Navigating a Blood Cancer in Adolescence and Young Adulthood (AYA): Challenging Conversations for Parents Caring for their Diagnosed AYA

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BACKGROUND

- Parents are AYAs' primary source of caregiving support but struggle to talk about cancer-related issues
- Parents need resources to facilitate critical care conversations
- We developed the *Healthy Communication Practice* Intervention to teach adult child blood cancer caregivers how to facilitate open, supportive communication
    - Intervention was acceptable/feasible and promoted better psychosocial outcomes
- Parents of AYAs have distinct needs and need targeted resources

AIM

Identify challenging conversations for parents and their diagnosed AYA to inform the adaptation of the *Healthy Communication Practice* intervention

METHODS

Inclusion Criteria

- Parent caring for adolescent (Adol; 15-18 years) or emerging adult (EA; 19-29 years) with a blood cancer diagnosis at least 3 months prior to recruitment
- Currently in treatment or completed treatment within the last 2 years

Recruitment and Method

- Recruited in partnership with The Leukemia & Lymphoma Society (LLS) for an in-depth, semi-structured interview

Analysis

- Transcribed interviews were separated into two age groups to triangulate (i.e., compare) findings
- Data thematically analyzed using a constant comparative approach

RESULTS

Age	M	SD	Min-Max
Caregiver age	52	6.76	38-69
Patient age at diagnosis	19.9	3.99	15-28
Developmental group	**% (n)**		
Adolescent	50% (10)		
Emerging adulthood	50% (10)		
Gender (patient)			
Male	75% (15)		
Female	25% (5)		
Gender (caregiver)			
Male	5% (1)		
Female	95% (19)		
Patient diagnosis			
Leukemia	75% (15)		
Lymphoma	25% (5)		

Challenging Topics	Data Exemplar
Negative Affect	**ADOL:** Unfortunately, the hospital or the doctors did not step down the steroid medication. … I don't understand why they wouldn't do that, especially in teenage boys when they know it's a larger issue. … He was out of his mind. He was cussing. He was throwing things. *(Mother, Son age 15)*
	EA: She was the baldest she had been through all the treatment. It sloughed off in one swoop, every bit of it and it was like somebody slammed her hand in the door when she came downstairs with just clumps. And she was howling. She's like, "Nobody told me I was going to lose my hair. You were the only one that was saying it. I thought you were crazy!" and [my husband] and I just—she collapsed on us. And we're all just holding clumps of hair. *(Mother, Daughter age 22)*
Caregiving "Tug and Pull"	**ADOL:** Because I just know his friends super well … [I asked him] "Do you want me to encourage them to reach out to you?"… At first he said "No." Then very humbly, he's like, "I do, but don't tell me. I want them to be my friends because they want to be my friends, but I know sometimes they forget. And so if every once in a while you want to encourage…" *(Mother, Son age 17)*
	EA: I felt like I was constantly treading a line. I mean down to like, "Should I get her water bottle?" All my mind is thinking [is] we need to push these nasty drugs through her system by hydrating her. …She would just snap at me, "I know I can get water when I need water." And that's not [my daughter] to snap like that. … It was very difficult because her independence was just clipped, just like that, one day. *(Mother, Daughter age 24)*
Mortality	**ADOL:** The test—I think he had a CAT scan—and that's when they found it. And he was really worried, and [was saying] "What if it's this?" and "What if I'm going to die?" *(Mother, Son age 17)*
	EA: I know that he had said that he looked up one thing online about lymphoma once he got the diagnosis. It said the life expectancy was really short. … And he was like, "That was it, Mom." *(Mother, Son age 19)*
Sexual Health	**ADOL:** He's 17! He's been raised in a church. He's been raised in a biblical family his entire life. Do we freeze your sperm? That was horrible. *(Mother, Son age 17)*
	EA: I definitely did not go in with him during the sperm banking. That was kind of funny, actually. Dropping him off, I'm like, "I don't know what to say. I hope it goes well. I'll see you later." *(Mother, Son age 19)*
Disease-Related Information	**ADOL:** Occasionally approaching it with the appropriate frame of mind, both for us and her, of being able to take that information in without it being preachy or judgey, but an open– "Here, this may be something you want to know about." It's hard to find that balance because it depends on how everybody is physically and mentally feeling, so finding the appropriate moment to do so is challenging. *(Mother, Daughter age 17)*
	EA: It was one time where we did, I did ask a question of her oncologist outside the room. … What I read was not very encouraging at all, and it scared the crap out of me. So, I certainly didn't want to say to [her], "Hey, you know it says, you know, five years, maybe." You know, I certainly didn't want to say it. *(Father, Daughter age 25)*
Private Information	**ADOL:** There's only one time he got mad at me. … He would get mad about—he wouldn't tell [the doctors] the truth about eating, and I would say, "No, he's only eating this very small amounts." Then he got really angry with me. *(Mother, Son age 15)*
	EA: I think the one time I did irritate him was when he went on his honeymoon and I mentioned that he was going out of the country. He wasn't gonna bring that up [to the doctors]. Are you kidding?… So, I put my foot in my mouth. *(Mother, Son age 22)*

UNIQUE FINDINGS FOR EA

- Only EAs described challenges talking about survivorship (all mother-son relationships)
- <u>Example:</u> how best to support child in regaining independence

Challenging Topics	Data Exemplar
Survivorship	I think it also has given us some kind of blinders in a way that's making it hard for us to help him move forward. And we talked about the physical limitations that are kind of in the way of that, but I think it's made us sort of not sure when to push him forward and how to help him now. *(Mother, Son age 22)*
	Now he works in a baseball field and he's digging up dirt, and he's cleaning the trash. [I am like] "Are you sure?" But that was one of those things the doctor said it's fine. So, I got to let it go. He was ready before he was even to me ready. … But as a mom, I have to talk to myself and coach myself into just taking each day at a time. *(Mother, Son age 19)*

CONCLUSIONS

- Parents caring for diagnosed AYAs must navigate many challenging but critical conversations.
- They have overlapping needs with children diagnosed in ADOL or EA, with some distinct needs
- Findings will inform the adaptation of the *Healthy Communication Practice* intervention to help parents facilitate more open, supportive communication with their AYA living with a blood cancer.

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