

AYA Transition to Survivorship

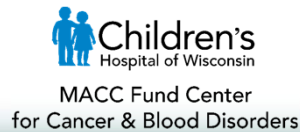
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Division of Hematology/Oncology/BMT

Medical College of Wisconsin/Children's Wisconsin



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Overview

- Psychosocial impact of cancer on AYAs
 - ✓ During and years after treatment
 - Transition adjustment
 - Transition needs
 - Bridge to Next Steps Transition Program
 - Transition preparation & support
-
- No conflicts of interest

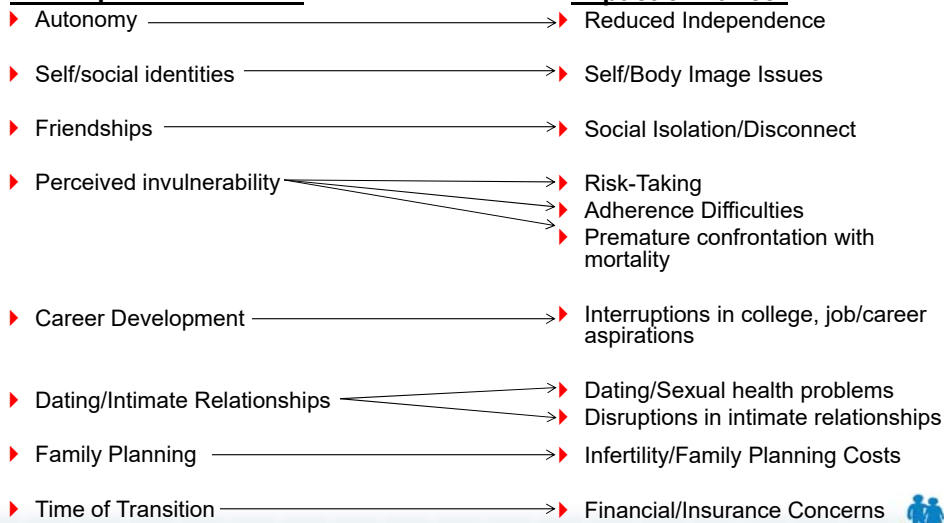


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AYA + CANCER =

Developmental Factors

Impact of Cancer



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Summary of Psychosocial Research

- AYAs are at risk for psychosocial problems due to impact of cancer:
 - Lower QOL
 - Lower self-image
 - Poor body-image
 - Medical adherence problems
 - Depression
 - High levels of distress
 - Post-traumatic stress symptoms
 - Risky behaviors
 - Social functioning problems
 - Greater financial toxicity/hardship

(Arden-Close et al., *Psycho-Oncol* 2008; Barrera et al., *Child Health Care* 2003; Butow et al., *J Clin Oncol* 2010; Kamney & Bearison, *Child Health Care* 2002; Kennard et al., *J Clin Psychol Med* 2004; Kondryn et al., *Lancet Oncol* 2011; Kwak et al., *J Clin Oncol* 2013; Salsman et al., *Pediatr Blood Cancer* 2019 Smith et al., *J Clin Oncol* 2013)



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AYA Survivorship (Tai et al., *Cancer* 2012)

Results from CDC's 2009 Behavioral Risk Factor Surveillance System:

Characteristic	% AYA Survivors (N=4,054)	% Comparison Grp (N=345,592)
Unemployed/ unable to work	24 (%)	14 (%)
Currently smoking	26	18
No leisure-time physical activity in past month	31	24
≥2 wks of poor mental health in past month	20	10
≥2 wks of poor physical health in past month	24	10
Unable to visit a physician d/t cost	24	15



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Transition to Life After Cancer Treatment

- We know very little about the transitional period between ending treatment and entering after treatment care



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Adjustment to Life After Treatment

Natural Reactions

- Excitement
- Hope
- Relief
- Distress/worries/anxiety
- Fears about cancer recurrence
- Future health concerns/LEs
- Uncertainty about the future
- Emotional fatigue
- Emotional processing of cancer experience
- Loneliness/social disconnect
- More likely to want to meet other survivors
- Survivor guilt
- Finding meaning/existential issues

