



Psychosocial Care of Off-Therapy Patients

Meg Canady, LCSW
Kimberly Volner, LCSW



Learning Objectives

- Identify and discuss the psychosocial needs of children with cancer and their families at the end of treatment and into survivorship.
- Recognize interventions social workers can incorporate into their practice for this population.
- Describe opportunities for interdisciplinary collaboration and leadership.



Literature Review

- It is well known that our patients are at increased risk of disease- and treatment-related physical and cognitive effects, needing access to local healthcare and medication management, special education, mental and behavioral health intervention, disability supports, and rehabilitation services



Literature Review

- There is some information in literature about life immediately following the completion of treatment (COT)
- Little to no information about programs implemented to assist with the transition off treatment
- Recurring issues in literature were also noted during off treatment social work assessments



Literature Review

- Recurring issues
 - Long-term/late physical side effects of treatment
 - Academic issues
 - Loss to follow up
 - Mental/behavioral health concerns
 - Anxiety (fear of relapse)
 - Loss of support
 - Mixed emotions (excitement, anxious, etc.)
 - Quality of life after treatment



Brief Review of Risks



Cognitive and Physical Risks

- Disease-specific risks (e.g., brain tumor)
- Treatment-related effects
 - acute (e.g., radiation necrosis, limb sparing)
 - following completion (e.g., cognitive late effects, physical impairments)
- Other
 - pre-existing medical incidents (e.g., traumatic brain injury)
 - genetic disorders
 - neurodevelopmental conditions (e.g., autism spectrum disorder, intellectual disability)



Psychosocial Risks

- Socioeconomic status
 - poverty, transportation
 - lack of health insurance, ~15% of St. Jude patients
- Mental health
- Quality of life
- System navigation
 - community resources; state-funded programs; disability income; legal representation; immigration



Social Justice Risks in Communities

- In the community, variable access to resources including:
 - specialized education
 - mental health services
 - health insurance, with coverage for psychological needs
 - rehabilitation therapies
 - vocational programming
 - disability supports

