

Psychosocial Care for Children with Cancer and their Families

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A little about Me...

- Leukemia/Lymphoma Social Worker at Helen DeVos
 - 3 ½ years
- Former School Social Worker
 - 4 ½ years
- Involved in the disability community
- Avid Pie Baker, Dog Lover, Traveler, and Symphony Fan



Learning Goal

At the end of this presentation, you will have a knowledge and understanding of the pediatric psychosocial standards of care as it applies to pediatric oncology patients in the state of Michigan.

Agenda

- Psychosocial Standards of Care
- Standard of Care as it related to HDVCH Peds Hem/Onc
- Questions

Pediatric Psychosocial Standards of Care₁

- Psychosocial care looks different from institution to institution
- Project started in 2012 with a Congressional Briefing
 - Data was needed for funding to address psychosocial needs
 - Led to workgroups, surveys, literature reviews, and overall appraisal of information
- Focus developed on the following:
 - Assessment of Child and Family Well-Being
 - Neurocognitive Status
 - Psychotherapeutic Interventions
 - School Functioning
 - Communication, Documentation, and Training of Psychosocial Services

15 Standards for the Psychosocial Care of Children with Cancer and Their Families

Standard 1

Youth with cancer and their families should routinely receive systematic assessments of their psychosocial health care needs.

Standard 2

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.

Standard 3

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 should also receive anticipatory guidance on the need for life-long follow-up health care.

Standard 4

Youth with cancer and their families should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed.

Standard 5

Assessment of risk for financial hardship among pediatric oncology families should be incorporated at time of diagnosis. Targeted referral for financial counseling and supportive resources (e.g., governmental/charitable supports) should be offered as needed along with longitudinal reassessment and intervention.

Standard 6

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.

Standard 7

Youth with cancer and their families should receive individualized psychoeducation, information and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation.

Standard 8

Youth with cancer should receive developmentally appropriate preparatory information about, as well as psychological intervention for, invasive medical procedures.

Standard 9

Youth with cancer should be provided opportunities for social interaction during and after cancer treatment according to developmental level, preferences for social interaction, and health status.

Standard 10

Siblings of youth with cancer should be provided with appropriate psychosocial support services.

Standard 11

In collaboration with parents, school-age youth with cancer should receive school reentry support, focused on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment.

Standard 12

Adherence should be assessed routinely and monitored throughout treatment.

Standard 13


Regardless of disease status, youth with cancer and their families should be introduced to palliative care concepts to reduce suffering. When necessary, individualized end-of-life and bereavement care plans should be developed.

Standard 14

A member of the health care team should contact the family after a child's death to assess family needs, identify individuals at risk for negative psychological sequelae, continue care, and provide resources for bereavement support.

Standard 15

Open, respectful communication and collaboration between and among medical and psychosocial providers, patients, and families is essential.



**Youth with Cancer
and their families
should routinely
receive systematic
assessments of their
psychosocial health
care needs.**

- Initial assessment–full biopsychosocial evaluation
- PORT supports
- Assigned Social Worker for every patient
- PHQ/GAD assessment




Youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological intervention for invasive medical procedures.¹

- Child Life
- Open and honest communication
- Recognizing treatment as trauma
- ACT (survivor) clinic



Youth with Cancer and family members should have access to psychosocial support and interventions throughout their cancer trajectory and access to psychiatry as needed,

- Helen DeVos Psychiatry and Psychology
 - Dedicated oncology psychologist
- Child Life Support
- Local Resources
 - Gilda's Club
 - Children's Healing Center

A decorative graphic on the left side of the slide consists of several hexagons. There is a large orange hexagon in the center, a smaller light blue hexagon above it, a white outline hexagon to its left, and a small orange hexagon below it.


**Assessment of risk for
financial hardship
should be
incorporated at time
of diagnosis for all
pediatric oncology
families.¹**

- Initial assessment
- Secondary insurance
- Government assistance
- Support organizations



**Children and Adolescent
with Cancer should be
provided opportunities
for social interaction
during cancer therapy
and into survivorship
following care
consideration of the
patient' unique
characteristics,**

- Covid challenges
- Child Life
- Informal connections
- AYA outings
- Camps/Retreats
- Children's Healing Center




**Siblings of children
with cancer are a
psychosocially at-risk
group and should be
provided with
appropriate
supportive services.**

- Sibling Bags
- Sibling Books
- Super Sibs
- Clinic specific challenges



In collaboration with parents, school-age youth diagnosed with cancer should receive school re-entry support that focuses on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience.