Red Flags

- Frequently thinking about cancer
- Difficulty returning to/poor performance at work, college, life activities
- Persistent mood problems, irritability that does not resolve
- Hypervigilance of bodily symptoms
- Flashbacks/intrusive memories
- Social withdrawal
- Sleep disturbance, nightmares
- Persistent/significant anxiety
- High symptom burden



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Psychosocial Research: Transition to After Treatment Care

- AYA HOPE study (Kwak et al., 2013)

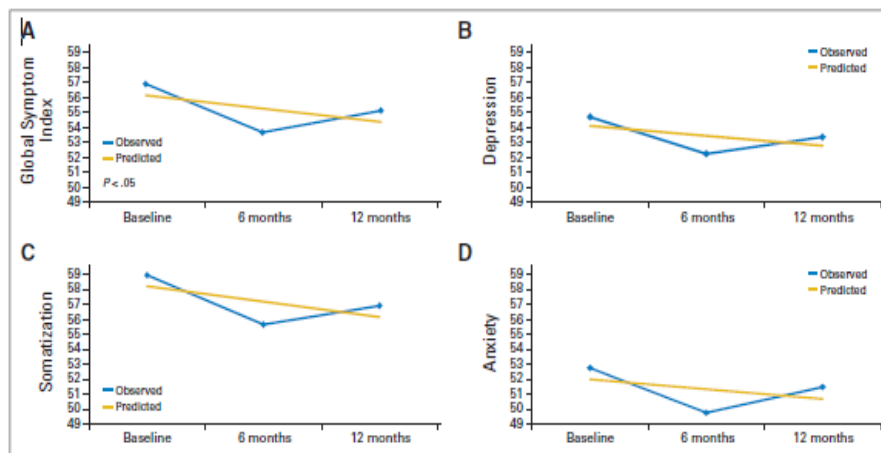


Fig 1. Predicted and observed mean changes in distress for the overall sample across the study period for the (A) Global Symptom Index and the (B) depression, (C) somatization, and (D) anxiety subscales. Age- and sex-adjusted means are presented.



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Qualitative studies: Transition to After Treatment Care

- Fears of recurrence
- Uncertainty related to future care
- Feel unprepared for transition/lack of info
- Ongoing health concerns
- Future health concerns
- Concerns about future education & employment
- Social disconnect/Feeling different

(Duffey-Lind et al., 2006; Thompson, Palmer, & Dyson, 2009)



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Survivorship Gap

- Ending cancer treatment can be stressful for pediatric & AYA survivors and caregivers.
- Many AYA survivors are not receiving adequate follow-up care.
- Many AYAs with cancer have unmet needs for information (57%), counseling (41%), & practical support (39%). (*Zebrack et al., 2014; AYA HOPE study; Keegan et al., 2012*)
- Unmet information & support service needs associated with worse HRQOL (physical, emotional, social, school/work functioning), mental health, fatigue (*AYA HOPE study; DeRouen et al., 2015; Smith et al., 2013*)
- No guidelines for preparing survivors to transition from active therapy to survivorship, prior to being seen in LTFU Clinic.
- Few transition programs have been developed & program efficacy remains unknown.



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Pediatric Blood & Cancer

RESEARCH ARTICLE |  Full Access

Assessment of end-of-treatment transition needs for pediatric cancer and hematopoietic stem cell transplant patients and their families

Jeffrey S. Karst, Jennifer A. Hoag, Sherilynn F. Chan, Debra J. Schmidt, Lynnette J. Anderson, Nicole E. Englebert, Eva C. Igler, Kristin M. Bingen

First published: 26 April 2018 | <https://doi.org/10.1002/pbc.27109>



Study Aims:

- To better understand the needs and preferences of pediatric & AYA cancer patients transitioning off of active treatment
- To inform development of a formal transition program for pediatric & AYA cancer patients and families



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Top 5 Pieces of Information Identified as Most Helpful

