

Preparing Patients & Families for the Off-Therapy Transition

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APHON 44th Annual Conference & Exhibit
September 4, 2020

Disclosure

- Emily Browne has no conflicts of interests to disclose.

Outline

- Cancer trajectory phases
- Transition Oncology Program (TOP) impetus
- Off-therapy transition research evidence
- Case examples – pre-TOP
- TOP today
- Multi-disciplinary team
- Case examples – post-TOP
- Outcomes
- Challenges
- Future directions
- Contact information

Childhood Cancer Trajectory Phases

- On-therapy
 - Receiving cancer-directed therapy (chemo/immunotherapy, surgery, radiation)
- Off-therapy/Early Survivorship
 - Surveillance for cancer recurrence, late effects
- Long-Term Survivorship
 - Late effect surveillance
 - St. Jude After Completion of Therapy (ACT) Clinic
 - Eligible at 5 years from diagnosis **and** 2 years off-therapy
 - Follow until at least 18 years old **and** 10 years off-therapy

TOP Impetus

- Time between on-therapy and ACT = 2.5 to 5 years
 - Disease-focused evaluations every 3-12 months
 - Primary focus of oncology clinics is on-therapy patients
- Clinic- and clinician- level differences re: psychosocial, cognitive assessments for off-therapy patients
 - Lack of prospective screening for psychosocial and cognitive problems
 - Many patients receiving services only after problem noted
- Variable coordination w/ local primary care provider (PCP), specialists
- Pediatric psychosocial standards of care in children with cancer not consistently met for off-therapy patients

Case Example #1: pre-TOP

- **5 y/o male w/ neuroblastoma, nearing completion of therapy**
- LOTS of anxiety about returning home after 1+ year
- Questions about health insurance coverage concerns
- Planning to enter kindergarten in the fall
- Needs PT, OT, speech therapy at home
- Needs local ophthalmology, gastroenterologist

Case Example #2: pre-TOP

- 4 y/o girl w/ Wilms tumor, first off-therapy visit (3-months)
- Parental concerns about lack of peer interaction
- Parents not very concerned about evident speech deficit
- Sub-specialty appointments out of sync w/ primary oncology visits
- Mild renal dysfunction in remaining kidney, hydration guidelines

Case Example #3: pre-TOP

- **13 y/o boy w/ osteosarcoma, off-therapy x 1 year**
- Disclosed being bullied & physical altercation at school
- Social anxiety, not wanting to return to school
- New onset hypertension dx at outside hospital

Off-therapy Transition Research Evidence

- Interviews with parents (n=17) of children with ALL, 2 months off-therapy
 - Fear of relapse
 - Juxtaposing emotions
 - Return to normalcy
 - Change in relationship w/ healthcare team
- Interviews with families (n=10) of Swedish children w/ cancer, 2-11 months off-therapy
 - “Returning to a changed ordinary life – incorporating a trying and contradictory experience”
 - “Feeling relief but still times of stresses and strains”
 - “Wanting closeness but sometimes lacking it”

Muskat et al., 2017; Bjork et al., 2011)