- HDVCH School Team!
 - Visits
 - Support with classroom
 - IEP/504 guidance
 - Check Ins
- Neuropsychology testing

A decorative graphic on the left side of the slide consists of several hexagons. The largest is a solid orange hexagon in the center. To its top right is a smaller, light blue hexagon. To its bottom right is a smaller, solid orange hexagon. To its bottom left is a white outline of a hexagon. To its left is another white outline of a hexagon, partially overlapping the large orange one.

**Adherence should be
assessed and
monitored throughout
treatment₁**

- Conversations throughout treatment
- Removing barriers
- Child Protective Services



A member of the health care team should contact the family after a child's death to assess family needs, to identify those for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.

- Call to family
- Attendance at funeral
- PORT supports
- Check ins on big days

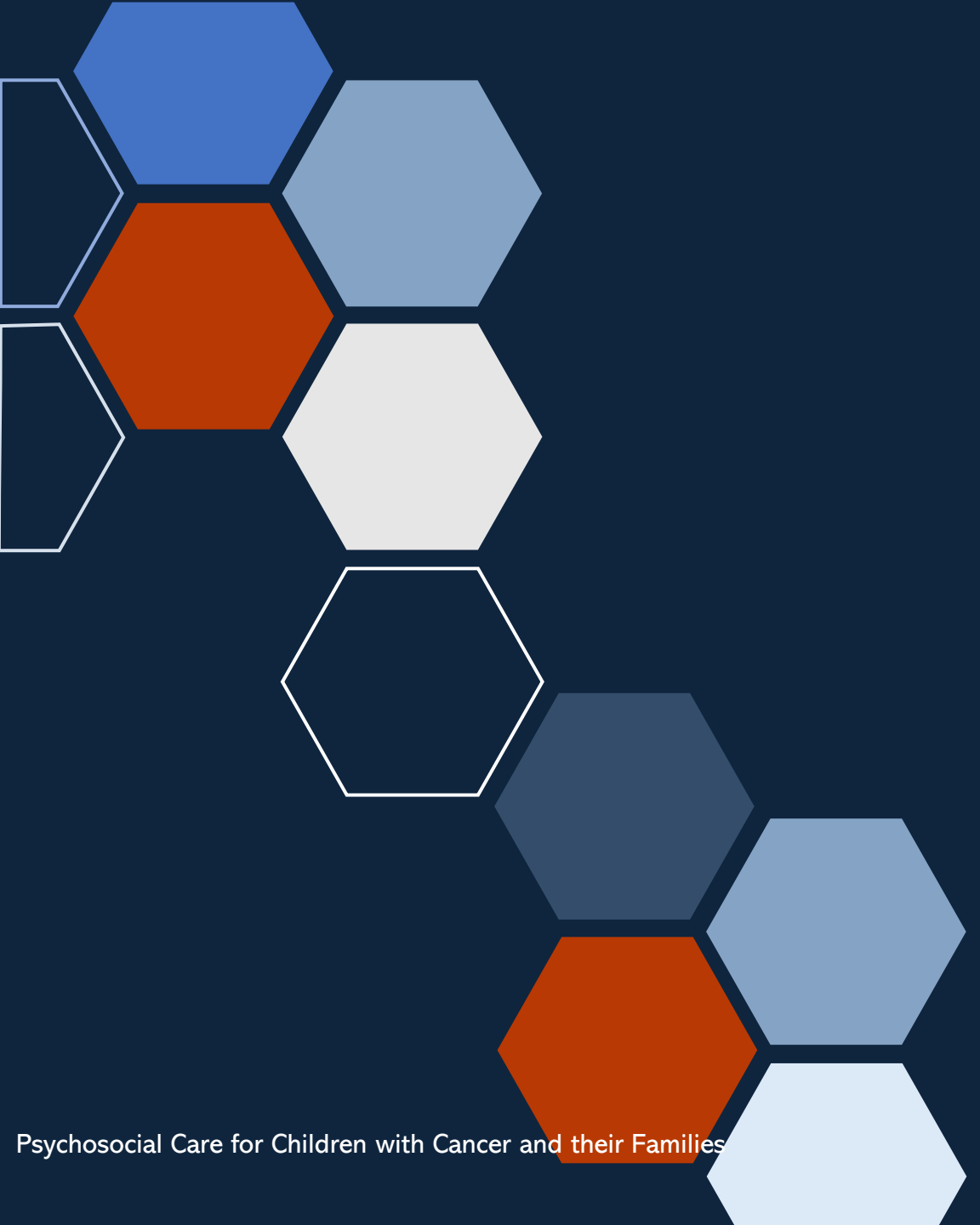


Open, respectful communication and collaboration among medical and psychosocial provider, patients and families is essential to effective patient-and family-centered care.

