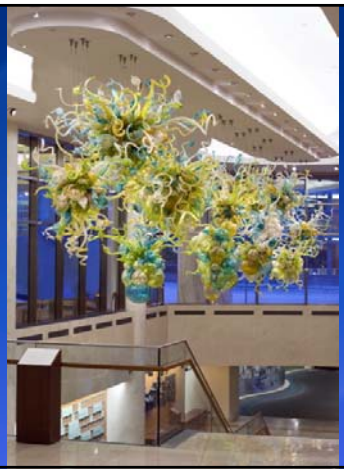

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Developing a Psychosocial Care Plan for Support of Pediatric Brain Tumor Patients with Neurological Complexities, Neuropsychological Limitations and Quality of Life Challenges

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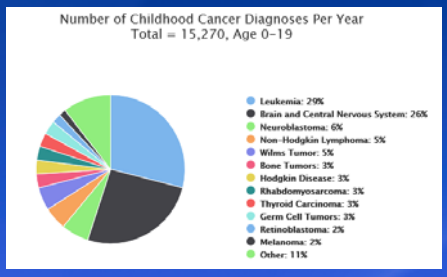
Mayo Clinic

No Disclosures

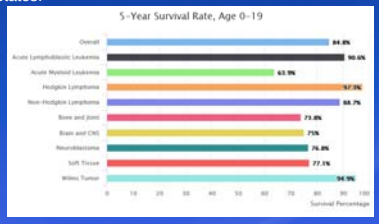
Childhood cancer remains the leading cause of death by disease among children in the United States. Every day, 43 children are diagnosed with cancer and the average age of diagnosis is 6. Cancer affects all ethnic, gender, and socio-economic groups and more than 40,000 children undergo treatment for cancer each year.



Sources: American Cancer Society, Cancer Facts and Figures (2018)
National Cancer Institute (2017)

In the last 40 years, the overall survival rate for children's cancer has increased from 10% to nearly 90% today, but for many more rare childhood cancers, the survival rate is much less.

- 12% of children who are diagnosed with cancer do not survive.
- 60% of children who survive suffer devastating late effects such as secondary cancers, muscular difficulties and infertility.
- There are approximately 375,000 adult survivors of children's cancer in the United States.



Source: Surveillance, Epidemiology, and End Results (SEER) Program (seer.cancer.gov)
SEER 9 areas based on follow up of patients into 2014

Expected Challenges

- Medical crisis
- Side effects
- Quality of life
- Impairments (communication, behavior, physical function)
- Lengthy rehabilitation (during and post treatment)

Late Effects and Risk Factors

- Medical compromise
- Psychosocial Challenges
  - Where one sees themselves (academics, employment and social)
- Behavioral challenges
  - Anxiety
  - Depression
  - Educational
  - Post trauma stress
  - Risky behavior
  - Social Withdrawal
  - Unemployment

Video

- https://videoexchange.mayo.edu/media/Moving+Forward+After+Your+Child%27s+Cancer+Treatment/1_svdciks7


Rochester
Mostly Cloudy
-28°
Wednesday TODAY -18 -32
Now 4AM 5AM 6AM 7AM
-28° -28° -28° -29° -29°
Thursday -1 -7
Friday 18 13
Saturday 39 37
Sunday 43 30
Monday 34 6
Tuesday 13 3

Social Work Role

- Multidisciplinary approach to care
- Ongoing clinical assessment for mood dysregulation
- Caregiver assessment and support
- Resource acquisition
- Vocational and educational planning
- Substance use assessment
- Trauma assessment

Potential Changes During and After Medical Treatment

- Confusion
- Memory challenges
- Attention and concentration/compromised executive function
- Difficulty with decision making/problem solving
- De-motivational Syndrome
- Inappropriate emotional response
- Psychiatric disorders
- Changes in Personality and Impaired Social Interactions
- Impaired coping mechanisms
- Altered self-concept
- Impact of brain injury on family dynamics

Confusion

- How to complete tasks
- Mixes past and present events

Memory Challenges

- Difficulty with recall of tasks, directions, people and day to day activities
- Processing new information
- Compromise in recall of new information and new surroundings
- Adapting to the usefulness of learning aids (calendar, notes)
- Completion of tasks

