



Don't Change Yourself for Other People.

How Adolescents and Young Adults (AYAs) Living with Cancer Offer Advice to Other AYA Patients

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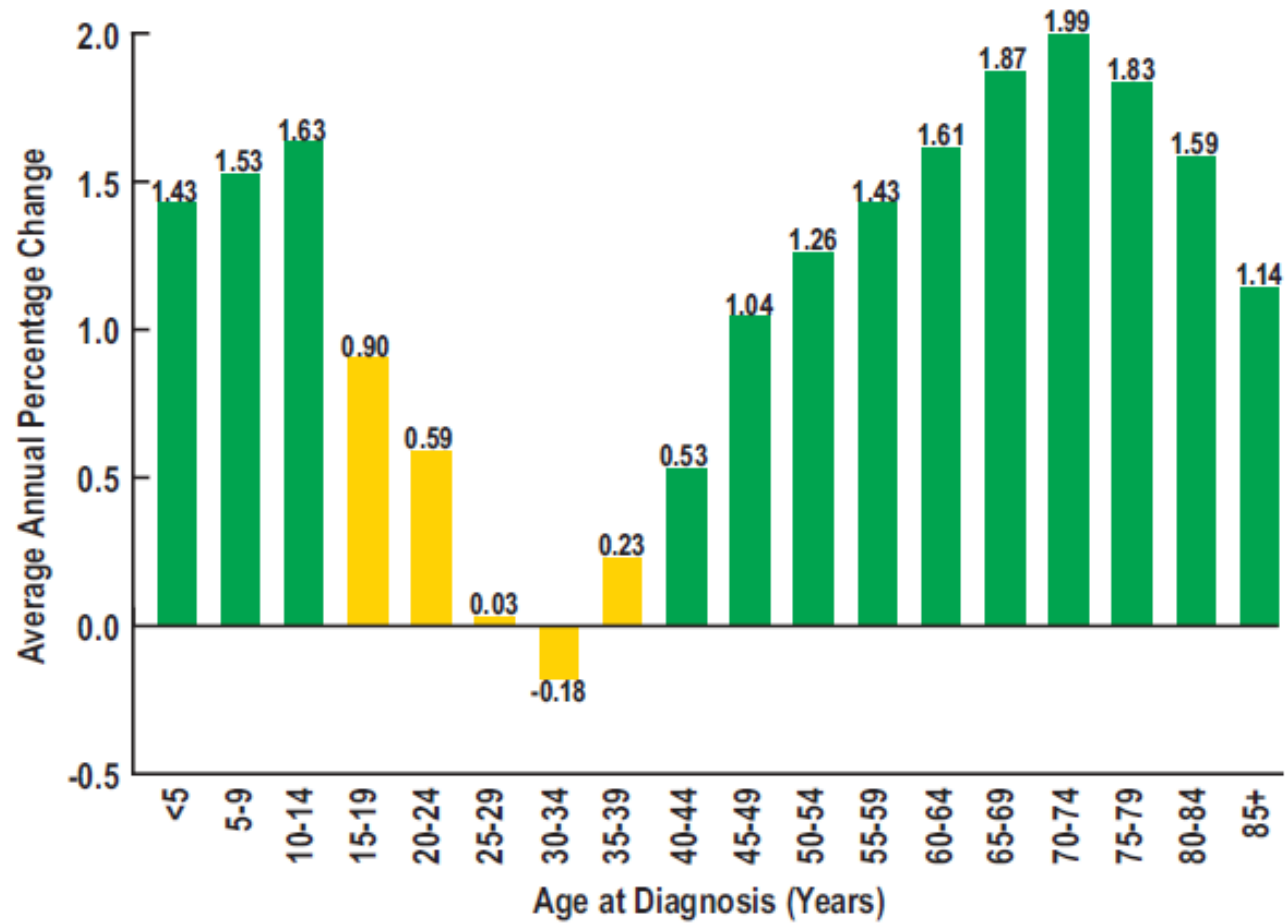
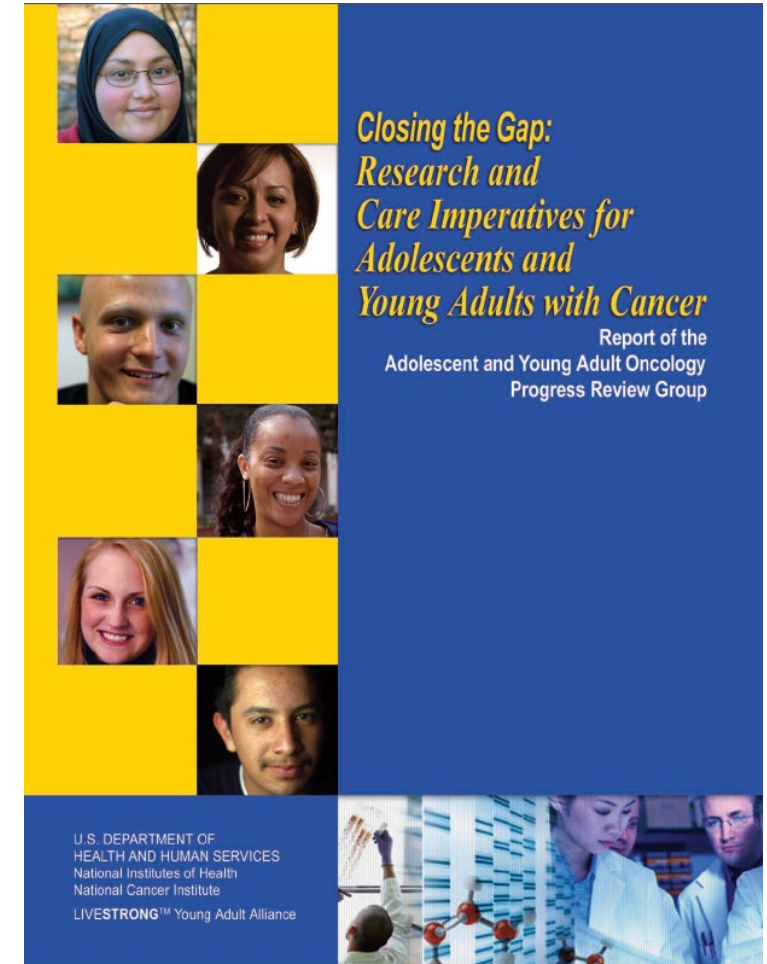


