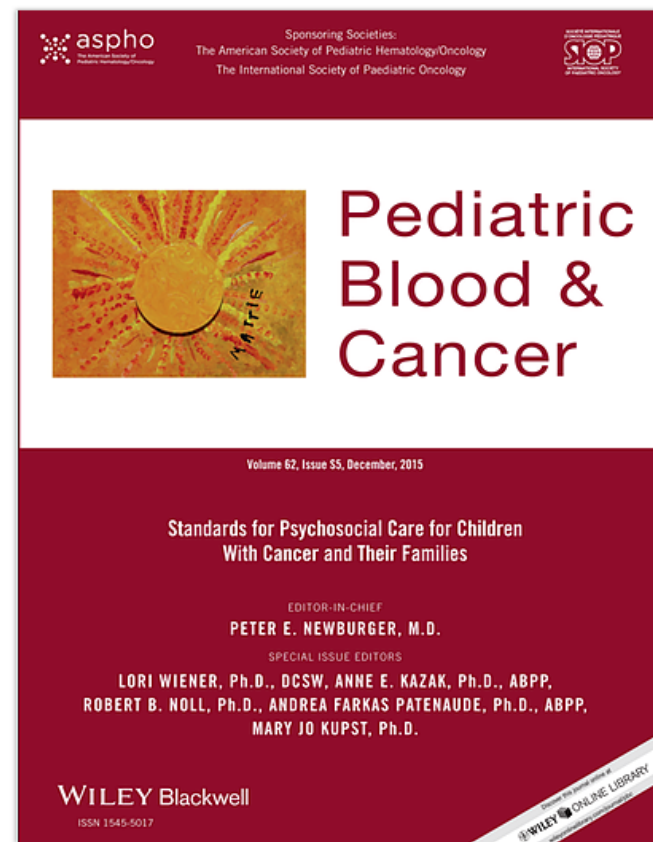
- Excessive fatigue
- Neuro-endocrinopathies requiring daily medication & lifestyle changes
 - DI, panhypopituitarism
- Hypothalamic obesity

**SUCH PROBLEMS IMPACT
PSYCHOSOCIAL FUNCTIONING**

PSYCHOSOCIAL STANDARDS FOR CARE

- Expert review of > 13,000 peer-reviewed articles
- Graded quality of evidence
- Identified 15 standards of care and summarized strength of evidence for each standard

<http://www.mattiemiracle.com/standards>



PSYCHOSOCIAL STANDARDS FOR CARE



- 1. Psychosocial Assessment**
- 2. Monitoring and Assessment of Neuropsychological Outcomes**
- 3. Psychosocial Follow-Up in Survivorship**
- 4. Psychosocial Interventions and Therapeutic Support**
5. Assessment of Financial Burden
- 6. Psychosocial Care for Parents of Children With Cancer**
7. Anticipatory Guidance and Psychoeducation
8. Procedural Preparation and Support
- 9. Providing Opportunities for Social Interaction**
10. Supporting Siblings
11. School Reentry Support
12. Assessing Medication Adherence
13. Palliative Care
14. Bereavement Follow-Up
15. Communication, Documentation, and Training Standards

STANDARD 1:

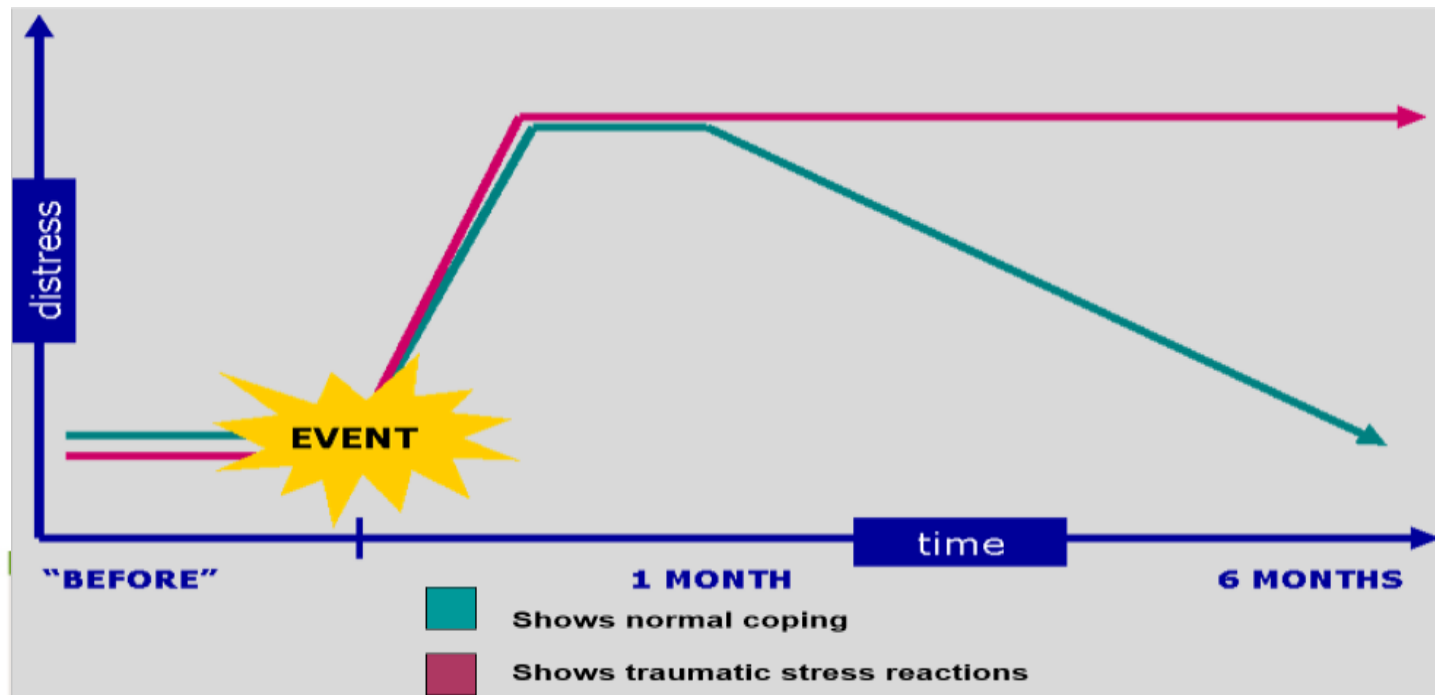
PSYCHOSOCIAL ASSESSMENT

STANDARD 1: PSYCHOSOCIAL ASSESSMENT

Youth and Family Distress in Pediatric Cancer

Trajectory of Distress

- Generally declines over time but continues in 20-30% of families
- Tends to increase again at transition periods (finishing cancer treatment)



Predicting parental distress among children newly diagnosed with craniopharyngioma

Pediatr Blood Cancer. 2018;65:e27287.

- Similar findings: increased distress at baseline that largely reduce over time
 - Subset remain w/ elevated distress (~15%)
- Distress largely related to parental perceptions of child cognitive difficulties
 - Greater discrepancy between perception & performance = higher distress

STANDARD 1: PSYCHOSOCIAL ASSESSMENT

Family Factors: Resources, Structure & Function

- Family resources (e.g., SES) related to access to care and disparities in outcomes (survival & neurocognitive)
- Social support and premorbid stressors strongly related to later psychosocial outcomes
- Single-parent families and families with poor cohesion are risk factors

➤ *Alternatively, family can be protective factor*



TAKE HOME POINT

- Resuming normal routines and establishing new routines at early stage is important
 - Reduce distress
 - Make managing complex medical condition easier
- Seek outside help if needed

FAMILY-BASED SERVICES

STANDARD THREE:

PSYCHOSOCIAL FOLLOW-UP IN SURVIVORSHIP

PSYCHOSOCIAL FOLLOW-UP IN SURVIVORSHIP

**CHILDREN'S
ONCOLOGY
GROUP**

outlines long-term follow-up guidelines

ANY CANCER EXPERIENCE					
Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation
1	Any Cancer Experience	Adverse Psychosocial/QoL Effects Social withdrawal Educational problems Dysfunctional marital relationships Under-employment/ Unemployment Dependent living	Host Factors Female sex Family history of depression, anxiety, or mental illness Younger age at diagnosis Neurocognitive problems Physical limitations Social Factors Lower household income Lower educational achievement Treatment Factors Hematopoietic Cell Transplant	Host Factors CNS tumor CNS-directed therapy Hearing loss Premorbid learning or emotional difficulties Social Factors Failure to graduate from high school	HISTORY Psychosocial assessment with attention to: - Educational and/or vocational progress - Social withdrawal Yearly
	Info Link The Children's Oncology Group Long-Term Follow-Up Guidelines apply to patients who have been off therapy for a minimum of 2 years.				