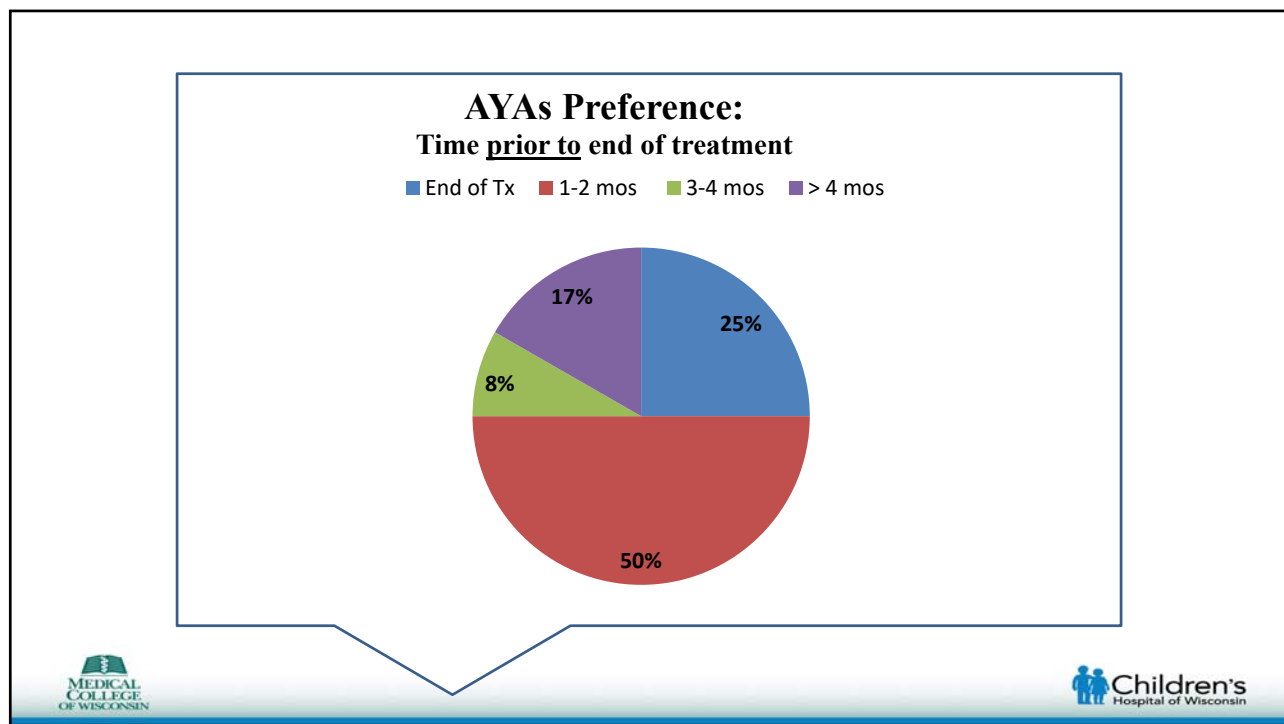
AYAs (15-26 yrs) also prioritized similar informational needs as well as these domains ($\geq 90\%$):

- Nutrition (T 1 & T2)
- Physical Activity (T2)
- Healthy Lifestyle (T2)
- School Needs (T2)
- Transition to Adult Care (T2)



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Conclusions

- Pediatric & AYA cancer survivors & caregivers identify similar informational needs during the transition from active treatment to survivorship care.
*****Sooner rather than later*****
- Information on late effects & structured follow-up plans are essential components of transition care.
- Information related to transitioning to adult care & physical health & well-being recommendations are often desired but not received by AYA survivors.
- Both survivors & caregivers wanted guidance about emotional adjustment after treatment ended.

