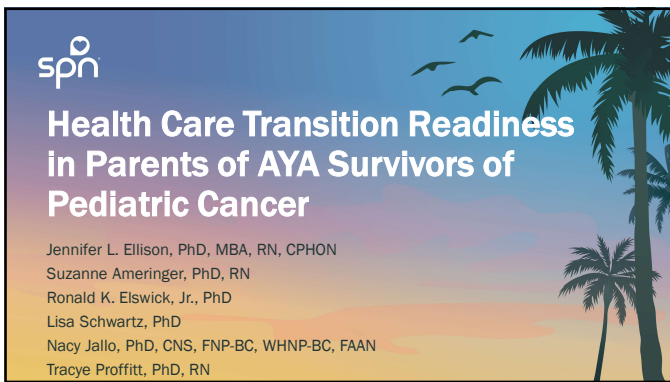
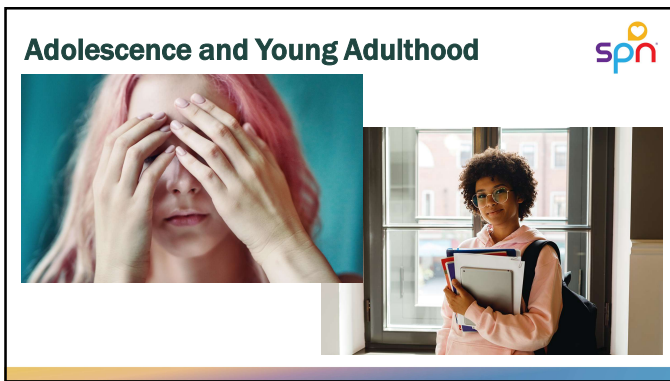




1



2



3

Health Care Transition¹



- Over 75% of all AYAs in the US do not receive transition services²
- For medically complex, successful transition is vital
- Survivors of pediatric cancer are medically complex and at risk³⁻⁶



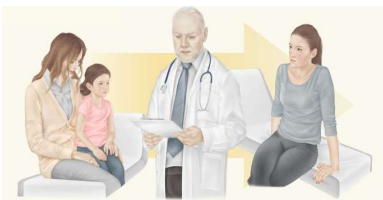
4

How Was I Inspired?



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Why Study Parents?



Parents are central to HCT⁷

90% of survivors' parents stay involved in AYA years⁸

Parents are understudied⁹

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Study Purpose



To measure HCT Readiness in parents of pediatric cancer survivors and consider factors that might influence readiness, such as SDOH or demographic characteristics.

To explore the experiences and expectations of parents prior to HCT to better understand their perspectives regarding HCT.

To integrate quantitative and qualitative findings in a way that enhances our understanding of HCT readiness in parents of pediatric cancer survivors.

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Mixed Methods Study Design



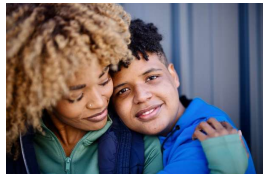
Quantitative Surveys

Social Media Recruitment

Qualitative Interviews

Flyer to Known Contacts

Parents of 16-21 year-old survivors

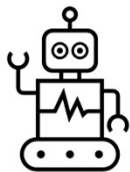


8

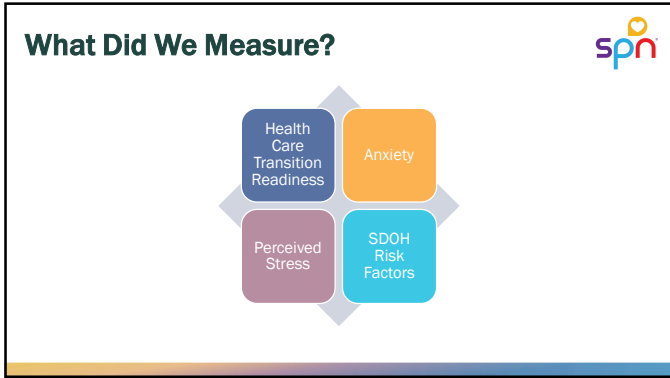
Bots and Fraud!



- Bots can beat Captcha
- Bots are fast
- Bots are persistent
- Human responders can misrepresent



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Results

	Participants n = 22	M (SD)
Parent Demographics	Age (years)	49 (5)
		n (%)
	Gender	
	Female	19 (86)
	Male	3 (14)
	Race	
	White	20 (95)
	Black/African American	1 (5)
	Relationship Status	
	Married/relationship	17 (77)
Divorced/separated	5 (23)	
Household Income		
\$35,000-\$99,999	6 (29)	
\$100,000-\$149,999	7 (33)	
\$150,000-\$199,000	3 (14)	
\$200,000+	5 (24)	

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Results

	Participants n = 22	n (%)
Parent Demographics	Highest level of education	
	some high school	1 (5)
	some college, vocational, or training school	2 (9)
	associate degree	6 (27)
	4-year college degree	7 (32)
	post-graduate education	6 (27)
	Social determinants of health risk factors	
	Zero	13 (59)
	One	6 (27)
	Two	3 (14)