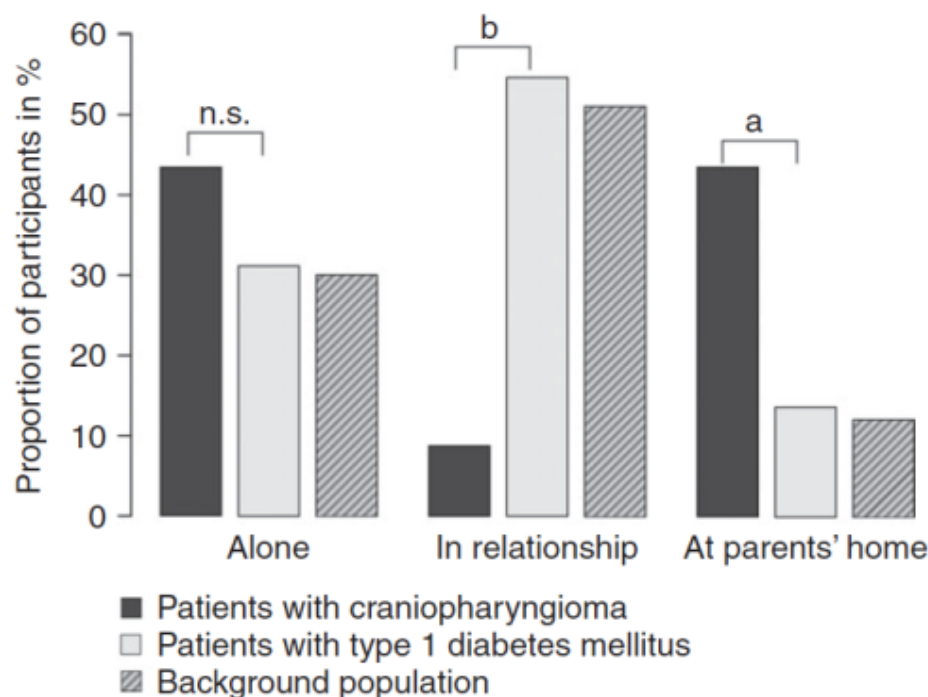
PSYCHOSOCIAL FOLLOW-UP IN SURVIVORSHIP

**CHILDREN'S
ONCOLOGY
GROUP**

Mental health follow-up guidelines

ANY CANCER EXPERIENCE					(CONT)
Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation
2	Any Cancer Experience	Mental health disorders Depression Anxiety Post-traumatic stress Suicidal ideation	Host Factors Female sex Family history of depression, anxiety, or mental illness Social Factors Lower household income Lower educational achievement Treatment Factors Hematopoietic Cell Transplant Medical Conditions Chronic pain	Host Factors CNS tumor CNS-directed therapy Premorbid learning or emotional difficulties Perceived poor physical health Social Factors Failure to graduate from high school	HISTORY Psychosocial assessment with attention to: - Depression - Anxiety - Post-traumatic stress - Suicidal ideation Yearly

Psychological well-being and independent living of young adults with childhood-onset craniopharyngioma



YA w/ Cranio (n = 59)
 compared to YA w/ T1DM

Elevated depression scores:
 20.7% YA w/ Cranio
 6% YA w/ T1DM

Depression levels related to:
 -BMI*
 -Negative event in last year*
 -Attention problems*
 --Sleep & vision difficulties

PSYCHOSOCIAL RISKS IN PITUITARY BRAIN TUMORS

- Increased depressive symptoms
- Disrupted sleep, excessive fatigue
 - Excessive daytime sleepiness ~74% in St Jude study
 - Related to hypothalamic involvement