Figure 2. Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975-1997

UNIQUE PSYCHOSOCIAL & SUPPORT CHALLENGES

- Disrupted social milestones and normative developmental characteristics
- Initiating and managing interpersonal communication with friends, family, romantic partners
- Lack of age-appropriate services
- Less is known about AYA supporters



One year post-diagnosis

57% unmet need for information

41% unmet need for counseling

39% unmet need for practical support

- AYAs report low levels of receipt/use of psychosocial care and substantial unmet needs
- Most interventions for AYAs delivered during treatment

Zebrack et al., 2011; Walker, et al., 2016

WHY ADVICE?

“The most important thing to offer a young person with cancer is another young person with cancer” (Simone, 2017)

How can this information benefit cancer survivors, caregivers, and healthcare providers interested in **policy change**?

Does providing hypothetical advice for other AYAs based on one’s own cancer experience reveal how AYAs attempt to **cope with, self-manage, or make sense of** their previous **unmet needs**?

Why are we well positioned to discuss this?



ADVICE THEMES ACROSS OUR DATASETS

- 1) Attitude framing
- 2) Engaging support network
- 3) Self-advocating with healthcare team
- 4) Normalizing mental health support





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Experts of their own Experience:

Adolescent and young adult cancer patients' advice as a coping mechanism

- Aims:
 - Identify and describe independently adopted coping strategies used by AYAs
 - Report advice they have for other AYAs diagnosed with a malignancy
- Methods:
 - Participants aged 12-25 yrs recruited from adult and pediatric oncology unit within an NCI designated Comprehensive Cancer Center from 10/2019-8/2020
 - Diagnosed within the previous 2-12 months
 - At risk for gonadal dysfunction following cancer therapy
 - Conducted semi-structured interviews designed to elicit thoughts on the general cancer experiences, goals and dreams for the future, experience with fertility preservation practices