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		Participants n = 22	n (%)
		Results AYA Demographics	Gender
Female	13		(59)
Male	9		(41)
Pediatric Cancer Type			
Leukemia/Lymphoma	10		(45)
Solid Tumor	8		(36)
Brain Tumor	4		(18)
Relapse			
No	19		(86)
Yes	3		(14)
Severity of Late Effects			
Minimal	7		(32)
Mild	11		(50)
Moderate	4	(18)	
Health Insurance Provision			
Parents' employer or school	15	(68)	
Medicare or state public assistance	2	(10)	
Other	5	(23)	

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		Participants n = 22	M (SD)
		Results AYA Demographics	Current Age (years)
Age at Diagnosis (years)	8.3		(4.4)
Time Since Diagnosis (years)	10.6		(4.0)
Time Since End of Treatment (years)	8.7		(4.1)


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Results				
Measure	Mean (SD)	Actual Score Range	Possible Score Range	
TRI-P	221 (25.0)	177-280	66-330	
PEDA	9.4 (3.6)	4-16	4-20	
PSS	16 (6.9)	4-32	0-40	

Note. TRI-P = Transition Readiness Inventory-Parent version; PEDA = PROMIS-short form Emotional Distress-Anxiety4a; PSS = Perceived Stress Scale

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Results




Variable		β	SE	P-value
Constant		121.5	66.1	0.08
PSS Score		-1.7	0.7	0.02
AYA Age		6.7	3.4	0.06
R ²	0.36			

Note. TRI-P = Transition Readiness Inventory-Parent version; PEDAs = PROMIS-short form Emotional Distress-Anxiety4a; PSS = Perceived Stress Scale; AYA = adolescent and young adult

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Qualitative Themes



- Parental uncertainty related to HCT
- Parent roles during treatment
- Parent-AYA roles now/future
- Relationships with providers
- Mental health of AYA survivors


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Parental uncertainty related to HCT



"There's not a lot of resources out there on this transition. And there's not support on moving, you know, to the next step."

"We're kind of a guinea pig group because a lot of our children—previous generations—didn't make it this long."



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Parent roles during treatment



"I did everything. All the medical things, all the appointments, everything . . . That was all me. All the time."

"I feel like I maybe crutched in a lot of ways."



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Parent-AYA roles now/future



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Relationships with providers




"I like the pediatric oncology place, you know. It's all the nurses, people who know you and you know. You have history."




"In her oncology survivorship appointments, I'm not even allowed to talk."

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Mental health of AYA survivors



"So she has a lot of anxiety, and that started with cancer. So, it comes and goes... we're in the thick of it, actually."



"He's afraid of that connection... And he doesn't want to go through that again... I don't think he wants to think about it... He doesn't really like to go to events and meet new kids that have cancer or any of that stuff."

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Data Integration

TRI-P Subscales (possible range)	Qualitative Quote
Knowledge (19-95)	She doesn't even know all the information. And she doesn't want to know all the information.
Skills/self-efficacy (13-65)	Now we're starting to let her take control, but it's a lot for an 18-year-old.
Beliefs/expectations (12-60)	I'm concerned, you know? Is a new general practitioner going to have the background, like, know all the things he's at risk for?
Goals/motivation (4-20)	Oncology, we just go in. We haven't really had that conversation [about transitioning to adult care.]... They haven't brought it up and neither have I, 'cause I don't want to go anywhere else.
Relationships/communication (8-40)	I feel like chemo survivorship kind of relies more on me. Not that they don't recognize [my son] as an adult, but since they're so used to dealing with parents versus the young adult aspect of this. It's a little hard for him to take the driver's seat.
Psychosocial/emotional (8-40)	I'm scared, I'm really nervous. I feel like they're not gonna understand how much he truly went through.

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Data Integration

TRI-P Subscales	Qualitative Quote
Mental Health not addressed on the TRI-P	You've been through something where you're facing your own mortality... Going to funerals of your friends... I don't know if it's PTSD, but... I don't know any kid who's gone through this... That isn't having some kind of mental health challenges.



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Pediatric Nursing Implications



- We can provide more information to parents and AYAs about the timing and process of HCT
- Understanding how parents' roles change over time is crucial
- Awareness of how much influence health care providers can have on the comfort level of parents and AYAs should guide our interactions with both
- We need to pro-actively support our patients' mental health

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Conclusions



- Parents clearly expressed a desire for more information and support regarding HCT
- Limitations:
 - Homogeneity of sample
 - Recruitment method
- Further research needed:
 - Mental health impacts in AYAs with medical complexity need exploration in the context of transition to adult care
 - More research is needed with parents—specifically, we need to study HCT readiness quantitatively and longitudinally across a larger and more diverse sample

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A note of thanks . . .



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Most importantly, I want to thank those parents who took time and opened up sometimes painful memories to participate in my study.



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