Psychosocial care for children with cancer and their families

A panel discussion with

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Mattie Miracle Cancer Foundation (Discussants)

Coalition Against Childhood Cancer (CAC2) 2016 Summit and Annual Meeting
Today’s session

- Define psychosocial care and its importance
- Psychosocial services overview and team members
- How psychosocial teams work
- Overview of the 15 Psychosocial Standards of Care in Pediatric Cancer with in depth presentations of 4 standards – psychosocial care to meet the standards
- Questions and discussion
What is Psychosocial?

- *Adjective* psy·cho·so·cial \ˌsī-kō-ˈsō-shəl\ involving both psychological and social aspects

- Consistent with a "whole person" view

- Includes the family or family-centered care

- Takes into account the broader systems that impact access to care, development and adaptation. For example:
  - School
  - Community
What is psychosocial care and why is it important?

The range of psychosocial topics is broad and all warrant attention in their own right…

…adjustment to illness/treatment, coping (child, siblings, parents), anxiety, depression, pain, procedures, adherence to treatment, uncertainty, financial difficulties, insurance, schools, peers, communities….

Psychosocial care:
- facilitates good medical care
- improves quality of life for all during treatment and into survivorship
- prevents escalation in distress and promotes positive adaptation
History of psychosocial care in pediatric cancer (CHOP):

Audrey Evans and Anna Meadows
Early research on psychosocial & neuropsych factors

Growth in psychosocial staff, teams and research
Who are the members of the psychosocial team?

- Social workers
- Psychologists
- Child life specialists
- Psychiatrists
- Neuropsychologists
- Patient Navigators
- Chaplains
- Creative Arts Therapies (art, music)
- Hospital school teachers and educational specialists
- Resource specialists
- Child Activity Coordinators
- Trainees (pre and post doctoral)
- Caregivers and other family members
How do psychosocial teams work?

Models (and resources) differ across cancer centers:

- Highly integrated with medical care
- Referrals to relevant hospital departments
- Consultation-liaison teams
- External referrals ("refer out" to the community)
- Need for benchmark data
Pediatric Psychosocial Preventive Health Model

**Clinical/Treatment**
- Consult behavioral health specialist.
- Intensify psychosocial services.
- Address impact on medical treatment.

**Targeted**
- Monitor child/family distress and risk factors.
- Provide interventions specific to symptoms or adherence needs.

**Universal**
- Provide psychoeducation and family-centered support.
- Screen for indicators of higher risk.

- Severe, escalating, or persistent distress.
- Acute or elevated distress. Other risk factors present.
- Children and families are distressed but resilient.

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Psychosocial Standards of Care in Pediatric Cancer

- Multidisciplinary group of ~80
- Identified key areas
- Conducted a series of 15 systematic reviews of the literature from 1995-2015
- Scientifically rigorous evaluations of the literature
- Derived a standard for each of the 15 areas
- Standards are intentionally broad
- Published in *Pediatric Blood and Cancer* December 2015

[www.mattiemiracle.com/standards](http://www.mattiemiracle.com/standards)
Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs.
Neuropsychological Concerns

Patients with brain tumors and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment.
Meeting the Standard on Neuropsychological Concerns at CHOP

(Targeted Level of Care)

Lamia P. Barakat
Why monitor neuropsychological functioning?

- Children and adolescents have experienced:
  - interrupted brain development due to oncologic genetic conditions
  - location of brain tumor
  - surgery, chemotherapy, and/or radiation
  - any treatment directed to the central nervous system
- These factors place them at risk for neuropsychological deficits
- Patients most at risk are those treated for brain tumors, ALL and NF
Goals of neuropsychological assessment

- Help caregivers and teachers better understand the child’s cognitive development after cancer diagnosis and treatment
- Help caregivers advocate for their child in the school (IEPs or 504 Accommodation Plans)
- Help identify need for additional resources and/or intervention
- Help plan for the child’s future
Domains assessed

- Intellectual Functioning
- Language Functioning
- Learning and Memory (Visual and Verbal)
- Visual-Motor and Visual-Spatial Functioning
- Attention
- Processing Speed
- Executive Function Skills--"how" skills (e.g., inhibition, planning, organization, self-monitoring) are out of sync with "what" skills (e.g., specific knowledge of facts)
- Emotional and Social Functioning
Neuropsychological assessment through the CHOP Cancer Center