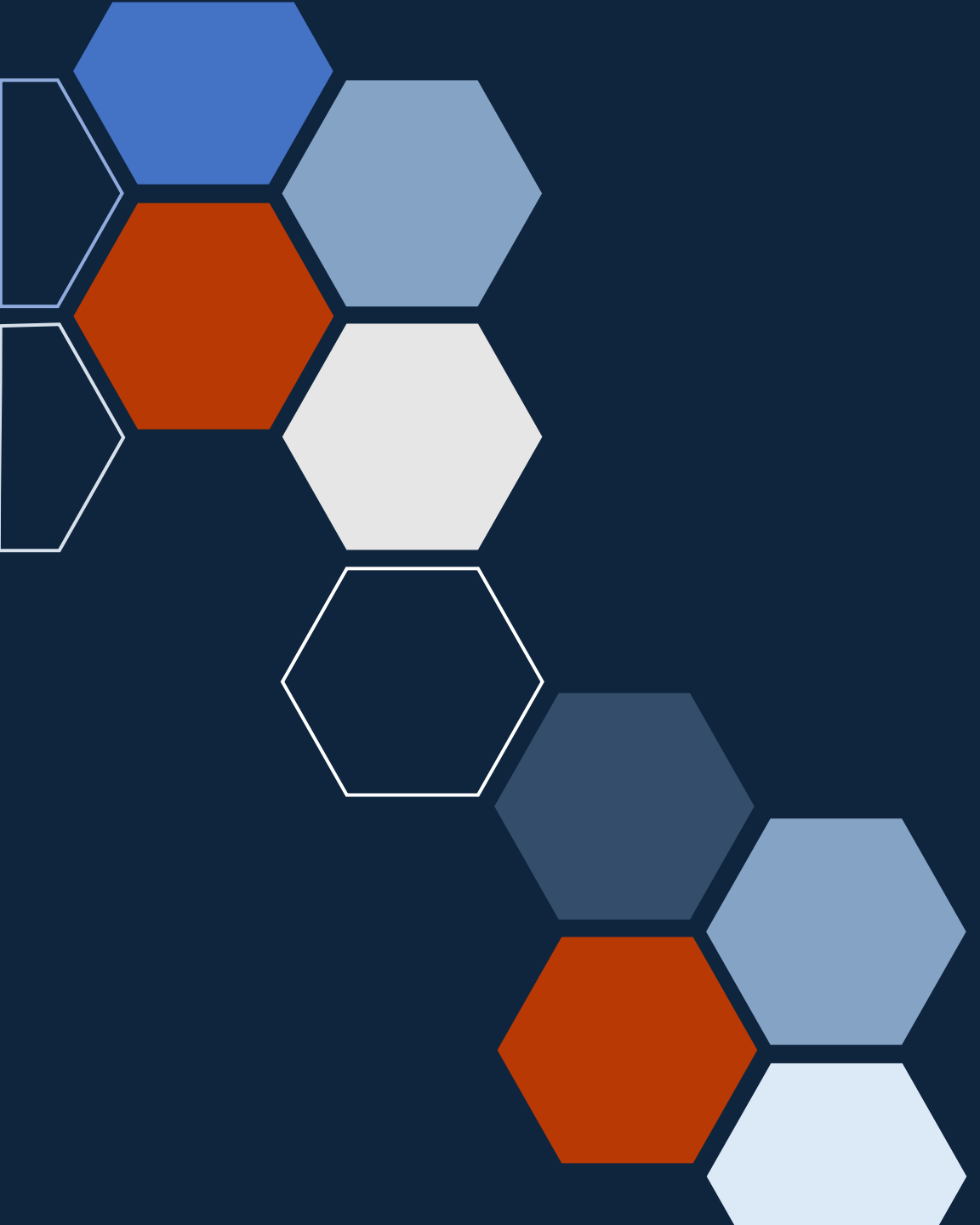
- Dedicated teams for diagnosis
- Social work as active participants in treatment teams
- PHQ/GAD Screening

References

1. Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for the Psychosocial Care of Children With Cancer and Their Families: An Introduction to the Special Issue. *Pediatr Blood Cancer*. 2015 Dec;62 Suppl 5(Suppl 5):S419-24. doi: 10.1002/pbc.25675. Epub 2015 Sep 23. PMID: 26397836; PMCID: PMC6397048.
2. Jones JK, Evans JF, Barfield RC. The Utility of Verbal Therapy for Pediatric Cancer Patients and Survivors: Expressive Writing, Video Narratives, and Bibliotherapy Exercises. *Front Pediatr*. 2021 Feb 4;9:579003. doi: 10.3389/fped.2021.579003. PMID: 33614548; PMCID: PMC7889798.



Questions?



Thank you

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