| Patient Demographics | # (%) |
|---------------------------------|-----------------|
| Sex | |
| Female | 10 (37) |
| Male | 17 (63) |
| TOTAL | 27 (100) |
| Age at Diagnosis (years) | |
| 12-17 | 11 (41) |
| 18-25 | 16 (59) |
| Clinical Unit | |
| Pediatric | 13 (48) |
| Adult | 14 (52) |
| Cancer Type* | |
| Solid Tumor | 13 (48) |
| Non-Solid Tumor | 14 (52) |
| Race | |
| Non-White | 6 (22) |
| White | 21 (78) |

| Theme sub-theme | Definition |
|------------------------------------|---|
| Self Advocacy | Actively engage with the medical team, independently seek out information |
| ask questions | |
| Engage Support Network | Take advantage of opportunities to connect |
| appreciate being cared for | |
| connect with others | |
| romantic relationships | |
| social media | |
| Attitude Framing | Acknowledge the reality and actively work to cope |
| positive outlook | |
| exercise control over what you can | |
| permission to take time off | |
| don't give up on goals | |
| new purpose and perspective | |
| keep fighting | |

| Theme sub-theme | Sample quote <i>Sex, age at time of interview, diagnosis</i> |
|--------------------------------------|---|
| Attitude Framing positive outlook | <p>I believe everything is a mindset. You got a great mindset; you'll be good. If you sit in your room and cry all day about it, nothing is gonna happen. It's not gonna change anything. I mean, you get out there and live. I mean, you never know anything could happen. I think I'd tell—I'd let him know I mean, it's all gonna work out in the end. Just keep going. Don't let it get you down.</p> <p><i>M, 20yrs, Hodgkin's lymphoma</i></p> |
| exercise control over what you can | <p>A lot of it's outside of your control, so trying to focus on what you can control, and don't worry about what you can't control...because that's really what's gonna get you through it and keep you sane. ...You can't control how the chemo is gonna make you feel, or the anti-nausea drugs... are gonna make you feel. You can do other stuff to make your life a little bit better. I guess that is probably the best advice that I can think of.</p> <p><i>M, 23yrs, germ cell tumor</i></p> |

| Theme sub-theme | Sample quote <i>Sex, age at time of interview, diagnosis</i> |
|---|--|
| Attitude Framing permission to take time off | It was mainly my mom, who was like, “Yeah. You’re not gonna want to do college at all [during cancer treatment]”, so I was like, “Okay. I can take a year off.” Many people do it. It’s nothing new. <i>M, 19yrs, Hodgkin’s lymphoma</i> |
| don’t give up on goals | Don't let go of your goals, either. Keep those goals in mind and keep pushing for 'em. <i>M, 23yrs, ALL</i> |
| new purpose | I want to be a journalist. That's not changed. I would say my experience made me especially interested in health care journalism because I think good health care is absolutely everything, which I didn't really realize before I was sick...That kind of made me think how health journalism maybe is something that I want to think more about, which is not something I really looked into before all of this. <i>F, 22yrs, sarcoma</i> |

| Theme sub-theme | Sample quote <i>Sex, age at time of interview, diagnosis</i> |
|-------------------------------------|---|
| Attitude Framing new perspective | <p>Just don't take things for granted. Don't take going walking outside, going for a 10-minute walk—I would never do that, but now I'm missing it. I hated working. I hated going to school, but now I want to go back. Yeah. Just don't take anything for granted.</p> <p><i>M, 16yrs, ALL</i></p> |
| keep fighting | <p>Now I'm just on the up-swing is what I keep telling myself. You've done this. You've got this... A lot of it is just mental, every day, like being, okay, get out of bed, and get up, and keep moving around. Don't just sit around and mope around. Sometimes forcing yourself to do stuff you don't really want to do for the day.</p> <p><i>F, 24yrs, AML</i></p> <p>The advice that I would give would be, "Keep your head up. It's not gonna be like this every day."</p> <p><i>M, 19yrs, Hodgkin's lymphoma</i></p> <p>Just keep fighting. Just don't give up. There is a light at the end of the tunnel. You just gotta push through it.</p> <p><i>M, 16yrs, osteosarcoma</i></p> |

<https://www.mottchildren.org/conditions-treatments/ped-cancer/aya-oncology-program>



<https://sites.google.com/umich.edu/aya-care>





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DATA COLLECTION

- Face-to-face (n=31) + video (n=54) individual semi-structured interviews with YA cancer patients/survivors
 - 18-39 at initial diagnosis and time of interview
 - Completed primary treatment (n=31)
 - Had at least consulted with a cancer care provider between March 2020 and April 2021 (n=54)
- Experiencing life disruption, managing uncertainty, (re)shaping identity, soliciting/receiving social support, making treatment decisions, using humor
- "What advice would you give to another person your age who was just diagnosed with a similar cancer?"