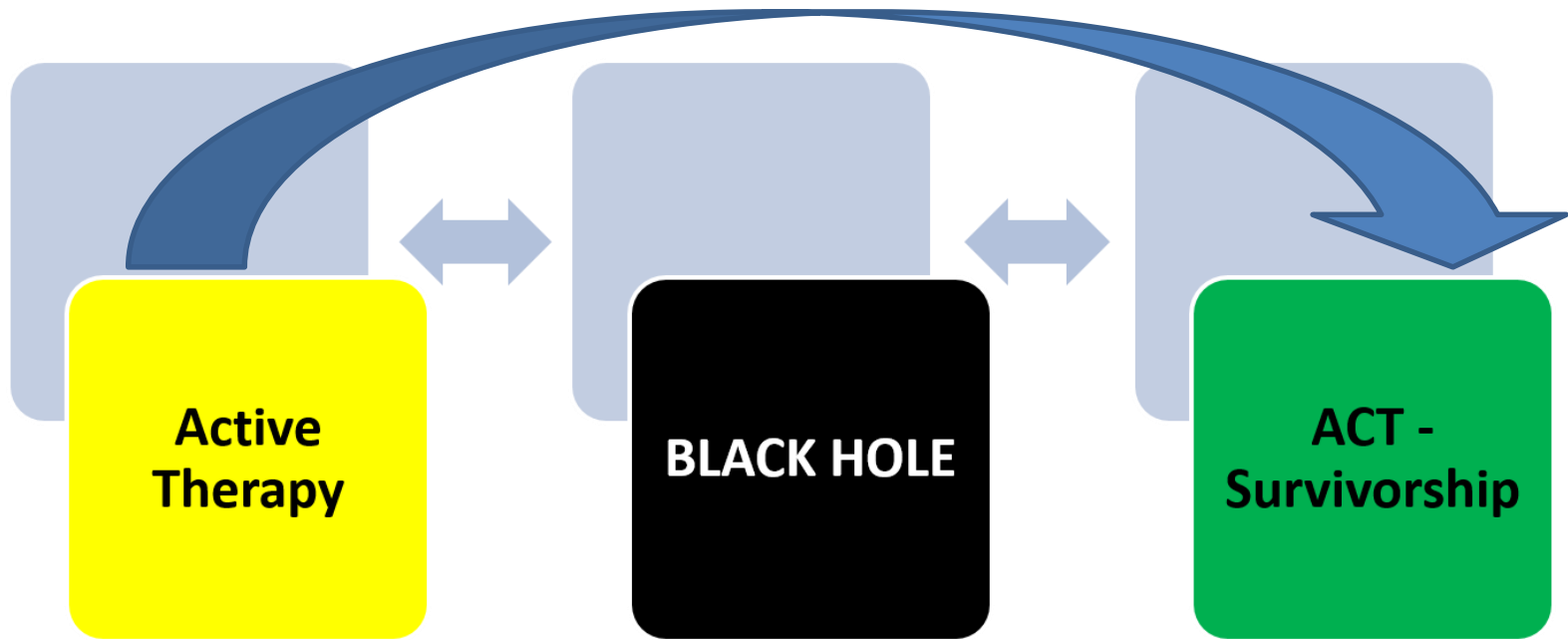


BACKGROUND

- Institutional level transition committee formed in 2011 to discuss the needs for transitioning patients across continuum of survivorship and into adulthood
- Recommended additional social work resources to provide standard transition psychosocial assessments at specific intervals for patients completing therapy prior to transfer to After Completion of Therapy (ACT) clinic



Transition Process in Oncology Clinics





Transition Survey

- Parents from the Family Advisory Council
- Mixture of closed and open-ended questions
- Questions focused on parents' opinions about the completion of treatment
 - Anxieties
 - Barriers to transition
 - What parents wished they knew prior to going home
 - What we can do to better serve our families during the transition off treatment



What has been the hardest thing YOUR CHILD has experienced since treatment ended?

- Difficulty with social interactions/Social delays
- Academic concerns
- Establishing a new normal
- Fear of relapse
- Physical effects of treatment
- Missing the treatment team