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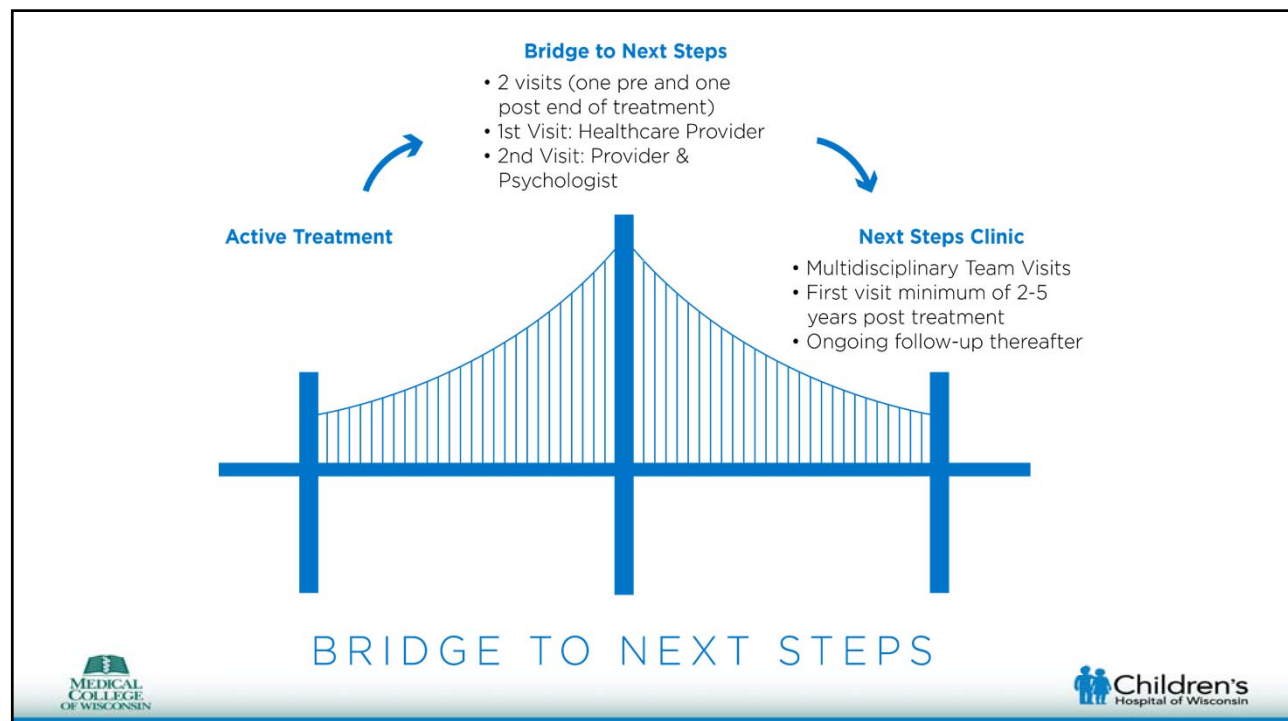
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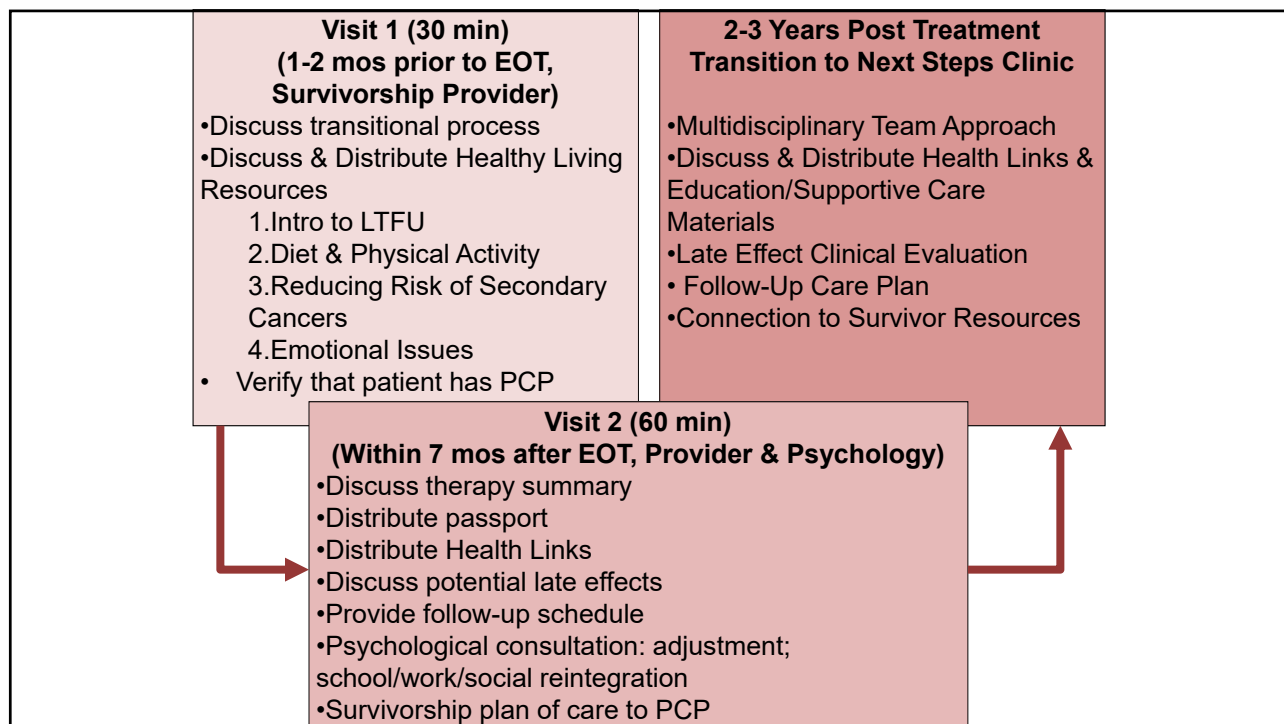
***How can the
Oncology Team help
prepare young adults
for the transition off
therapy?***