- Two pediatric neuropsychologists with expertise in oncology perform ≈ 200 neuropsychological assessments per year
  - Clinical assessments primarily through referrals from the Survivorship Program and Neuro-Oncology Section
  - Proton therapy protocol
  - Assessments through research:
    COG ALTE07C1 and other consortium studies
    BMT protocol; Neuroblastoma protocol
Evidence-based interventions for neuropsychological late effects at CHOP

CogmedRM for children with brain tumors
(Hardy et al., 2003)

- Two research protocols for children with brain tumors post-radiation treatment
- CogmedRM as part of clinical care for children who demonstrate working memory deficits on neuropsychological assessment
Executive Functioning Clinic at CHOP

- Neuropsychology consultation to Multi-disciplinary Survivorship and NF clinics that includes:
  - Parent proxy and patient self-report screener for neuropsychological functioning
  - Identify barriers to success, provide anticipatory guidance (understand functioning from a brain-based perspective) and make recommendations (tips and tricks)

- Enhanced web resources tailored by age and neuropsychological challenges
Neuropsychological assessment: Quality Improvement initiatives at CHOP

- Prior QI projects: educational needs of patients and survivors (Hocking et al.):
  - Significant ongoing concerns regarding school functioning
  - Patients with brain tumors and patients with solid tumors most at risk for ongoing educational challenges
  - Support needed for negotiating with schools on obtaining school evaluations, 504 plans, accommodations and IEPs

- Current QI projects: evaluate family satisfaction with neuropsychological assessment, feedback and report, and follow-up
Moving Forward at CHOP . . .

- EF Clinic available to all patients/families at risk for neuropsychological deficits
- Special education teacher on staff
- Additional interventions during and after treatment including targeting social functioning
- Research to increase understanding of risk factors for more severe neuropsychological deficits
- Barriers: Billable clinical service; Funding for education liaison
Survivorship

Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for
a) adverse educational and/or vocational progress, social and relationship difficulties;
b) distress, anxiety, and depression, and
c) risky health behaviors.

Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life long follow-up care by the time treatment ends and repeated at each follow-up visit.
Youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed.
Assessment of financial hardship should be incorporated at time of diagnosis for all pediatric oncology families. Domains of assessment should include: pre-existing low income or financial hardship, single parent status, distance from treating center, anticipated long/intense treatment protocol and parental employment status. Targeted referral for financial counseling and supportive resources should be offered. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement.
Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child and family well being.
Meeting the Standard on Parent/Caregiver Mental Health at CHOP

(Universal and Targeted Levels of Care)

Chelsea Keeler
The Role of the CHOP Social Worker: Navigation

- Every family in the Cancer Center is assigned a social worker.
  - Point of contact to address impact of diagnosis across entire family within the whole unit or environment in which they live.
- 10 full time social workers, specializing in specific diagnoses: Leukemia/lymphoma, solid tumors, neuro oncology, bone marrow transplant.
- Patient Resource Navigator
The Role of the CHOP Social Worker: Assessment to Guide Intervention

- Social work completes an initial psychosocial assessment with every family at diagnosis
  - Re-assessments as needed and throughout treatment, including relapse

- Psychosocial assessment includes:
  - Family structure
  - Mental Health History
  - Housing/lodging
  - Transportation
  - Financial picture
  - Sibling Needs
  - Work
  - Patient/Family Coping
  - School
  - Insurance

- Also, respond to needs identified through psychosocial screening assessed through research at diagnosis and as the child moves off treatment (2 protocols)
The Role of the CHOP Social Worker: Education

- Social workers incorporate teaching within the therapeutic relationship

- Social work (and Child Life) participate in Patient Family Education (PFE) at diagnosis in collaboration with nursing

- Distribute educational materials to family
The Role of the CHOP Social Worker: Counseling

- Inpatient Caregiver Support Groups:
  - Inpatient Newly Diagnosed Group
  - Inpatient Spiritual Care Group
  - Inpatient Art Therapy Group
- Outpatient Caregiver Support Groups in conjunction with sibling/patient groups
- Social workers and psychologists trained in Surviving Cancer Competently Intervention Program (SCCIP) and Bright IDEAS
- Caregiver Webinar Series
- Additional Caregiver Support
  - Ronald McDonald Room
  - Caregiver support materials in caregiver binder provided at diagnosis
The Role of the CHOP Social Worker: Collaboration