Off-therapy Transition Research Evidence

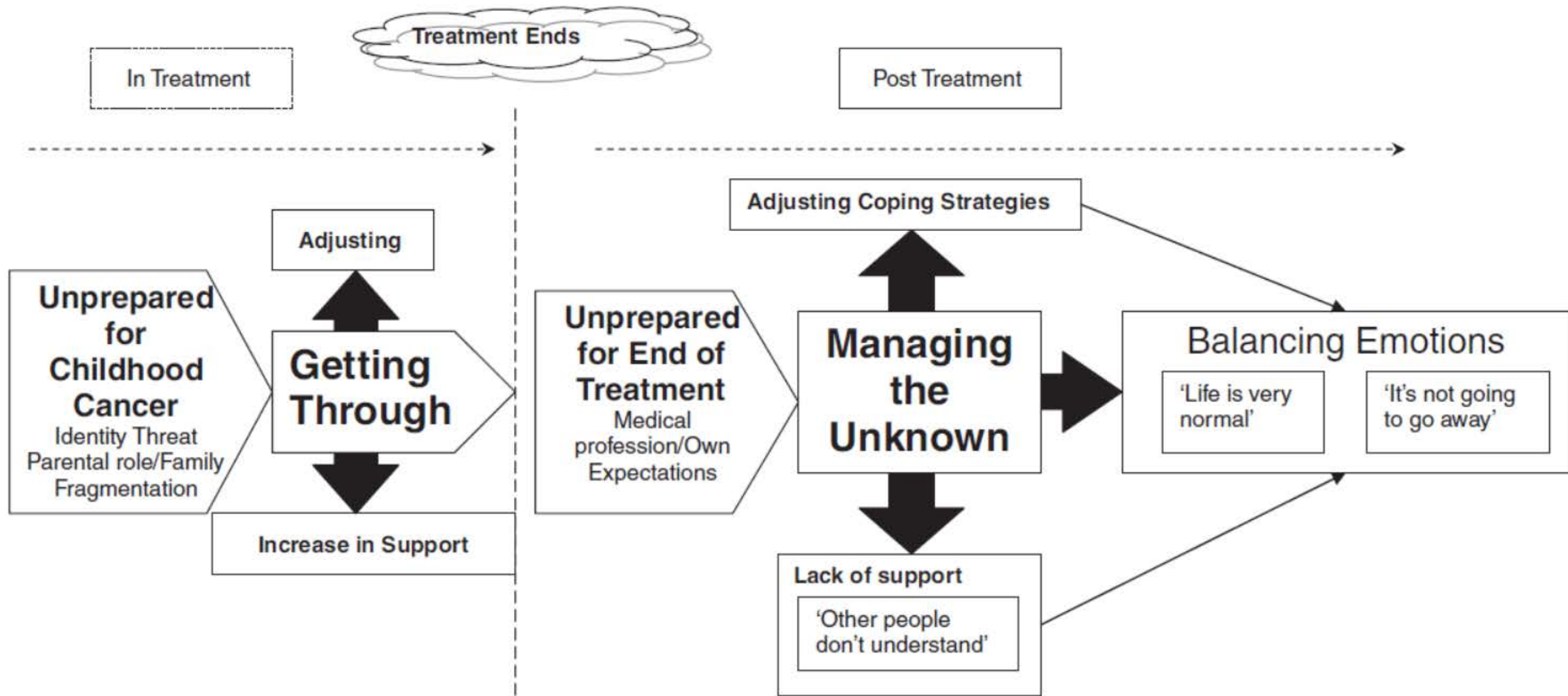


Figure 1. Grounded theory model: 'the end of treatment is not the end'

McKenzie & Curle, 2012

Off-therapy Transition Research Evidence

Who Should Provide Transition Information?