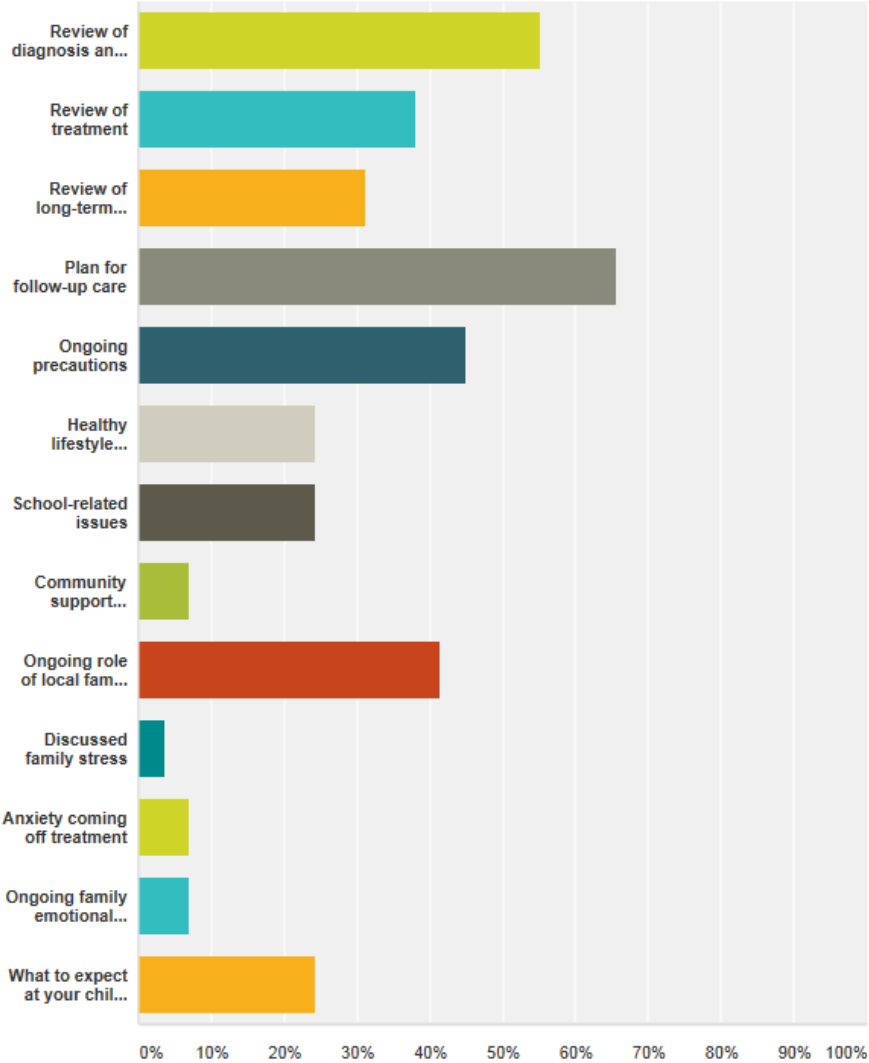


What has been the hardest thing YOUR FAMILY has experienced since treatment ended?

- Academic issues
- Establishing a new normal
- Anxiety and fear of relapse
- Watching my child struggle academically, socially, and physically
- Late effects and cognitive impacts
- Financial insecurity/Finding employment
- Transitioning medical care home
- Insurance coverage
- Lack of information about transition off therapy

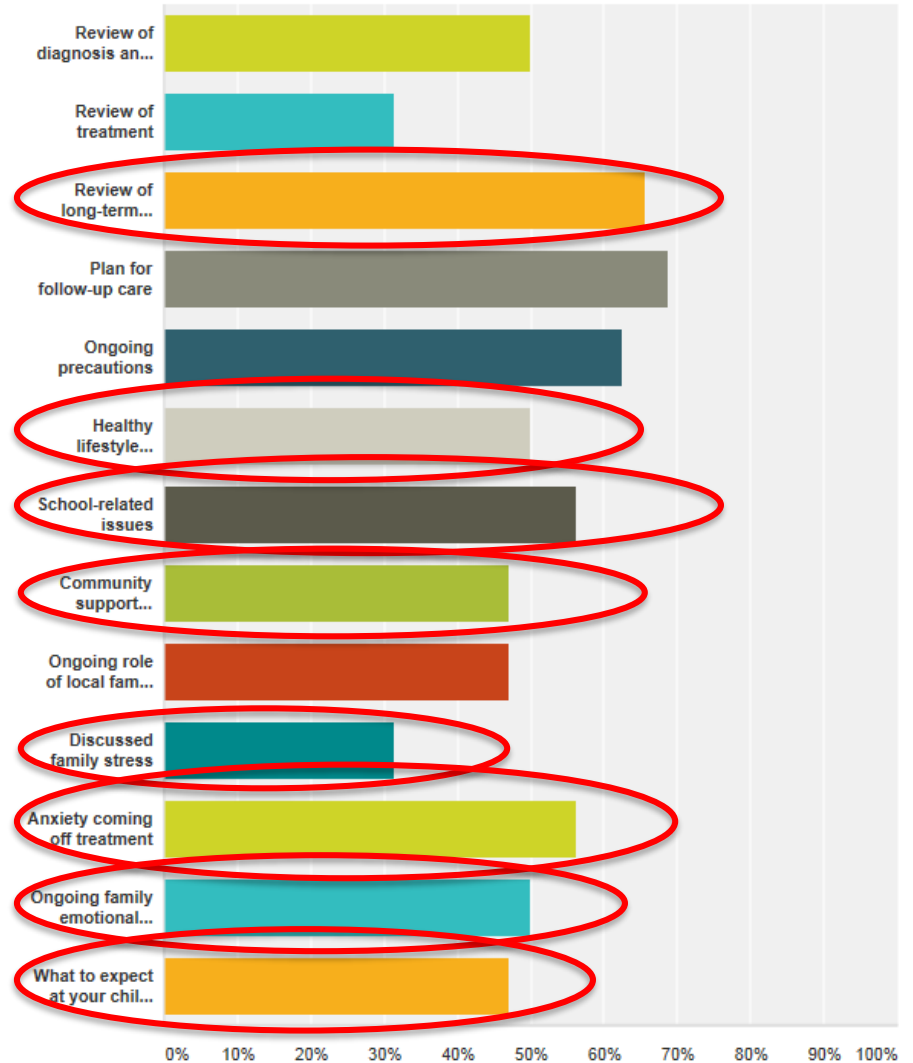
What information did you receive before the end of your child's treatment? Check all that apply.