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Next Steps Clinic
Survivor Healthcare Passport
Recommended Follow-Up

Patient: DOB: Updated: February, 2017
Providers: Dr. J. APNP/Deb Schmidt, APNP 414-266-2420

System	Exam	Time Frame
<i>All Survivors: History and Physical Exam Yearly, Dental Exam Every 6 Months</i>		
Secondary Cancer	Routine cancer screening for secondary malignancies Inspection and palpation of skin and soft tissues in irradiated fields CBC with manual differential	Yearly/Ongoing Yearly dermatology follow-up recommended As clinically indicated
Cardiology	Echocardiogram	Yearly, Every 4 years
Ophthalmology	Eye exam, screen for cataract development	Yearly
Renal	Blood pressure and Urinalysis BUN, Creatinine and Electrolytes	Yearly Baseline, then as clinically indicated
Hearing	Audiological evaluation	Yearly
Endocrine	TSH, Free T4 FSH, LH, Estradiol, Testosterone Monitor for signs and symptoms of early menopause MRI/Mammogram Monitor growth and pubertal development	Yearly Baseline at age 13,14, then as clinically indicated Ongoing Age 25 (year) or 8 years post end of therapy Ongoing
Pulmonary	Pulmonary Function Testing (PFT's)	As clinically indicated
Musculoskeletal	Monitor for scoliosis/kyphosis	As clinically indicated
Neuro-cognitive	Neuro-psychologic testing	As needed if school problems develop
Reproductive	Referral to a reproductive medicine physician	As clinically indicated

Abbreviated Treatment History

Diagnosis:
Protocol:
Start date:
End of therapy date:

Chemotherapy	Dosage
Total anthracycline dose: . Age at first dose: .	
Doxorubicin	mg/m2
Cyclophosphamide	1 gm/m2
Cytarabine	600 mg/m2
Methotrexate	1 gm/m2
Vincristine, PEG-Asparaginase Mercaptopurine, Thioguanine, Dexamethasone and Prednisone	
Significant Surgery	
Date	
Radiation Treatment	Start End Fractions Dose

For detailed Long-Term Follow-Up Guidelines (V4.0):
www.survivorshipguidelines.org
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Evaluation of the Bridge to Next Steps Program

1. Evaluate program feasibility & acceptability.
2. Determine preliminary efficacy of program for reducing distress & anxiety & increasing perceived preparedness.



Hypothesis: Implementation of a structured transition intervention will be associated with reduced distress and feeling prepared for transition for pediatric cancer survivors & caregivers.