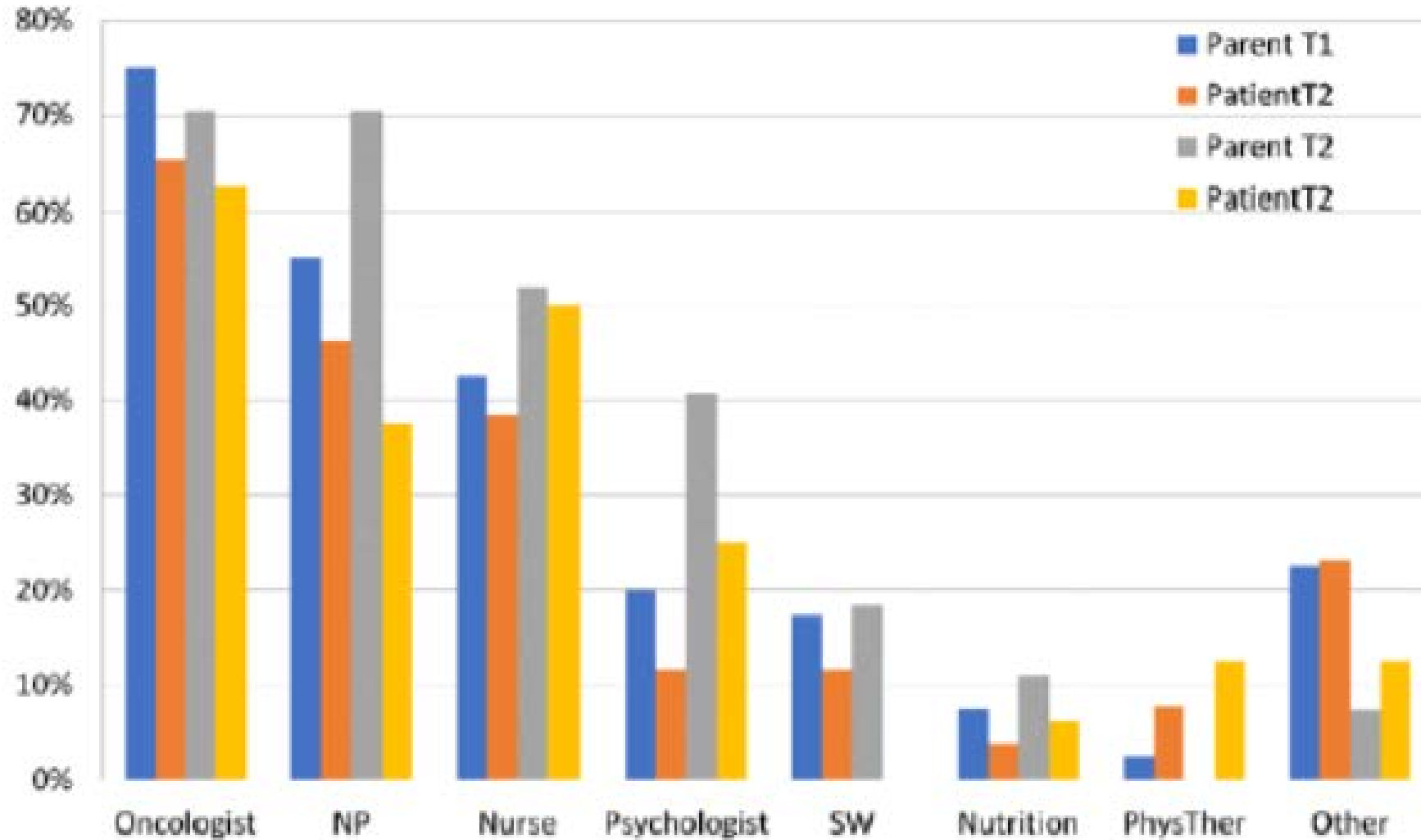


FIGURE 2 Transition information providers

Karst et al., 2018

Off-therapy Transition Research Evidence

TABLE 2 Information desired by parents and patients (%)

	Parent		Patient	
	Time 1	Time 2	Time 1	Time 2
Communication with school staff	52.6	87.5	95.8	93.8
Communication with PCP	88.4	87.5	95.8	88.9
Emotional/adjustment issues	81.4	87.5	66.7	77.8
Financial concerns/resources	56.1	76.7	58.8	81.8
Health insurance information	53.5	54.8	55.6	83.3
Health/physical restrictions	93.02	93.8	95.8	83.3
Lifestyle behavior education	83.72	78.1	79.2	88.9
Nutritional needs	67.44	71.4	77.3	87.5
Patient employment/career	27.3	64.3	72.2	81.3

	Parent		Patient	
	Time 1	Time 2	Time 1	Time 2
Physical activity recommendations	74.42	78.1	62.5	58.8
Review of follow-up tests	100	78.1	83.3	77.8
Review of late effects	97.62	96.9	95.7	94.4
Schedule of follow-up appointments	93.3	93.8	83.3	94.4
School needs and resources	58.5	22.2	50	80
Supportive care/psychosocial services	74.42	75.9	65.2	82.4
Transition to adult healthcare	85.7	78.1	83.3	88.9
Treatment summary	88.37	75	83.3	88.9