Answered: 29 Skipped: 5



What information would you have found helpful to receive before the end of your child's treatment? Check all that apply.

Answered: 32 Skipped: 2

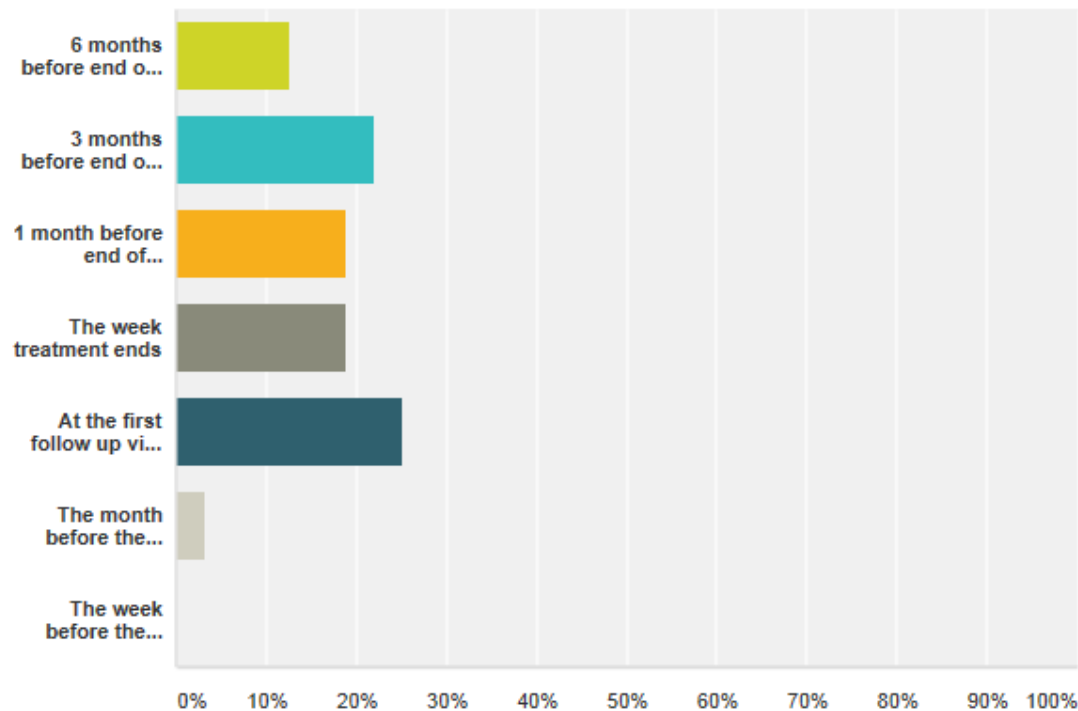




Transition Survey results

At what time point would you want to receive information regarding the end of treatment and long term follow up?

Answered: 32 Skipped: 2





Population

- **Leukemia/Lymphoma Clinic**

- Any off therapy patient
- Target patients as they are completing treatment
- Some orders embedded as patients complete treatment

- **Neuro-Oncology Clinic**

- Patients 2 years post completion of treatment, or
- 5 years post diagnosis of Low Grade Glioma



Social Work Psychosocial Assessments

Provide comprehensive patient and family-centered psychosocial assessments targeting:

- Emotional adjustment to treatment completion and coping post-treatment
- Academic and vocational planning in the home community
- Emotional and behavioral health concerns and local access to services
- Insurance status and access to local care
- Custody and consenting issues post-treatment
- Financial hardship and ability to become self-supporting again
- Healthy lifestyle behaviors