Attention and Concentration

- Somnolence
- Short attention span
- Distraction
- Processing new information
- Lowered sensory tolerance (light, noise, smell, movement)

Difficulty with Decision Making/Problem Solving

- Impulsivity
- Compromised reasoning
- Anxiety
- Inability to recognize a problem

Demotivational Syndrome

- Apathy
- Disinterest in previous activities
- Difficulty with initiation of a task
- Lack of follow through with planned tasks

Inappropriate Emotional Responses

- Emotional lability
- Decreased affect (flat)
- Increased affect (euphoria)

Psychiatric Disorders

- Psychiatric Disorders
- Mood disorders
- Anxiety
- Premorbid mental illness, alcohol and drug use can greatly impact the recovery process and severity of the psychosocial sequelae

Changes in Personality and Impaired Social Interactions

- Acts or speaks impulsively (poor judgment, inappropriate comments, preservation)
- Impaired self-awareness
  - Unaware of limitations
  - Inaccurate self-image
  - Self-perception
- Difficulty in social settings
  - Difficulty engaging in past relationships
  - Difficulty developing new relationships
  - Socially inappropriate
  - Difficulty taking turns
  - Minimal social boundaries
- Communication
  - Aphasia
  - Speech impairments (slurred)
  - Too loud or too quiet
  - Lack of emotion

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Impaired Coping Mechanisms

- Difficulty managing emotions (particularly in the later stages of recovery)
  - Frustration
  - Anger
  - Sadness
- Grief of loss of personality
- Grief of personal and social relationships
- Inability to engage as prior
- Loss of occupation or previously enjoyed activities
- Ineffective coping strategies prior to injury may contribute to even more impairments and may lack the ability to learn new strategies to cope with additional stressors.

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Altered Self-Concept

- Altered body image
- Position in family
- Peer relations and community
- Long term memory will often return before the short term
- Potential identity crisis may establish if a person is unable to rebuild a post-injury self-concept
- Compromised sense of self

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Impact of Brain Injury on Family Dynamics

- Resentment
- Guilt
- Increased care-giving role for parents
- Financial

Social Work Role

- Psychosocial assessment
- Ongoing re-assessment
- Ongoing collaboration with multidisciplinary team
- Utilization of clinical treatment interventions
- Resource acquisition
- Rehabilitation support

Psychosocial Impact of Survivors

- Fatigue
- Depression
- Anxiety
- Isolation
- Behavioral
- Grief
- Social difficulties
- Decreased self-esteem
- Dependency on parents/family
- Substance use
- Loss of self
- Post Trauma stress

Psychosocial Clinical Assessment

- Current medical information
- Current challenges
  - Global medical
  - Psychosocial
  - Personal
- Patient perception of current circumstance
- Patient feelings of current circumstances
- Current routines
  - Medical appointments
  - Academic
  - Occupational
  - Social
- Relationships
  - Peer
  - Parental
  - Spousal
  - Caregiver
  - Community

Psychosocial Clinical Assessment Cont.

- Risk Taking Behavior
  - Alcohol or drug use
  - Sexual
- Emotional Status
- Sexuality and Fertility
- Insurance
- Neuropsychological Results
  - Amnesias
  - Intellectual ability deficits
  - Dysphagia
  - Memory concentration and Information process

Psychosocial Clinical Assessment Cont.

- Memory
- Support Resources
- Caregiver Support
- Mental Health
- Academics
- Vocation
- Coping
- Drug and Alcohol Use
- Previous and Current Goals

Clinical Treatment Interventions

- CBT
- Behavioral Modification
- Group Therapy
- Parent Psychoeducation and Support
- Exposure Therapy
- Cognitive Remediation Therapy (Self talk, Learning Theory)
- Family Therapy
- Resilience and Rehabilitation Therapy (Strengths based theory)
- Family and Caregiver psychoeducation

Considerations During Therapy

- Cognitive deficit vs. pseudo-depression
- Denial
- Practice from the perspective of patience
- Engage the patient and family as active participants
- Encourage normal routines