Karst et al., 2018

Off-therapy Transition Research Evidence

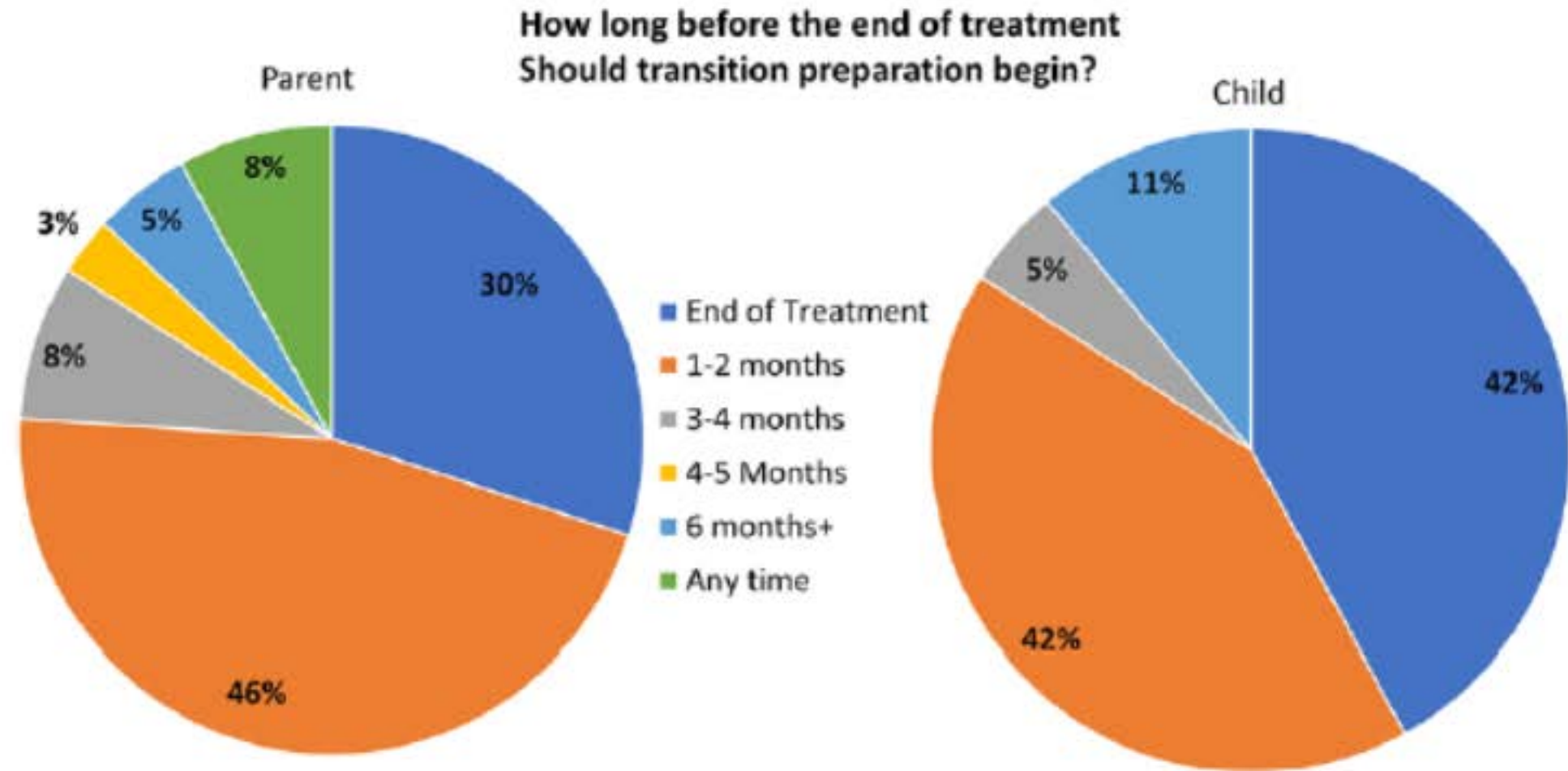


FIGURE 3 Transition timing

Karst et al., 2018

Discussion Question

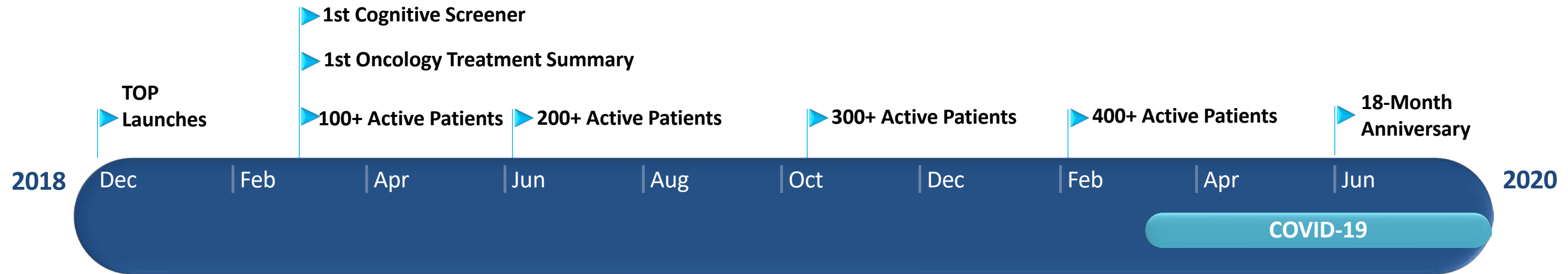
- What challenges do you have related to patients transitioning off-therapy?
- What type of education do you provide at the end of therapy?
- Do you have any formal/informal off-therapy transition programs?
- Please include your name & where you work