- Coping and Mental Health needs addressed by:
  - Social Work
  - Child Life
  - Psychology and Psychiatry as needed
Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care.
Youth with cancer and their family members should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological interventions for invasive medical procedures.
Meeting the Standard on Preparation for Procedures at CHOP

(Universal and Targeted Levels of Care)

Rebecca Rector
The Role of a Child Life Specialist

- Provide opportunities for your child to play as a way to normalize the hospital experience and support development.
- Prepare patients for medical procedures using language that children understand.
- Provide support during medical procedures.
- Explain a patient’s diagnosis and treatment plan through use of age-appropriate language.
- Provide opportunities for expression and support for patients and siblings through keepsake making and at end of life.
CHOP Cancer Center Child Life & Creative Arts Services

- Inpatient Oncology
  - 3 Child Life Specialists
  - 1 Child Activity Coordinator
  - Music and Art therapy groups and referrals

- Outpatient Oncology Clinic
  - 2 Child Life Specialists
  - Music and art therapy group

- Radiation Oncology
  - 2 Child Life Specialists

- King of Prussia Oncology Clinic
  - 1 Child Life Specialist (also covers radiology)

- Voorhees Oncology Clinic
  - 1 Child Life Specialist
The Role of Child Life through Treatment

- Coping trends are often set at diagnosis. http://pediatrics.aappublications.org/content/133/5/e1471

- Child life specialists provide patients with safe outlets for therapeutic expression in all phases of treatment beginning at diagnosis.

- Child Life is a consistent service that provides continuity of care throughout treatment.

- Child Life and Creative Arts Therapies promote normalcy by providing therapeutic experiences and events for patients and families.
  - Playroom groups & volunteers
  - Prom & Battle of the Bands
  - AYA & Oncology Sibology
  - Parkway Run & Beyond Cancer
Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patients’ unique characteristics. The patient, parent(s) and a psychosocial team member...should participate in this evaluation at time of diagnosis, throughout treatment and when the patient enter survivorship; it may be helpful to include school personnel or additional providers.
Siblings of children with cancer are a psychologically at-risk group and should be provided with appropriate supportive services. Parents and professionals should be advised about ways to anticipate and meet siblings’ needs, especially when siblings are unable to visit the hospital regularly.
School

... school age youth diagnosed with cancer should receive school re-entry support ... providing information to school personnel about the patient’s diagnosis, treatment and implications for the school environment ... Pediatric oncology programs should identify a team member ... who will coordinate communication between the patient/family, school and the health care team.
Adherence should be assessed routinely and monitored throughout treatment.
Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status. When necessary, youth and families should receive developmentally appropriate end of life care which includes bereavement care after the child’s death.
Bereavement

A member of the healthcare team should contact the family after a child’s death to assess family needs, to identify those at risk for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.
Meeting the Standard on Bereavement at CHOP
(Universal and Targeted Levels of Care)

Chelsea Keeler and Rebecca Rector
Social Work Support at End of Life at CHOP

- Voicing My Choices
  - Advanced Directives
  - Healthcare Power of Attorney
Who I Want to Make My
Medical Care Decisions
If I Cannot Make Them On My Own

There might be a time when you cannot make medical decisions for yourself. If this happens, it might be necessary for someone else to speak with the doctors and make decisions about your medical care. This person, called a healthcare agent, would make sure that your thoughts or wishes are respected.

Things To Consider When Choosing a Healthcare Agent:
It can be helpful to choose someone who knows you well, cares about you, lives nearby, and can make difficult decisions. If you are under the age of 18, your parents/guardians will have legal rights to make decisions, so the person you recommend can be your parents/guardian or someone you would like your parents/guardians to work with.

Remember:
• Your healthcare agent must be at least 18 years old.
• Your healthcare agent cannot be your doctor or any of your other healthcare providers, nor can it be an employee of any of your healthcare providers.
• To talk to the people you are choosing to make sure that they agree to follow your wishes.