Methods to Enhance Individual Counseling

- Keep distractions to a minimum
- Model calm and controlled behavior
- Do not over stimulate the patient
- Patient may be more attentive at different times of the day
- Pair new learning tasks with old ones
- Utilize rehearsing
- Make interpretations explicit to avoid misunderstanding
- Modify open ended statements to avoid confusion
- Redirect patient's attention when agitated rather than confronting the topic
- Start with easy task, use verbal praise and reinforce task completion
- Give the patient extra time to respond
- Use reflection and re-statement for clarification

https://www.youtube.com/watch?v=ijNeN6LqF4w&feature=youtu.be

Palliative Care

- Pain Management
- Hospice Support
- Bereavement Counseling

Multidisciplinary Collaboration

- Variety of health professionals
- Exchange of information
- Benefits of tumor boards
- Transition readiness for the patient
  - Knowledge of diagnosis and treatment
  - Knowledge of potential late effects and surveillance recommendations
  - Identification of primary health care setting and providers.
  - Ability to make and keep appointments, follow health care recommendations.

Barriers to Successful Multidisciplinary Clinics

- Time constraints
- Resources
- Time pressures
- Low attendance by members
- Lack of leadership
- Financial
- Excessive caseload
- Lack of institutional support

Resource Acquisition and Collaboration

- Collaboration with community support
- Social skills trainers
- Brain waivered services through local counties
- Brain Injury Association of America (BIA)
- Vocational Rehabilitation
- Education Rehabilitation
- Support Groups

Rehabilitation

- Inpatient Acute Rehabilitation
- Outpatient Rehabilitation
- Day Treatment
- Community Re-Entry
- Independent Living

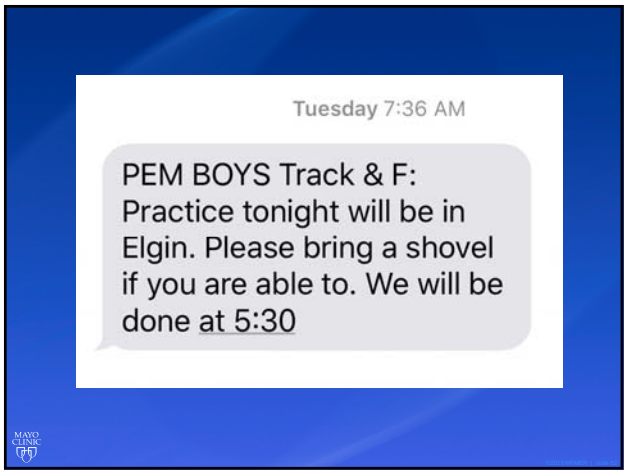
Caregivers

- Parents of Children surviving a brain tumor have been reported to be a greater risk for both post trauma stress disorder and general distress. (Carpenteri)
  - Surrogocy

Caregiver Assessment

- Recognize each parent may have a different response to information and support and may require individual time.
- Identify how the family roles may have a shifted with adjustments necessary to fulfill family obligations.
- Personal loss and grief (
- Identify resources and respite options (community)
- Provide psychoeducation in reference to emotional support and ways to manage their own behavior with the patient.
- Encourage family involvement for the patient as the outcomes are typically more positive.

https://www.youtube.com/watch?v=u2EhQVU4dXk&feature=youtu.be



Case Presentation

First Year

- **Diagnosis and Treatment**
  - Diagnosed at age 18 (3/2015) with a CNS germ cell tumor, pineal region
    - Chemotherapy
    - Radiation therapy
    - Inpatient rehabilitation
    - Outpatient Brain Rehabilitation Program (9/2015)
    - Therapy concluded in 10/2015 and patient returned home.
    - Vocation supports assessed and patient referred

First Year Cont.

- **Medical Complications**
  - Tumor resection required
  - Hydrocephalus with shunt placement
  - Parinaud Syndrome
  - Diplopia (prism of R eye)
  - Post-operative kinetic mutism
  - Fatigue
  - Poor appetite
  - Weight loss (25-30 lbs)
  - Cognitive deficits
  - Sleep disturbance (sleep too much)

First Year Cont.

- **Psychosocial**
  - Appropriate crisis response to diagnosis and treatment
  - Grief
    - Loss of independence
    - Relationships
    - Education
  - Episodic sadness; depressed mood, provisional
  - Positive progress with therapies

First Year Cont.