N = 85 YA CANCER PATIENTS AND SURVIVORS

| OH | KY | PA | MI | CA | TX | ONT | NY | VA | NJ | WI | NC |
|--|----|----|----|----|----|-----|----|----|----|----|----|
| 25 | 13 | 12 | 8 | 4 | 3 | 3 | 2 | 2 | 2 | 2 | 2 |
| n= 7 from IN (1), MN (1), MD (1), FL (1), WA (1), IL (1), CO (1) | | | | | | | | | | | |

| LYMPHOMA | BREAST | LEUKEMIA | HEAD/NECK | TESTICULAR | OSTEOSARCOMA | |
|------------|--------|--------------------|-------------|------------|----------------|----------|
| 19 | 16 | 15 | 12 | 6 | 6 | |
| COLORECTAL | LIVER | OVARIAN UTERINE | MEDIASTINAL | THYMUS | NEUROENDOCRINE | CERVICAL |
| 3 | 2 | 2 | 1 | 1 | 1 | 1 |



N = 85 YA CANCER PATIENTS AND SURVIVORS

| Gender | Race | Age @ Interview | Years Since Primary tx Completion | Recurrence/ Secondary Malignancy? |
|---------------------------|----------------------------------|--|---|-----------------------------------|
| 73% Female – 62 | 82% Euro American – 70 | 28.5 Range = 18-38 18-25 = 40 26-32 = 34 33-38 = 11 | 2.93 Range = 0-13 years <i>Still in primary tx = 8</i> | 79% No - 67 |

ENGAGE SUPPORT NETWORK

Emotional support

You don't have to tell everybody, but make sure you have a couple of people in your life that you're confident you'll be able to just cry to and vent to and laugh with. If you're crying, they'll cry with you. If you're laughing, they'll laugh with you.

-Bailey, 24 at leukoplakia diagnosis

Instrumental support (*communication work*)

Get a spokesperson. It could be the boyfriend, the mom, whoever it is to kinda answer everybody's questions and keep everybody from panicking and keep them apprised of what's going on. Get that spokesperson to take notes during every appointment and write down your questions before you go and ask about them

-Sarah, 25 at lymphoma diagnosis



ENGAGE SUPPORT NETWORK



Don't change yourself for other people

I was scared to tell the first significant other I had during this process about my diagnosis. Like, "He's not gonna wanna date me. He's gonna look at me differently." My [18-year-old] brother was like, "If he's looking at you differently because you can't have kids, then he's not the right guy."

-Agnes, diagnosed with lymphoma at 23

Do not let their initial reaction change how you feel about the situation or how you are gonna go about your cancer because that initial reaction is a reaction of shock. You're gonna get so many different reactions. You will. I mean, everyone will take it differently.

-Ofelia, diagnosed with liver cancer at 23



ENGAGE SUPPORT NETWORK



Don't be afraid to ask for and accept support

I guess accept help. Yeah, tell people exactly what to give you. I mean, I would give advice that I wouldn't follow [laughter]...I just think it's embarrassing to need help. I'm very independent and don't need anybody. I guess it just made me feel weak, at a time when you already are weak. And I was already sensitive to being weak, and asking for help made it seem worse.

-Kate, 31 at lymphoma diagnosis



I always tell them, they're not the first person to go through this. There's a lot of people out there. I tell them to call in all their shots or their cards or whatever it is. If people offer, "Oh, hey, anything I can do?" just say, "Maybe you can clean my house," or, "Maybe you can go get some food from the grocery store or bring me over dinner." You should definitely take advantage of those things.

-Brad, 22 at testicular cancer diagnosis

ENGAGE SUPPORT NETWORK

Find secondary and tertiary supporters

I would suggest finding other people to talk to outside of your family too. I guess based on my own situation, I think there were certain things that were hard for me to speak about with my family. But I probably could've talked to someone else more about it. And that might've given me a little bit better perspective.