The person I want to make healthcare decisions for me is:

First Person Name:

Address:

Phone:

If the person I chose above is somehow unavailable, others who can make healthcare decisions for me are:

Second Person Name:

Address:

Phone:

Third Person Name:

Address:

Phone:

I give my healthcare agent permission to make these choices for me about my medical care or services.
(Please check all that apply)

To allow or refuse:
- Test
- Medicines
- Surgeries
- Other care that can help keep me alive
- Medication(s) or procedure(s) to help with pain
- Stop previously started treatment
- Donate usable organs and/or tissue of mine if it can help others

Act on my behalf:
- Hire and/or fire any healthcare worker I may need to take care of me
- See and approve release of my medical records
- Apply for Medicaid or insurance benefits for me
- See my personal files, like bank records, to access necessary information
- Perform any necessary legal action(s)

Arrange for:
- I hospital or hospice admission
- Admission to a facility in another state to get the care I need or to carry out my wishes
- My healthcare agent is also allowed to make decisions based on conversation(s) we have had about my wishes and what I believe my wishes to be.

Other things I wish my health care agent to do are:

____________________________________________________

6
How I Wish To Be Remembered

My Remembrance

- I prefer not to be a part of planning my service.
- I prefer to plan my service. (Please check all that apply)

<table>
<thead>
<tr>
<th>The type of service(s)</th>
<th>I would like:</th>
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<tbody>
<tr>
<td></td>
<td>To be buried</td>
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<tr>
<td></td>
<td>To be cremated</td>
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<tr>
<td></td>
<td>To donate my body</td>
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<td></td>
<td>To be an organ donor</td>
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<td>A limited autopsy</td>
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<td>A standard autopsy</td>
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<td></td>
<td>A research protocol autopsy</td>
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<td></td>
<td>I would like my healthcare agent to make the autopsy decision</td>
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</tbody>
</table>

The clothes that I would like to be wearing (for service/cremation/burial) are:

The items that I would like to be with me are:

The music/food I want at my service are:

The people I would like to be present are:

I would like these readings at my service:

I would like these other arrangements at my service:

If my family or friends want to make contributions or donations I would like them to go to:
Social Work Support at End of Life at CHOP

- Provide support through end of life decisions
  - DNR, withdrawing care

- Partnership with Pediatric Advanced Care Team (PACT)

- Collaborate with other psychosocial team members (psychology, creative arts therapists, chaplains) as well as medical team to provide support to patient and their family throughout end of life care
Child Life Support at End of Life at CHOP

- The journey of keepsake making…
- Doesn’t always begin at end of life but often at time of diagnosis.
- Child life specialists can provide safe outlets for patients to talk about death and dying allowing for ideas of legacy building.
  - Art, music, trips, video diaries, letters to loved ones, etc.
Child Life Support at End of Life at CHOP
Social Work Support after the Death of a Child at CHOP

- At immediate end of life
  - Walk parents to car
  - Assist with funeral home identification and identify financial support as needed

- After families have left the hospital
  - Contact from social worker, by phone, email, and mail
  - Assess for family coping and distress
  - Referral to PACT bereavement social worker as needed
  - Family invited to bereavement events, including yearly hospital-wide Candle Lighting Ceremony
  - Coordinate CHOP visits

- Seasons of Grief
Seasons of Grief

- Retreat for bereaved caregivers who lost their child to cancer since 2014

- Share memories of their children
- Connect with other bereaved families
- Share approaches for managing grief
- Offered 3 times a year and now funded through donation from bereaved family
Moving forward…

- How can we better support our patients and families at end of life?
  - Increased resources for end of life care including: improved staffing of and communication with Pediatric Advanced Care Team (PACT), and more programs for bereaved families.
- Earlier involvement with patients and families facing complicated prognosis, progressive disease or relapse, or end of life.
- Oncology specific palliative care team: PACT vs Oncology PACT (Social work, child life, art and music therapies, psychology and chaplain)
- Address barriers to ongoing care following the death of the child including child is not longer a patient.
Communication, Documentation and Training

Pediatric psychosocial professionals should
…be integrated into pediatric oncology settings as
integral team members....
... follow documentation policies of the health systems
where they practic...
...have specialized training and education and be
credentialled in their discipline...
...have ongoing relevant supervision/peer support
Discussion and Questions