- **Psychosocial Continued**:
  - Improved sense of memory and self-concept
  - Parental support
  - Resource acquisition
    - Financial supports
    - Vocational resources
    - Brain rehabilitation
    - Wishes and More

1 Year Later (2/2016)

- **Medical**
  - Germ cell tumor, stable
  - Hydrocephalus, treated with shunt placement
  - Parinaud syndrome and diplopia
  - Fatigue
  - Weight loss
  - Cognitive concerns

1 Year Later (2/2016)

- **Psychosocial**
  - Lives with parents who remain as his primary caregivers.
  - Depression PHQ 9=9 and Anxiety GAD 7=5. Antidepressant started in January of 2016
  - Passive suicidal ideation
  - Loss of independence
    - Living with parents
    - Memory challenges limits autonomy
    - Reliant on parents for answering questions and decision making

1 Year Later (2/2016)

- Psychosocial Continued:
  - Disconnected social situations
    - friends entered college in the fall
    - Girlfriend breaks up with him
    - Social expression is challenged (sarcasm, he doesn't see it)
  - Fatigue
  - Blunted affect and facial expression
  - Attends a few psychology sessions but doesn't feel this helps
    - Has usually relied on avoidant strategies for coping

1 Year Later (2/2016)

- Psychosocial Continued:
  - Feels burdensome to his parents
  - No drug use
  - Some use of alcohol
  - Neuropsychological deficits
    - Verbal memory impairment
    - Slowed processing speed
    - Blunted affective facial expression
    - History of akinetic mutism, improving

1 Year Later (2/2016)

- Psychosocial Continued:
  - Excellent parental support
  - Vocational Rehabilitation supports are in place
  - Parent stress
    - Struggle with observing the changes
    - Memory
    - Emotions
    - Lack of initiation/motivation
    - Blunted social expression
      - Hugely sarcastic

1 Year Later (2/2016)

- **Psychosocial Continued:**
  - **Parents express concern for "needing more" rehabilitation**
    - **Limited local support for rehabilitation**

3 Years Later (5/2017)

- **Medical**
  - Germ cell tumor, stable
  - Akinetic mutism, improving
  - Verbal memory impairment
  - Seizure activity (spring 2017)
  - Slowed processing speed
  - Blunted affect and facial expression

3 Years Later (5/2017)

- **Psychosocial**
  - Cognitive concerns remain
  - Attends college
    - Academic supports in place
    - Parents crucial in academic success
  - Remains connected to Vocational supports, locally
  - Initiation and motivation remain challenges
  - Depressed mood (non- suicidal)
    - "I will never get better"
  - No drug use
  - Some alcohol use

3 Years Later (5/2017)

- **Psychosocial Continued:**
  - Independece
    - Wishes to do more than what is capable
      - Attend an internship away from home
  - Parent stress
    - Frustrated by slow recovery
    - Wish for alternative rehabilitation options
  - Social settings remain challenged
  - Fatigue
  - Blunted affect and expression

4 Years Later (8/2018)

- **Medical**
  - Germ cell tumor, stable
  - Akinetic mutism history, resolved
  - Parinaud syndrome and diplopia, improved s/p strabismus surgery
  - Cognitive concerns
  - Seizure activity, asymptomatic on Vimpat (last seizure May 2017)

4 Years Later (8/2018)

- **Psychosocial**
  - Successful outpatient rehabilitation out of state (summer of 2017)
  - Vocational supports remain, locally
  - Independence
    - Interned away from home (8/2017)
    - Driving
    - Moving to college (4 hours away from home)
  - Motivation and initiation improved
    - Using alarms and lists

4 Years Later (8/2018)

- **Psychosocial Continued:**
  - Mild depressive symptoms
  - Physically strong
  - Strength in faith
  - Relationships
    - Improved relationships with parents (less sarcastic)
    - Developing new relationships
    - Difficulty with social engagements, improved
  - Visibly more relaxed and engaged

4 Years Later (8/2018)

- **Psychosocial Continued:**
  - Parents
    - Calm
    - Relief
    - Remain concerned as they move towards independence