-Eva, diagnosed with leukemia at 24

Sometimes you feel like you're the only person in the whole world that's thinking the way you're thinking. But then to hear all these other people are like, "I'm afraid to go to the store too," or "I'm afraid that my neighbor is outside not wearing a mask." It's good to know that there are other people that think the crazy way that your brain works. So if they don't have a support group, I would hope now would teach them how much more important having one is.

-Phoebe, diagnosed with ovarian cancer at 33



SELF ADVOCACY

Ask questions, check for understanding, express concerns

Write down your questions before you go there and ask about them.

-Sarah, 25 at lymphoma diagnosis

Always ask as many questions to your doctors as humanly possible.

-Selina, diagnosed with breast cancer at 29

I think sometimes I didn't say things that I wish I would've said or asked questions that I should've asked

-Eva, diagnosed with leukemia at 24

If you don't like what [a medicine's] doin' to you, speak up. If you want something changed, speak up. I didn't speak up for a long time. I didn't know I could. You trust what they're doin' to you. You trust the process. Don't be afraid to speak up for yourself. Be your best advocate. It's not embarrassing. It's not being selfish.

-John, diagnosed with testicular at 24



SELF ADVOCACY

Educate yourself and speak up beyond the exam room

As scary as it is—and it is so scary, you just see the statistics out there and they're frightening, they truly are—um, but you have to get past that and know what's going on.

-Amber, diagnosed with breast cancer at 36

Don't panic [laughter]. Ask all the questions, get all the second, and third, and fourth opinions that you can. I think the reason that I'm tolerating treatment so well is because I'm a Type A, proactive patient. Maybe that doesn't work for everybody, but I just think, if you're your own best advocate and if you understand and know everything that's going on, then you can cope better through the journey.

-Sue, diagnosed with breast cancer at 29



thecancerpatient



Nothing has change. Put the phone down. Don't google your prognosis again. Just go to sleep.



Liked by nogriefftouristsallowed and 1,915 others

thecancerpatient Late night shenanigans



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Overview

- Part of larger dissertation study (**Exploring Multilevel Factors Influencing Quality of Life in Young Adult Cancer Survivors: A Mixed Methods Study**)
 - Explore the relationship of work-related goals and quality of life in young adult cancer survivors with a focus on factors influencing quality of life at the individual level, and work-related factors at the microsystem and mesosystem levels.



(NY/NJ ERC National Institute for Occupational Safety and Health, Grant # T42 OH008422)

Evolution of interview guide

“What do you know now about young adult cancer survivorship that you wish you knew when you were first diagnosed?”