Interventions

- Anticipatory guidance regarding behavioral and emotional expectations
- Supportive counseling
- Referral to community or hospital based resources
- Problem solving
 - Ability to become self supporting again
 - Accessing care without insurance



Resources

- Needy Meds
- National Children's Cancer Society booklet
- American Cancer Society article
- Camp information
- Scholarship information
- Vocational Rehabilitation information
- Got Transition website



Resources

[About Pediatric Cancer](#)[Diagnosis and Treatment](#)[Care and Support](#)[For Families](#)[Life After Cancer](#)

Be Your Own Health Care Advocate

Survivorship Care Plans

Building Relationships with Health Care Providers

[Learn more about being your own health care advocate >](#)

Long-Term and Late Effects

Bladder Late Effects

Bone Late Effects

[Find more late effects >](#)

Healthy Living

Healthy Eating After Cancer

Physical Activity After Cancer

[Learn more about healthy living >](#)

[LEARN MORE ABOUT LIFE AFTER CANCER](#)

School and Work

Financial Aid and College Scholarships

Workplace Training and Services

[Find more school and work resources >](#)

Post-Treatment and Beyond

Transition Off Treatment

[Learn more about post treatment >](#)

Emotional Well-Being

Survivor Stories



Why We're Here



Quotes from Parents

- **“Felt like we were a football punted down the football field”**
- **“Felt like we were thrown from the kiddie pool into the ocean”**
- **“Felt like we had been shoved out the door”**
- **“He [patient] expected a reward every time he did something”**
- **6 years after completing treatment, “we will always worry about relapse”**
- **“I couldn’t sleep for two months before she [patient] completed treatment**
 - **I was terrified to go home with no support**
 - **No one understood**
 - **Our PCP didn’t know about cancer. I felt like I had to educate him.**
 - **A meeting with social work would have been helpful”**



Quotes from Patients

- **Two years after treatment, patient expressed she was just now getting to ‘new normal’**
- **I want to go back to St. Jude “where no one told me no”**
- **4 years after treatment, patient indicated it was hard to talk about cancer shortly after treatment ended but now she writes about her cancer experience for school assignments and brings her friends to St. Jude for visits**
- **Closer to dad because we bonded on car rides to and from St. Jude**
- **I am nervous about scans**
- **Just glad to be done and go home**



Identified Needs



Leukemia/Lymphoma Patient Needs

- **Academic Concerns: 45.7%**

Interventions: Referrals to the School Program for academic advocacy; Referrals to Psychology for updated psychological testing to assist with academic planning; Education for families on Educational Plans and student rights; Ongoing monitoring

- **Mental/Behavioral Health Concerns: 30%**

Interventions: Education on accessing local mental health resources; Identification of local providers; Referrals to Psychology for support; Ongoing monitoring

- **Health Insurance Coverage and Access to Local Medical Care Concerns: 15.7%**

Interventions: Referrals to FirstSource, Identification of local medical and dental providers; Identification of community health resources for the under- and uninsured including local clinics and prescription assistance programs



Neuro-Oncology Patient Needs

- **Academic Concerns: 79.69%**
Interventions: Referrals to the School Program for academic advocacy; Referrals to Psychology for updated psychological testing to assist with academic planning; Education for families on Educational Plans and student rights; Ongoing monitoring
- **Mental/Behavioral Health Concerns: 45.31%**
Interventions: Education on accessing local mental health resources; Identification of local providers; Referrals to Psychology for support; Ongoing monitoring
- **Health Insurance Coverage and Access to Local Medical Care Concerns: 20.31%**
Interventions: Identification of local medical and dental providers; Identification of community health resources for the under- and uninsured including local clinics and prescription assistance programs
- **At-Risk for Needing Conservatorship/Surrogate Decision Maker: 18.75%**
Interventions: Educating families on the conservatorship process and local resources to assist with this; Referrals to Psychology for psychological testing to determine appropriateness of conservatorship



Case examples

- Susie is a 22-year-old female patient who completed treatment for ALL in September 2014.
- She first met with a transition social worker one month post-treatment completion and continued to meet during her follow up visits.