Case Consultation

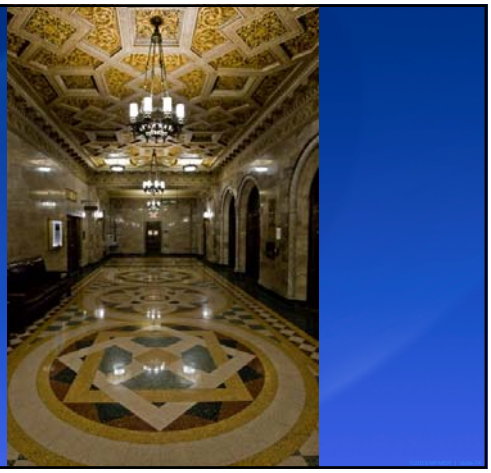
Medical:

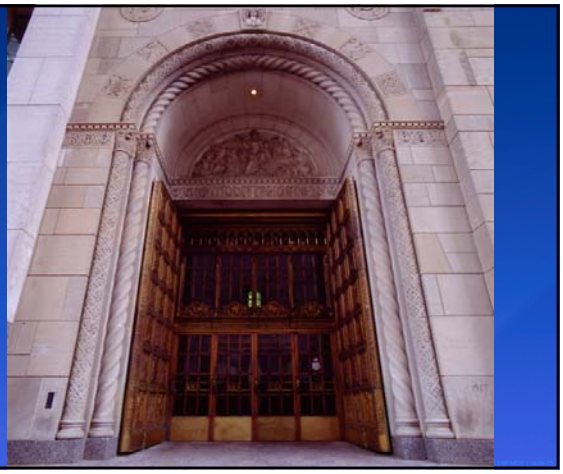
- 2 Year old boy with a medulloblastoma.
- Received chemotherapy, radiation and 3 autologous transplants.
- Child remained in the hospital for most of his treatment due to psychosocial factors.
- When he was outpatient prior to returning home (4 weeks), SW saw him 3 times per week.

Case Consultation Cont.

Psychosocial:

- Married parents who are 19 years of age.
- Father remained home to work while mother managed the patient's needs
- Noncompliance, although mother seemed fine in the hospital she would not bring him in or call with problems.
- Mother's mental health, untreated.
- Mother's unreliability in the hospital as being present.
- Grandparents would come at times.
- Father would come on some weekends.
- Mother has various friends who would come to the hospital or clinic. These friends would be friends she just met.
- Refused resources.
- Mother was typically pleasant.
- She would become quickly frustrated with patient and had a totalitarian approach to discipline.
- He is fully tube fed and very few structured meal times to encourage normal feeding routines.
- Mother overwhelmed when he went outpatient and was with her at the RMH.





Case Consultation Cont.

Plan:

1. **Patient has finished treatment and he is due to return home.**
2.
3.
4.

Ethics Basic Principals

Terms

- **Autonomy**: Requires the patient have autonomy of thought, intentions, and action when making decisions regarding health care.
- **Justice**: Requires that procedures uphold the spirit of existing laws and are fair to all players involved.
- **Beneficence**: Requires that the procedures be provided with the intent of doing good for the patient.
- **Non-maleficence**: Requires that a procedure does not harm the patient involved or others in society.
- **Assent**: Assent is not consent and minors are not allowed to give consent. Assent is viewed as focusing on capacity, a developmental term. This is about respecting a child's developing capacity and assisting them in understanding their condition.
- **Consent**: Informed consent is a process grounded in the notion of respect for persons. The capacity to consent requires the legal ability to enter into a valid contract and the psychological or developmental ability to make a sound decision.

MEDICAL INDICATIONS
The Principles of Beneficence and Nonmaleficence

1. What is the patient's medical problem? Is the problem acute? Chronic? Critical? Reversible? Emergent? Terminal?
2. What are the goals of treatment?
3. In what circumstances are medical treatments not indicated?
4. What are the probabilities of success of various treatment options?
5. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

PATIENT PREFERENCES
The Principle of Respect for Autonomy

1. Has the patient been informed of benefits and risks, understood this information, and given consent?
2. Is the patient mentally capable and legally competent, and is there evidence of incapacity?

1. If mentally capable, what preferences about treatment is the patient stating?
2. If incapacitated, has the patient expressed prior preferences?
3. Who is the appropriate surrogate to make decisions for the incapacitated patient?
4. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?