Analysis

Secondary data analysis

Qual interview → interview transcribed verbatim → rapid content analysis



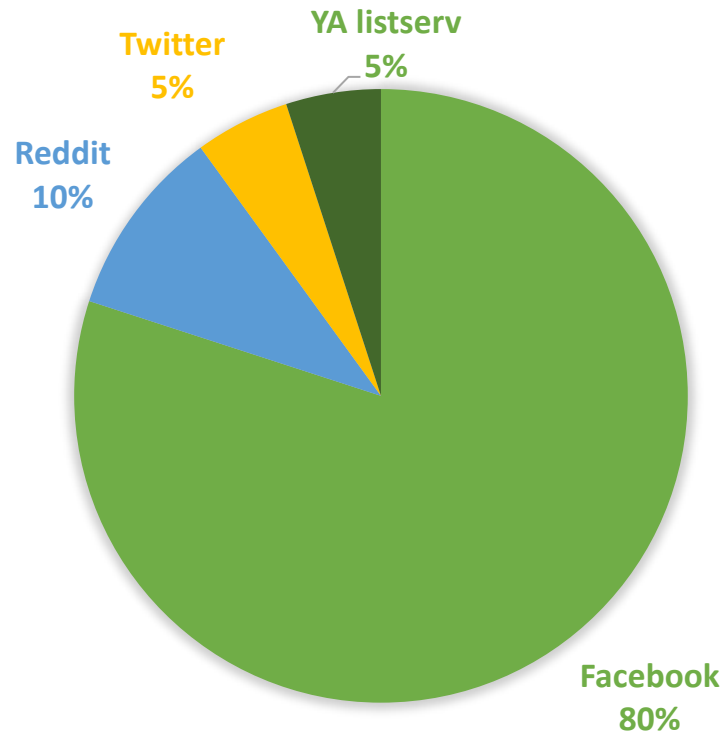
Methods: Sample

- YAs (20-39 years old) diagnosed with a hematologic malignancy (**N=40**)
 - Inclusion:
 - 1-5 years since diagnosis
 - Working/attending school at diagnosis
 - Exclusion
 - In active treatment
 - Poor prognosis (terminal <6 months)
- Maximum Variation Sampling: sex, race, age at diagnosis, type of work



Methods: Recruitment

- Online & social media platforms
- Young adult cancer organizations



ARE YOU A YOUNG ADULT SURVIVOR OF LEUKEMIA OR LYMPHOMA?

PARTICIPATE IN ONE SURVEY AND PHONE INTERVIEW FOR A NYU RESEARCH STUDY EXPLORING QUALITY OF LIFE IN YOUNG ADULT CANCER SURVIVORS

UPON COMPLETION OF THE STUDY, PARTICIPANTS WILL BE GIVEN AN AMAZON GIFTCARD

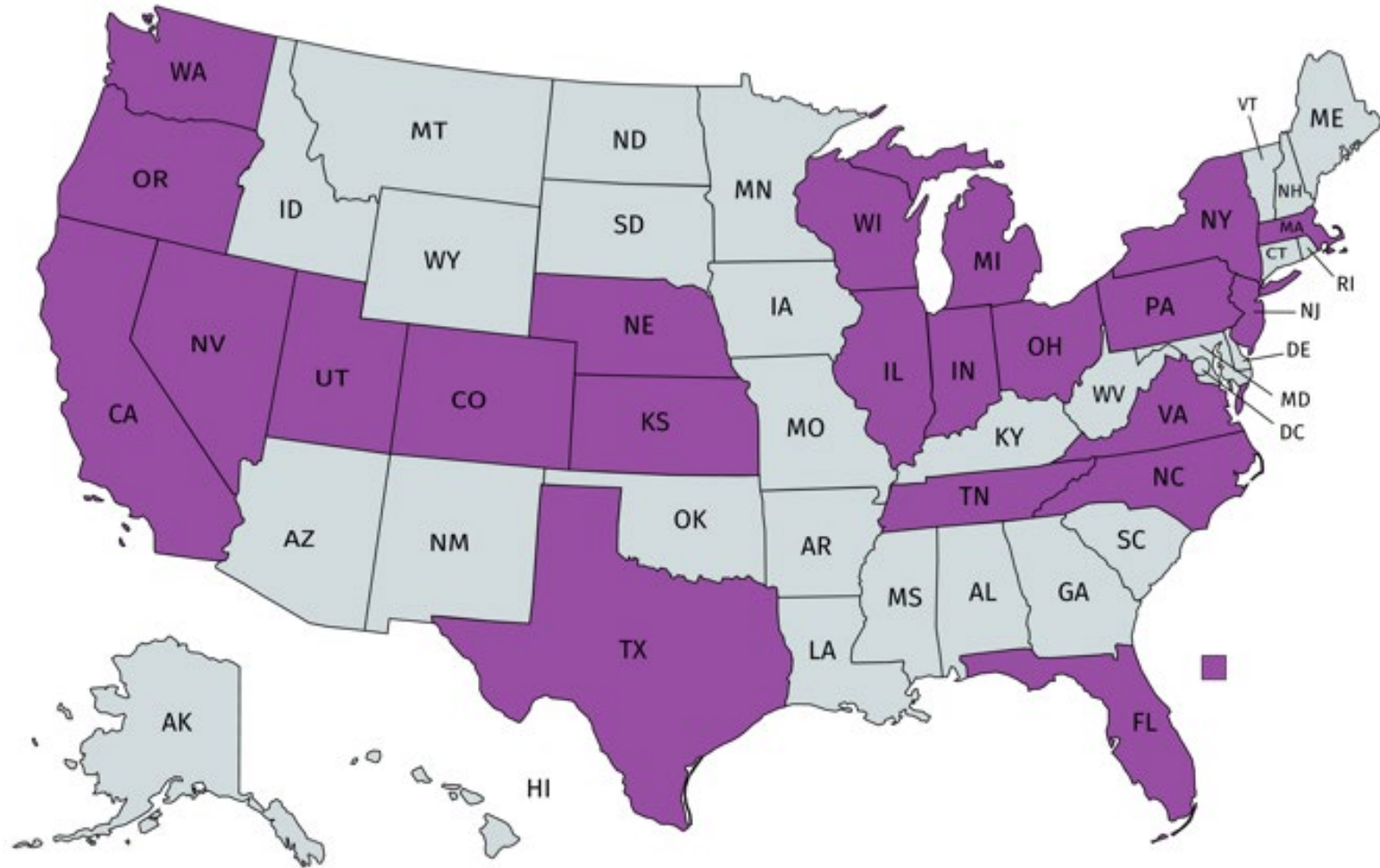
PLEASE EMAIL LVG220@NYU.EDU FOR MORE INFORMATION