TOP Scope

- Support oncology patients prior to end of therapy through first ACT visit
- Provide anticipatory guidance for major transitions:
 - On-therapy to off-therapy, community re-entry
 - Off-therapy to ACT
 - Adolescent to age of majority, adult health care
- Provide education and resources for transition-related needs
- Screen for psychosocial, cognitive, and physical effects/risks
- Assist with transition to local health care providers



TOP Timeline



TOP Multi-Disciplinary Team

Role	Team Members	Visit Schedule
Academic Coordinators	3	Age 3+: Pre-EOT & PRN
Nurse Practitioner Navigators	3	Intro, Initial (1-2 months pre-EOT), EOT, yearly, PRN; screening b/t visits
Rehabilitation Services Coordinator	1	w/ Rehab needs: ~1-month pre-EOT & PRN
Psychologists	3	1-2 months pre-EOT & PRN
Psychological Examiner	-	1 st off-therapy visit
Social Workers	2	1 st off-therapy visit & PRN
Total	12	

EOT = End of Therapy

Academic Coordinators

- Educate patients/families about the potential for cognitive late effects that can influence learning and school performance
- Assist school personnel in understanding the impact of treatment so they can monitor for changes in learning or behavior
- Provide recommendations for an IEP or 504 Plan and support families in navigating the evaluation process
- Follow up with patients/families regarding results of psychological testing

Nurse Practitioner Navigators

- Introduce TOP services to patients/families
- Develop and update oncology treatment summaries
- Serve as a liaison between primary oncology team, St. Jude sub-specialists, primary care providers, local sub-specialists
- Provide education about late effects, healthy behaviors, health literacy
- Screen for physical, psychosocial, cognitive concerns between appointments
- Serve as a point of contact for transition-related needs

TOP Oncology Treatment Summaries

- Diagnostic information
- Chemotherapy, surgery, radiation therapy details
- Disease status
- Late effect surveillance
- Past medical history, ongoing problems
- Central line, other devices
- Current medications
- Management recommendations (fever, immunizations, dental)
- Healthy lifestyle recommendations
- Contact information

Rehabilitation Services Coordinator

- Help families identify providers
 - Physical therapy, occupational therapy, speech/language pathology, audiology
- Educate families on obtaining services in their local community
- Assist families with navigating insurance benefits
- Care coordination with Head Start, early intervention, and school via IEPs and 504 plans
- Ensure continuity of care between outpatient and inpatient rehab facilities

Psychologists

- Evaluate potential behavioral, social, emotional, or family functioning factors that may impede successful transition
- Locate or provide support to mitigate the impact of transition barriers
- Assess for potential cognitive and academic risks
 - Collaborate with the family and TOP Academic Coordinators to implement recommendations to bolster academic success
- Provide anticipatory guidance and psychoeducation on potential emotional/adjustment, social, and academic concerns, as well as strategies for seeking support

TOP Cognitive Screen

- Scheduled for first off-therapy visit, approximately 90 minutes
- Follow-up letter with results, recommendations
- Academic Coordinator consultation for “flagged” screens

Domains Assessed
Developmental Skills (0-3.11)
Estimated IQ
Working Memory
Processing Speed
Attention
Academics
Mood/Behavior

Social Workers

- Conduct psychosocial transition assessments
 - Vocational, educational, and mental and behavioral health
 - Insurance status
 - Access to local medical care
 - Medical decision making (e.g. conservatorship)
- Interventions
 - Psychoeducation and anticipatory guidance
 - Supportive counseling
 - Connect to hospital- and community-based resources

TOP Resources

- Oncology Treatment Summaries
- Cognitive screen
- Local service navigation
 - Rehab, Mental Health, Medical (Primary/Specialty)
- Health insurance assessment (MedAssist)
- *Together* website (www.together.stjude.org)
- Patient Family-Centered Care (Parent Mentors)
- Adult health care skills assessment/education (TRAQ)