**Level of hypothalamic involvement →
worse outcomes across many domains of
function**

QUALITY OF LIFE OUTCOMES

- Parents view QoL as worse than kids do
- QoL improves over time w/ GH tx
 - Worsens over time w/out GH tx
 - Autonomy, cognition, & physical function
- 44-61% characterized as at least obese
- Higher BMI & worse QoL related to:
 - Hypothalamic involvement
 - Maternal BMI

LONG-TERM FOLLOW-UP CARE

Recommendations:

Yearly psychosocial screening for

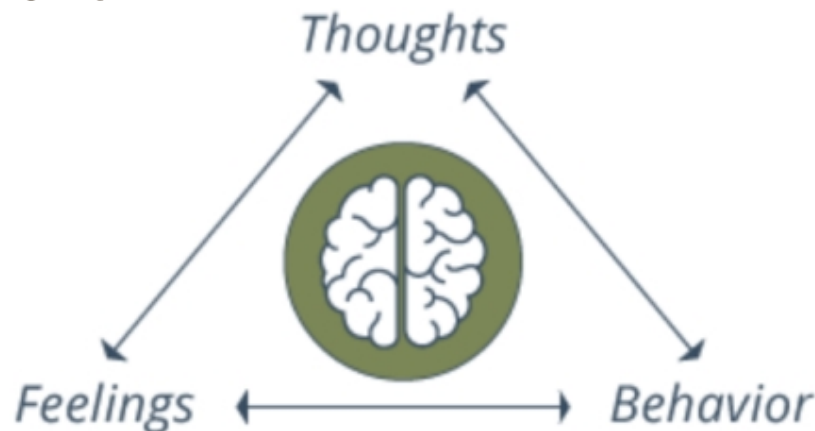
- Adverse educational and/or vocational progress
- Social and relationship difficulties
- Distress, anxiety, and depression
- Health behaviors
 - Good (exercise, sleep) & not so good (smoking, poor diet)

Anticipatory guidance on management of health over time



CONSIDERATIONS

- If have concerns – ask for help!
- Psychotherapy is effective (cognitive-behavioral therapy)
 - Depression and anxiety
 - Behavioral sleep interventions
- Role of medications
 - Stimulant medications
 - Antidepressants



PSYCHOSOCIAL INTERVENTIONS: FAMILY BASED

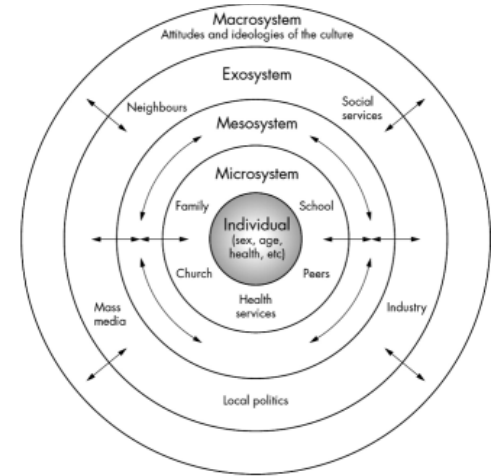
STANDARD SIX: STANDARDS OF PSYCHOSOCIAL CARE FOR PARENTS OF CHILDREN WITH CANCER



PSYCHOSOCIAL INTERVENTIONS: FAMILY BASED

Directed at Parents/Families

- Much larger evidence base
- For parents:
 - Problem-Solving Skills Therapy (Sahler et al, 2005)
 - CBT for coping with uncertainty (Mullins et al, 2012)
- For families:
 - Surviving Cancer Competently Intervention Program (Kazak et al, 1999, 2005)



STANDARD 2:

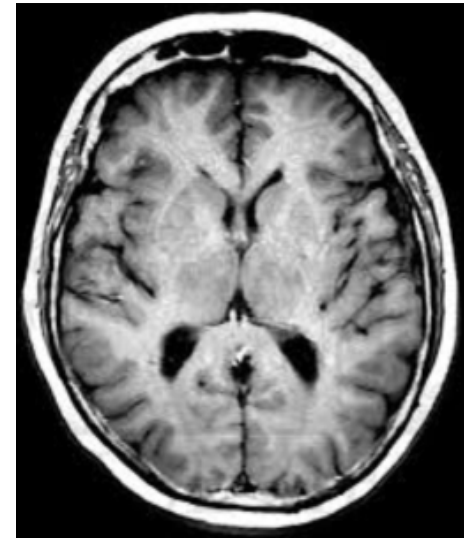
MONITORING AND ASSESSMENT OF NEUROPSYCHOLOGICAL OUTCOMES



RISK FACTORS: NEUROPSYCHOLOGICAL LATE EFFECTS

- Central Nervous System (CNS) disease (e.g., brain tumors)
- CNS-directed treatment
- Higher doses/volumes of radiation therapy
- Multimodal therapies
- Younger age at time of treatment
- Neurological complications
 - Seizure, hydrocephalus, e.g.
- SES factors

Disrupted white matter development
causing progressive declines over time



NEUROPSYCHOLOGICAL OUTCOMES IN PITUITARY BRAIN TUMORS

- Impairments in
 - Learning & memory
 - Executive functioning (working memory)
 - Attention regulation
 - Processing speed
- Predictors of worse outcomes:
 - Hypothalamic involvement
 - Extent of surgery
 - Vision impairments
 - Radiation therapy



NEUROPSYCHOLOGICAL ASSESSMENT

- Document cognitive strengths/weaknesses to guide educational plans & accommodations
- Comprehensive assessments v. screening/monitoring batteries

Timing:

- Consider obtaining a baseline
 - Facilitate school reentry or transitions
 - Provide context for change
- Every 2-3 years routinely
- When functional changes observed in classroom or at home



STANDARD NINE:

PROVIDING CHILDREN AND ADOLESCENTS OPPORTUNITIES FOR SOCIAL INTERACTION



“I had the same thing with (child) with sleepovers. **Eight and half pills a day...nine needles a day. Who wants to take her for a sleepover?** Oh, that’s a challenge.”
-parent of 11 year-old survivor of craniopharyngioma



SOCIAL INTERACTION

Classroom research shows:

- School-age children w/ cancer similar or better than peers in terms of peer acceptance

HOWEVER,

- Brain tumor survivors accepted less by peers and experience more social isolation

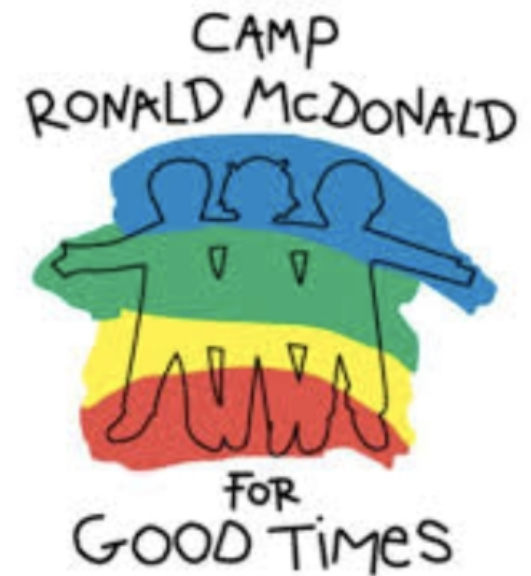


SOCIAL INTERACTION

Risk factors for poor social functioning

- School absence
- Reduced participation in school activities
- Adolescence – increased importance of peers

Programs or camps seen as helpful by youth



CHILDHOOD CANCER SOCIAL NEEDS

- Provide frequent opportunities for social interaction
 - Consider patient developmental level, preferences, and health status
 - Resume/continue social activities
- Promote social interactions through camps and groups
<https://www.alexslimonade.org/campaign/supersibs-sibling-support-childhood-cancer-families/camps-childhood-cancer-families>
- Maintain focus on social development goals



SUMMARY

- Pediatric pituitary brain tumors → physical and psychosocial consequences
- Entire family is affected
 - Family as potential buffer
 - Family-based interventions
- Risk factors for poor psychosocial outcomes
 - Hypothalamic involvement, radiation therapy

GENERAL RECOMMENDATIONS

Regular follow-up with medical teams to screen for

- Depression
- Adherence issues
- Cognitive problems

Importance of

- Sleep
- Exercise
- Family routines to promote health behaviors
- Engagement in social activities