QUALITY OF LIFE
The Principles of Beneficence, Nonmaleficence, and Respect for Autonomy

1. What are the prospects, with or without treatment, for a return to normal life, and what physical, mental, and social deficits might the patient experience even if treatment succeeds?
2. On what grounds can anyone judge that some quality of life would be undesirable for a patient who cannot make or express such a judgment?
3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life?
4. What ethical issues arise concerning improving or enhancing a patient's quality of life?
5. Do quality-of-life assessments raise any questions regarding changes in treatment plans, such as forgoing life-sustaining treatment?
6. What are plans and rationale to forgo life-sustaining treatment?
7. What is the legal and ethical status of suicide?

CONTEXTUAL FEATURES
The Principles of Justice and Fairness

1. Are there professional, interprofessional, or business interests that might create conflicts of interest in the clinical treatment of patients?
2. Are there parties other than clinicians and patients, such as family members, who have an interest in clinical decisions?
3. What are the limits imposed on patient confidentiality by the legitimate interests of third parties?
4. Are there financial factors that create conflicts of interest in clinical decisions?
5. Are there problems of allocation of scarce health resources that might affect clinical decisions?
6. Are there religious issues that might affect clinical decisions?
7. What are the legal issues that might affect clinical decisions?
8. Are there considerations of clinical research and education that might affect clinical decisions?
9. Are there issues of public health and safety that affect clinical decisions?
10. Are there conflicts of interest within institutions or organizations (e.g. hospitals) that may affect clinical decisions and patient welfare?

Medical Indications: Patient is a 15 year old with a DIPG, has not responded to any chemotherapy interventions or radiation. Symptom management is difficult. Worsening symptoms with blindness, seizures, fatigue, headaches, and nausea. Patient has a very close relationship with her mother, and she has been an active participant in every treatment conference. For the most part, the patient tolerated the palliative oral chemotherapy well along with radiation. However, symptoms persisted with the increase of the tumor and the patient struggled physically as well as emotionally. Mother wants to proceed with (unproven) experimental therapy in an effort to prolong her life but the patient does not desire this plan and wishes to die on her "own terms". Mother insists on this decision being her own and states she will take the patient to a doctor who will treat her. Patient does not wish to pursue further treatment.	**Client Preferences:** Patient is mentally stable and sufficiently mature to understand the issues related to her treatment and to participate in decision making. Her experience with her disease and past treatment has also resulted in a level of maturity that exceeds her age. The patient understands the nature of the proposed treatment, including risks and expected benefits. She consistently wishes to allow natural death.
Quality of Life: Experimental treatment would likely cause severe side effects that would likely alter the course of his illness, would be profoundly disrespectful and potentially harmful and there was a growing concern that the patient would feel isolated and distressed during the process.	**Contextual Features:** The patient is sufficiently mature to understand the issues related to her treatment and to participate in decision making. Her experience with her disease and past treatment options has resulted in a level of maturity that exceeds her age. The patient understands the nature of the proposed treatment. She has voiced the opinion that she does not wish to proceed with the experimental regimen, an opinion not shared by her mother. Given her level of maturity, failure to respect her wishes, especially regarding an experimental treatment regimen that is unlikely to alter the course of her illness, would be profoundly disrespectful and potentially harmful, leading to feelings of isolation and distress.
Recommendations: Situations like this does not lend themselves to easy solutions. The challenge for physicians is to do so in a way that is both sensitive and respectful of the child's and parents' need which are in conflict with one another. The best option is to provide space where the patient and mother can freely talk about their choices and reasons which will lead to a solution that is acceptable to both. The patient needs her mother to hear what she is saying and our role in this case is not to simply override her desires, but to facilitate the opportunity for her mother to understand what she needs in the difficult situation. In this case, assent was accepted and encouraged.	

Conclusions

Social work support and role on the multidisciplinary team is crucial in the care of children with neurological complexities, limitations and QOL challenges.

Ongoing assessments and interventions by social work adds value to the multidisciplinary approach.

Ongoing collaboration enhances the social work mental health assessment and treatment plan.

Social work interventions improve and empower survivors to take charge of their own health, promote a healthy lifestyle, provide education about late effects and minimize risks.

Future Direction

- Focusing on specific diseases and the limitations associated with those diseases may be helpful to be proactive in developing a specific care plan to support the vulnerabilities of these patients.
- Studying the different methods of improving QOL in pediatric brain tumor patients by continued use of psychosocial support and therapeutic interventions to find the most effective approach.
- Long term follow up clinics will encourage emotional and social functioning assessments for community based needs.

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