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Design & Methods

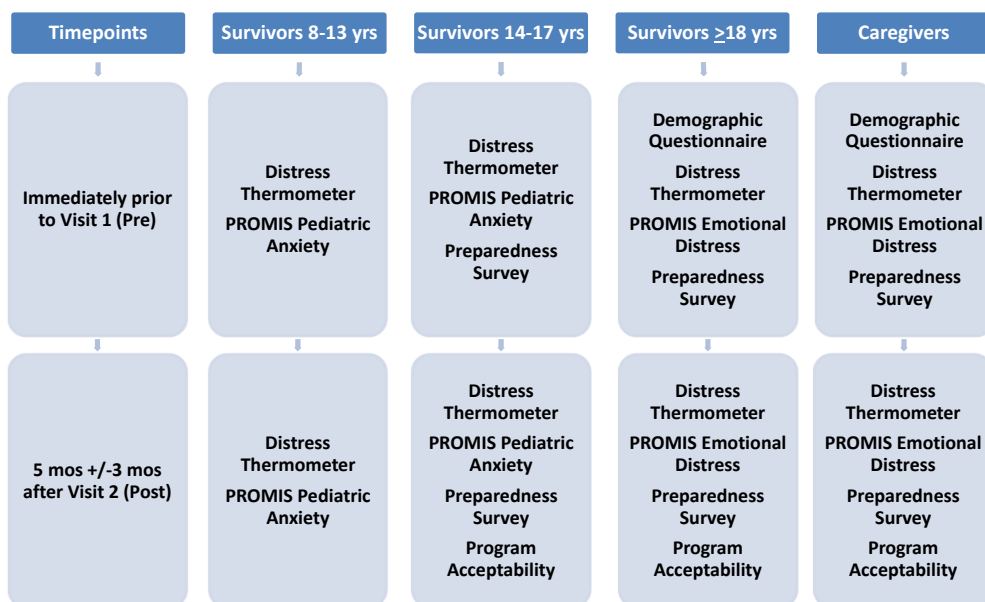
- Pilot study utilizing prospective, repeated measures design
 - Pre/post intervention
- Eligibility criteria:
 - Childhood cancer patients of all ages & caregiver
 - Within 8 weeks from EOT
 - Able to complete measures in English or Spanish
- Exclusion criteria:
 - Disease progression or relapse/recurrence



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Variables & Measures



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Survivors (N=26)

	Age-years
Median (SD)	7.5 (6.65)
Range	1-22
	< 8 (n=13)
	8-13 (n=4)
	≥ 14 (n=9)
	N (%)
Males	15 (57.7)
Race-Caucasian	24 (92.3)
Diagnosis	
Solid Tumors	12 (46.1)
Leukemias	8 (30.8)
Lymphomas	6 (23.1)

Caregivers (N=22)

	Age-years
Median (SD)	37.5 (8.78)
Range	26-56
	N (%)
Mothers	17 (77.3)
Race-Caucasian	21 (95.5)
Married	17 (77.3)
Education-College	21 (95.2)
Employed	
FT	11 (52.4)
PT	5 (23.8)
Unemployed	5 (23.8)
Income	
$\geq \$75,000$	9 (45.0)
\$50-\$74,999	6 (30.0)
<\$50,000	5 (25.0)

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Results: Feasibility & Acceptability



- Program Feasibility (Refusal & Retention)
 - ✓ 5 out of 134 (3.7%) provider or patient refusal
 - ✓ 103 out of 134 (76.9%) completed both visits
- Program Acceptability ("Not at all helpful...Very helpful")
 - ✓ 67% of caregivers endorsed "Somewhat to Very Helpful" (33% neutral)
 - ✓ 56% of AYAs (ages 14-22 yrs) endorsed "Somewhat to Very Helpful" (33% neutral)
- Number of Visits ("Too few-Just right-Too many")
 - ✓ 90% of caregivers endorsed "Just Right" (10% too few)
 - ✓ 78% of AYAs endorsed "Just Right" (11% too few, 11% too many)
- Educational Content ("Not acceptable...Very acceptable")
 - ✓ 100% of caregivers endorsed "Somewhat to Very Acceptable"
 - ✓ 89% of AYAs endorsed "Somewhat to Very Acceptable"



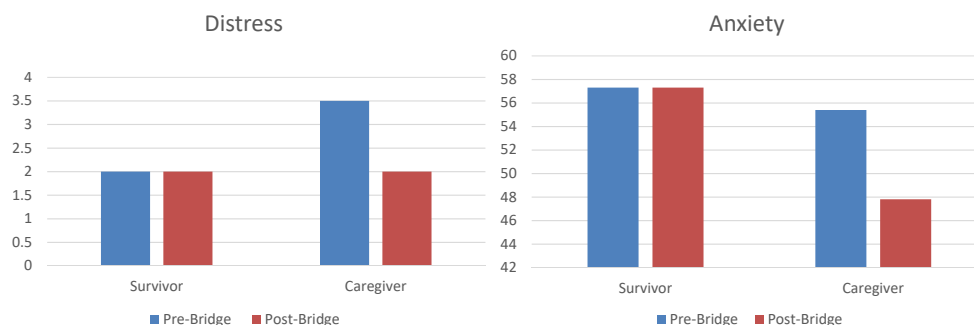
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Distress & Anxiety Outcomes