Case Example #1: pre-TOP

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Case Example #1: post-TOP

- 5 y/o male w/ neuroblastoma, nearing completion of therapy
- **Psychologist:** Emotional support, coping strategies related to transition anxiety
- **Social Worker:** Addressed insurance coverage concerns
- **School Liaison:** School entry, accommodations for hearing deficits
- **Rehab Coordinator:** Arrangements for local PT, OT, speech
- **NP Navigator:** Coordination w/ local ophthalmologist, gastroenterologist, pediatrician

Case Example #2: pre-TOP

- 4 y/o girl w/ Wilms tumor, first off-therapy visit (3-months)
- Parental concerns about lack of peer interaction
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Case Example #2: post-TOP

- 4 y/o girl w/ Wilms tumor, first off-therapy visit (3-months)
- **Social Worker:** Addressed parental concerns about lack of peer interaction
- **Psychologist:** Cognitive Screener flagged concern for speech delays
- **School Liaison:** Follow-up re: concerns for speech delays
- **Rehab Coordinator:** Arrangements for local speech therapy
- **NP Navigator:**
 - Worked w/ SJ sub-specialty clinics to avoid prolonged or additional return visits
 - Oncology treatment summary outlined hydration recommendations, letter

Case Example #3: pre-TOP

- **13 y/o boy w/ osteosarcoma, off-therapy x 1 year**
- Disclosed being bullied & physical altercation at school
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Case Example #3: post-TOP

- 13 y/o boy w/ osteosarcoma, off-therapy x 1 year
- **NP Navigator:**
 - Screening contact revealed new issues: being bullied & physical altercation at school, social anxiety, new onset hypertension
 - Obtained records related to hypertension, updated treatment summary
- **Social Worker:** Follow-up re: bullying, local mental health
- **School Liaison:** Follow-up re: plans for school this fall; bullying resource for teachers
- **Rehab Coordinator:** Previously identified local PT options
- **Psychologist:** Previously worked with patient on school avoidance

Outcomes Measurement

- Process measures:
 - Transition to PCP, local specialists, medications, mental health
 - Immunization catch-up
 - Oncology treatment summaries for every patient
- Outcome measures:
 - Adequate social and emotional support
 - Improved health literacy
 - Patient/Family, oncology team, PCP satisfaction
 - Successful school re-entry with appropriate accommodations
- Balance measures:
 - Additional appointments
 - Role confusion

Current Metrics

	%
Patients w/ PCP identified by EOT	82%
Successful between-appointment screening contacts	68%
Patients “flagged” by cognitive screener	44%
Patients w/ established local rehab services (as recommended)	80%

Survey of Primary Services (May 2020)

- What is the TOP team doing well?
 - “**Everything!** We love the program and honestly **haven't had near the amount of problems** as before with patients transitioning. Excellent resource, very comprehensive!”
 - “I really appreciate the concept of TOP and that **psychosocial support** is integrated in. The transition back to home and real life can offer significant psychosocial difficulties, so this is great!”
 - “Preparing patients to leave SJ campus. Setting **realistic expectations** for off therapy services from SJ.”
 - “**Accessibility, communication** with primary team, response to families in a **timely manner.**”

Survey of TOP Families (Spring 2020)

- **How did TOP support your family during the transition off therapy?**
 - “We had a few appointments leading up to our end of therapy. Each time it was good to know **what was coming** and how we **would be supported** as we transitioned off therapy. Now just two weeks off therapy we have already had a TOP rep **call to check in** and see how things are going. While we are in the midst of COVID especially it is nice to know that we haven't been tossed to the wind with the hopes it all works out.”
 - “They have **kept in touch** to see how my son is doing since off treatment and always ask if we have any concerns or need any additional services after moving home. Rehab services **followed up** with us regarding speech and referred us to MO First Steps.”

Survey of TOP Families (Spring 2020)

- **How did TOP support your family during the transition off therapy?**
 - “Primarily, TOP gave me a **point person** to talk to regarding "life after chemo and weekly trips to St. Jude." We were able to **discuss needs and options** for our child in regards to nutrition, physical therapy, occupational therapy, psychology, education and overall care. We were concerned about the side effects and TOP made it a priority to help us **calm our concerns.**”
 - “I had many questions and worries when my son finished treatment, and the TOP team were super helpful. They **eased my worries.**”

Challenges

- Rapid expansion
- Patient tracking
- Inconsistency among clinicians re: recommendations
- Avoidance of redundancy
- “Too many cooks”
- Lack of baseline data

Future Directions

- Research studies
- Telehealth
- Transplant population

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Let's continue the discussion & questions...

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