Case examples

- **Problems Identified:**
 - Lack of insurance
 - Barriers to accessing local medical care
 - Questions about college admission
 - Mood concerns and pain management issues related to severe AVN
- **Interventions:**
 - Referred to First Source
 - Referred to School Program
 - Education on accommodations in the college setting
 - Education on Vocational Rehabilitation services
 - Identified local providers
- **Outcomes:**
 - Obtained Medicaid coverage
 - Enrolled in a local college and received financial assistance and appropriate accommodations
 - Able to access local care



Case examples

- Sam is a 7-year-old male patient who completed treatment for ALL in February 2012.
- He first met with a transition social worker in August 2013.



Case examples

- **Problems Identified:**
 - Never attended a full-time school setting
 - Grandmother wanted attending physician to continue to advocate for homebound school services
- **Interventions:**
 - Educated family on importance of school attendance both academically and socially
 - Collaborated with the medical team
 - Referred to School Program
- **Outcomes:**
 - Entered full-time school setting in October 2013
 - Obtained academic accommodations under an IEP



A Multidisciplinary Approach

- Hospital administration identified the need for increased support for patients as they transition off treatment
- Focus groups were formed to identify gaps in care in each oncology clinic
- From the focus groups, it was evident that our transition-related services for oncology patients were **nonsystematic**, **referral-based**, and **crisis-oriented**, with resources in primary oncology clinics, social work, psychology, rehabilitation services, and the school commonly being directed to high-risk patients.



Transition Program Goals

1. Develop a transition program for **all oncology clinics** beginning in the **active therapy** phase
2. Establish **transition staff** for oncology patients
3. Incorporate **technology** and **education** as components of this program
4. Demonstrate strong **adherence** to COG and **psychosocial practice standards**



Standards of Psychosocial Care



Standards of Psychosocial Care in Pediatric Oncology

Pediatric Blood & Cancer Journal

- **Psychosocial screening**
 - assessing and reassessing risks, making referrals, and providing anticipatory guidance
- **Cognitive and mental health surveillance**
 - baseline and changing cognitive functioning; recurring assessment of cognitive disorders; evaluating conservatorship risk; emotional adjustment
- **School entry/re-entry programming**
 - liaison between the patient/family, hospital, and school
- **Financial hardship assessment**
- **Evaluation of medication adherence**



Children's Oncology Group (COG)

- Establish **an approach** in institutions treating children with cancer, linking specialty (e.g., hospital) and primary care providers (e.g., community)
- Develop a **systematic plan of care**, emphasizing transition from
 - therapy to survivorship
 - adolescence to young adulthood
- Improve **awareness** of late effects (e.g., cognitive and physical)



COG:

Nursing Discipline Clinical Practice Subcommittee Survivorship and Late Effects Committee

Therapy to Survivorship	Adolescence to Young Adulthood
<ul style="list-style-type: none">• educate regarding risks	<ul style="list-style-type: none">• involve the patient and family
<ul style="list-style-type: none">• provide a summary of cancer diagnosis and treatment	<ul style="list-style-type: none">• focus on patient as a self-advocate
<ul style="list-style-type: none">• discuss follow-up care	<ul style="list-style-type: none">• identify healthcare providers
<ul style="list-style-type: none">• address emotional issues	<ul style="list-style-type: none">• emphasize importance of minimizing risks
<ul style="list-style-type: none">• promote healthful behaviors	<ul style="list-style-type: none">• educate insurance companies and managed care organizations
<ul style="list-style-type: none">• encourage self-care practices	<ul style="list-style-type: none">• communicate with state and federal legislators



Transition Oncology Program (TOP) Personnel

- Nurse Practitioner Navigators
- Transition Social Workers
- School Liaisons
- Transition Psychologists
- Transition Rehabilitation Coordinator



Nurse Practitioner Navigators

- An **introductory point** to transition programming, educating families about the full range of services in active therapy, treatment completion, and survivorship phases
- Serve as **transition care coordinator** in active therapy and treatment completion phases
- **Educate patients/families** prior to returning home
- Be a **point of contact** for transition needs in the treatment completion phase and after completion of treatment



Transition Social Workers

- Conduct **psychosocial transition assessments** in active therapy and treatment completion phases
 - vocational, educational, and mental and behavioral health
 - insurance status
 - access to local medical care
 - medical decision making (e.g., conservatorship)
 - financial burden
- Provide **intervention**
 - psychoeducation and anticipatory guidance
 - supportive counseling
 - connect to hospital- and community-based resources
- Collaborate with ACT social workers in the treatment completion phase and serve as a **point of contact** to assess barriers for patients who do not show to their first ACT appointment.