	Pre-Bridge Distress*	Post-Bridge Distress*	p	Pre-Bridge Anxiety*	Post-Bridge Anxiety*	p
Survivor (ages 8-22 yrs)	2	2	.49	57.3	57.3	.87
Caregiver	3.5	2.0	.01	55.4	47.8	.00

*Median differences between pre- and post-Bridge

Analysis: Paired Samples Wilcoxon Signed Rank Test



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Preparedness Outcomes

(survivors ages 14+ & caregivers)

- Q1 How much do you understand about the plan after treatment ends?
(“0” no understanding... “10” understand everything)
- Q2 How much do you understand about your future health issues that are important to be aware of after treatment ends?
(“0” no understanding... “10” understand everything)
- Q3 How much have you been prepared for going off therapy by any member of your Oncology team? (“0” no info... “10” comprehensive info)

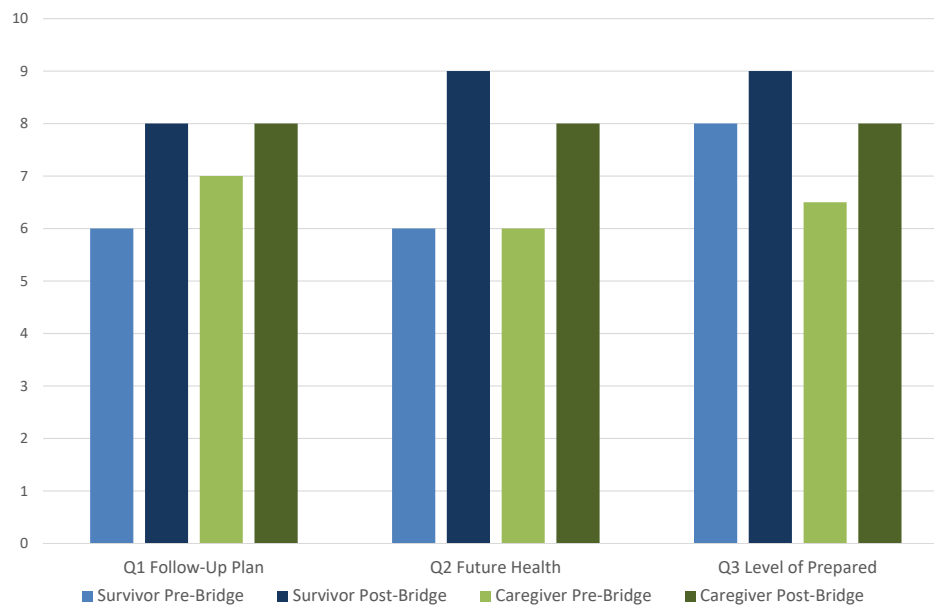
	Pre-Bridge Q1*	Post-Bridge Q1*	p	Pre-Bridge Q2*	Post-Bridge Q2*	p	Pre-Bridge Q3*	Post-Bridge Q3*	p
Survivor	6	8	.16	6	9	.11	8	9	.10
Caregiver	7	8	.31	6	8	.23	6.5	8	.04

*Median differences between pre- and post-Bridge

Analysis: Paired Samples Wilcoxon Signed Rank Test

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Preparedness Outcomes



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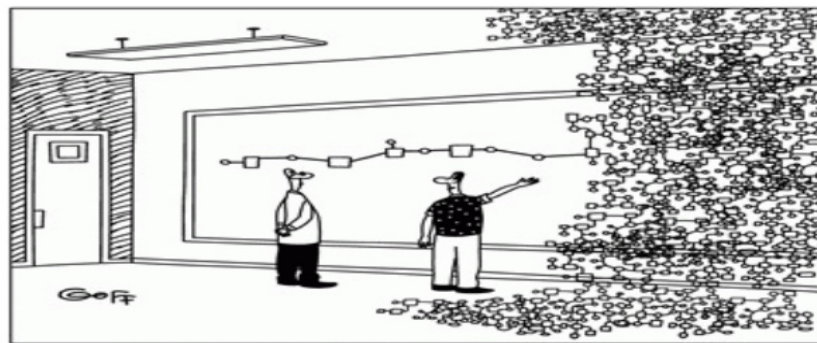
Conclusions