School Liaisons

- Assess need for **academic accommodations** or special education services
- **Consult** with patients/families and **educators in the community**
- Function as an **ongoing liaison**, participating in reoccurring special education programming with educators in the community



Transition Psychologists

- Conduct **cognitive surveillance**
- Provide **mental and behavioral health** consultation
- Provide **psychoeducation and anticipatory guidance**



Rehabilitation Coordinator

- **Collaborate with therapists** in St. Jude Rehabilitation Services (e.g., physical, occupational, speech/language therapists; audiologists)
- **Facilitate access to rehabilitation services** in the community across the continuum of care
- **Educate patients/families** about changing rehabilitation needs across the continuum of care from active therapy to alumnus status



Future Directions

- Systematically serve all oncology patients and families
- Deliver services at optimum time points
- Improve integration into the home community, both medically and psychosocially



Acknowledgements

Transition Task Force:

Traci Adams
Sheila Anderson
Christina Bosley
Dr. Kristin Canavera
Pat Cathey
Eric Caron
Dawn Corneau-Dia
Dr. Valerie Crabtree
Sheila Dalrymple
Dr. James Downing
Dr. Pat Flynn
Justin Gardner
Dr. William Greene

Valerie Groben
Dr. Jennifer Harman
Jo Ann Harper
Joni Holdiness
Dr. Melissa Hudson
Margery Johnson
Dr. Niki Jurbergs
Jeanette Lavecchia
Laurie Leigh
Martha May
Dana McLure
Dr. Andrew Molnar
Dr. Daniel Mulrooney

Dr. Ellis Neufeld
Dr. Kendra Parris
Dr. Nehali Patel
Zoey Phelps-Bergeron
Jane Raymond
Justine Rodriguez
Kristin Scobey
Daniel Smith
Jessica Sparrow
Kathy Steuer
Dr. Anna Vinitzky
Alicia Wright

TOP Team:

Nurse Practitioners:
Elizabeth Barnwell, FNP
Emily Browne, DNP, PNP
Sandra Jones, DNP, PNP

School Liaisons:
Justin Gardner
Sarah Klein
Allison Young

Psychologists:
Brian Potter, PhD
Rachel Tillery, PhD
Rehab Coordinator:
Regina Wilkes, RN

Family Advisory Council

St. Jude Patients and Families



References

- Annett, R., Patel, S., and Phipps, S. (2015). Monitoring and Assessment of Neuropsychological Outcomes as a Standard of Care in Pediatric Oncology. *Pediatric Blood Cancer*; 62, 460–513.
- Canter, K. and Roberts, M. (2012). A Systematic and Quantitative Review of Interventions to Facilitate School Reentry for Children With Chronic Health Conditions. *Journal of Pediatric Psychology*, 37(10), 1065–1075.
- Chan S., Hoag J., Karst J., and Bingen K. (2018). Social adjustment of adolescent cancer patients transitioning off active treatment: a short-term prospective mixed methods study. *Pediatric Blood & Cancer*, e27530.
- Conklin, H., Xiong X, L., Ogg, RJ., Merchant, T. (2008). Predicting change in academic abilities after conformal radiation therapy for localized ependymoma. *Journal of Clinical Oncology*; 26, 3965-3970.
- Conklin, H., Krull, K., Reddick, W., Pei D., Cheng C., and Pui CH. (2012) Cognitive outcomes following contemporary treatment without cranial irradiation for childhood acute lymphoblastic leukemia. *Journal of the National Cancer Institute*; 104, 1386-1395.
- Landau, M.E, Kenney, K., Deuster, P., and Campbell, W. (2012). Exertional rhabdomyolysis: A clinical review with a focus on genetic influences. *Journal of Clinical Neuromuscular Disease*, 13(3), 122-136.
- Lown, E., Phillips, F., Schwartz, L., Rosenberg, A., and Jones, B. (2015). Psychosocial Follow-Up in Survivorship as a Standard of Care in Pediatric Oncology. *Pediatric Blood Cancer*; 62, 514–584.
- Mody, R., Li, S., Dover, DC., Sallan, S., Leisenring, W., and Oeffinger, KC. (2008) Twenty-five-year follow-up among survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. *Blood*; 111 (12), 5515-5523.