- Delivering a 2-visit transition program is feasible & acceptable to most survivors & caregivers
- Survivor distress & anxiety:
 - ✓ No significant change from pre- to post-intervention
- Caregiver distress & anxiety:
 - ✓ Decreased from pre- to post-intervention
- Survivor & caregiver level of perceived preparedness:
 - ✓ Trend of increased scores from pre- to post-intervention for knowledge of follow-up plan & future health issues
 - ✓ Caregivers felt better prepared by team post-Bridge



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Challenges, Opportunities Future Directions



- Multi-site Randomized Controlled Trial
- Larger sample size, More diverse sample
- Evaluate program components
- BMT population
- Transition readiness



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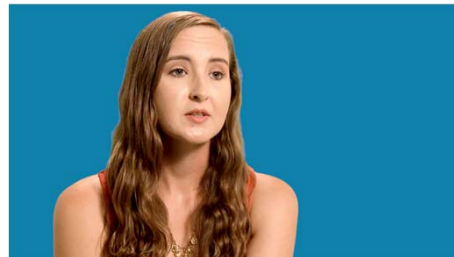
Transition Preparation: What Helps

- **Provide anticipatory guidance/education:**
 - ✓ Importance of follow-up care
 - ✓ Review of health risks/late effects
 - ✓ Emotional adjustment
 - ✓ Developing a new normal
 - ✓ Schedule of follow-up appointments, labs, scans
 - ✓ Healthy lifestyle behaviors
 - ✓ Fertility/family planning
 - ✓ Sexual health
 - ✓ Transition to Adult Health Care
- **Survivorship Care Plan (share with PCP)**
 - ✓ Treatment Summary
 - ✓ Follow-up Care Plan
- **Ask your patient how he/she is adjusting to life after cancer treatment at each visit**
 - ✓ Normalize feelings/concerns
- **Psychosocial assessment/distress screening**
- **Provide supportive care resources and referrals to reintegrate**
 - ✓ College/employment reintegration
 - ✓ Social reintegration
 - ✓ Psychological support
 - ✓ Financial counseling



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***What helped me cope
with the transition off
therapy?***



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Transition Support: What Helps

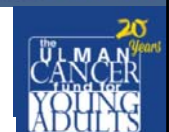
- **Anxiety/Stress Management Strategies**
 - ✓ Meditation/Relaxation
 - ✓ Mindfulness
 - ✓ Exercise
 - ✓ Behavioral Activation
- **College/Job Reintegration**
 - ✓ Division of Vocational Rehabilitation:
 - ✓ Career Counseling
 - ✓ Vocational Support
- **Social Support/Social Reintegration**
 - ✓ Connect with friends, family
 - ✓ Connect with other cancer survivors/support groups
 - ✓ Social Media
- **Professional Psychological Support**
 - ✓ Counseling
 - ✓ Neuropsychological Testing
- **Financial counseling/planning**



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National AYA Resources & Services

- **Camps**
 - ✓ Camp-Mak-A-Dream
- **Adventure Programs**
 - ✓ First Descents
 - ✓ True North Treks
 - ✓ Epic
- **Peer/Online Support**
 - ✓ Imerman Angels
 - ✓ Stupid Cancer
 - ✓ CancerCare
 - ✓ Lacuna Loft
 - ✓ Dear Jack Foundation
 - ✓ Elephants and Tea
- **Financial Assistance**
 - ✓ The SamFund
- **Vocational Assistance**
 - ✓ Cancer and Careers
- **Fertility Resources**
 - ✓ Oncofertility Consortium
 - ✓ LIVESTRONG
- **AYA Advocacy/Education**
 - ✓ 15 to 40 Connection
 - ✓ Seventy K
 - ✓ Ulman Cancer Fund
 - ✓ Triage Cancer
- **NCI AYA Snapshot** <https://www.cancer.gov/types/aya#5>
- **NCCN**




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<http://www.survivorshipguidelines.org/>




American Cancer Society®

<https://www.cancer.org/cancer/cancer-in-young-adults/late-effects.html>

Cancer.Net

Doctor-Approved Patient Information from ASCO®

<https://www.cancer.net/survivorship/late-effects>




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National Comprehensive Cancer Network

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https://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf



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Acknowledgements

- Next Steps Survivorship Team
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Thank you to survivors & caregivers!



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