References

Moitra, E. & Armstrong, C.L. (2013). Neural Substrates for Heightened Anxiety in Children with Brain Tumors. *Developmental Neuropsychology*, 38, 337-351.

Moore, Gary. (2015). The Physical Environment and Cognitive Development in Child-Care Centers. *Spaces for Children*; 41-72.

Nathan P., Hayes-Lattin B., Sisler J., & Hudson M. (2011). Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer*, 117, 2335-2341.

Palmer KT., Bonzini M., Harris EC., Linaker C., and Bonde JP. (2013) Work activities and risk of prematurity, low birthweight, and pre-eclampsia: an updated review and meta-analysis. *Occupational and Environmental Medicine*;70(4),213–222

Pelletier, W. and Bona, K. (2015). Assessment of Financial Burden as a Standard of Care in Pediatric Oncology. *Pediatric Blood Cancer*;62, 619–631.

Pui CH., Sandlund JT., Pei D., Rivera GK., Howard SC., Ribeiro RC., Rubnitz JE., Razzouk BI., Hudson M., Cheng C., Raimondi SC., Behm FG., Downing J., Relling MV., and Evans WE. (2003) Results of therapy for acute lymphoblastic leukemia in black and white children. *JAMA*; 290:2001-2007.

Spiegler BJ., Kennedy K., and Maze R. (2006) Comparison of long term neurocognitive outcomes in young children with acute lymphatic leukemia treated with cranial radiation or high dose or very high dose intravenous methotrexate. *Journal Clinical Oncology*; 24,3858-3864



References

Stam H., Grootenhuis M., Brons P., Caron H., & Last B. (2006). Health-related quality of life in children and emotional reactions of parents following completion of cancer treatment. *Pediatric Blood & Cancer*, 47, 312-319.

Thompson, A. and Young-Saleme, T. (2015). Anticipatory Guidance and Psychoeducation as a Standard of Care in Pediatric Oncology. *Pediatric Blood Cancer*; 62, 684–693.

Thompson, A., Christiansen, H., Elam, M., Hoag, J., Irwin, M.K., Pao, M., Voll, M., Noll, R. and Kelly, K. (2015). Academic Continuity and School Reentry Support as a Standard of Care in Pediatric Oncology. *Pediatric Blood Cancer*; 62, 805–817.

Wakefield C.E., McLoone J., Goodenough B., Lenthen K., Cairns D., & Cohn R.J. (2010). The psychosocial impact of completing childhood cancer treatment: a systematic review. *Journal of Pediatric Psychology*, 35(3), 262-274.

Wakefield C.E., Butow P., Fleming C., Daniel G., & Cohn R.J. (2011). Family information needs at Childhood Cancer Treatment Completion. *Pediatric Blood & Cancer*, 58, 621-626.

Willard, VW., Leung W., Huang Q., Zhang H., and Phipps S. (2014) Cognitive outcome following pediatric stem cell transplantation: The impact of age and total body irradiation. *Journal of Clinical Oncology*; 32, 3982-3988.

Willard VW., Conklin HM., Boop FA., Wu S., and Merchant TE. (2014) Emotional and behavioral functioning after conformal radiation therapy for pediatric ependymoma. *International Journal of Radiation Oncology Biology Physics*; 88, 814-821.

Zeltzer, L.K., Recklitis, C., Buchbinder, D., Zebrack, B., Casillas, J. and Tsao, J.C. (2009) Psychological status in childhood cancer survivors: a report from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 27 (14), 2396-2404.



Questions?