*You must have been diagnosed between ages 20-39.

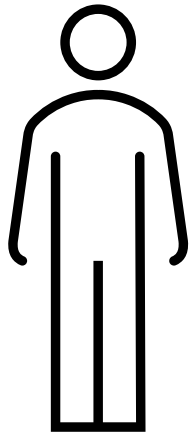
NYU RORY MEYERS COLLEGE OF NURSING

The poster features a dark blue background with white and yellow text. It includes a decorative pattern of white dots in the upper right and a small illustration of a person sitting on the ground in the lower right.

Participants



Participants: Sociodemographics & Clinical Characteristics (N=40)

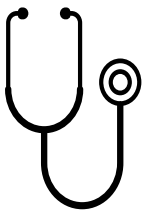


Age: 28 ± 5.3 years

Sex: Female (65%)

Race: White (72.5%)

Ethnicity: Non-Hispanic (87.5%)

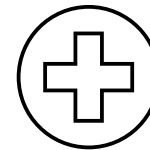


Lymphoma (82.5%)

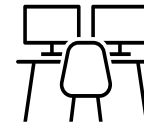
Time since diagnosis (2.5 ± 1.3 years)



\geq Bachelor degree (60%)



Private insurance (80%)



Professional, technical (40%)

Health care (22.5%)

Education or Research (17.5%)

Findings

- Normalize mental health support
 - Reflecting on pre-cancer self
 - And preparing for post-treatment self:
 - *“cancer doesn’t end when treatment ends”*

“You expect surviving to be the end of it and to move on with your life, and it’s not that way. No one really tells you, ‘No, this will change you forever.’ You have to make a new path for yourself and get to know the new you.”

(28 y/o female)

Mental health fall-out preparedness

When you're first finished, you have this exhilarating feeling where you think you're gonna have this amazing life. Then you have to face the reality all the stuff. It feels a lot more alone because you go from during treatment when everyone was helping you, but a year out, I feel better now. It's like I said, it's ups and downs. At first, it's like, "Whoo," and then you kinda crash. I don't know. Everything's always changing.

(35 y/o female)

I wish I knew just about all this afterwards crap. I wish I knew to be getting help. Then, that way, I knew how to react now to certain things. Like therapy... to prepare myself for what is to come. Of course, you're excited to be out and stuff, but you really have no idea what you're doing. I feel like my life is—I've always felt like life is like a book. You're just goin' through your pages, your whatever. I feel like cancer, it wasn't another chapter. It's a whole 'nother book. I'm having to figure out who I am all over again and what this new body is like and all this stuff I have to deal with.

(23 y/o female)

*How you feel, how you think, your beliefs, what you stand for, what you want, what you think you've accomplished, your outlook, **everything is different.** I think once a young adult cancer fighter and survivor understands that and really accepts it and grasps it, they will accept things easier. 'Cause I've been able to accept things a lot better once I stopped comparing myself to my old self. **Once I stopped mourning my old self.** It's just like, "Okay, that was you then, this is you now, and it's okay that this is you now. Don't guilt yourself that this is you now. **Just try and find that comfort and happiness in who you are now because you are different.** You can't go back even if you tried.*

(26 y/o male)

Implications

- Normalize mental health support and referral

*“At least to talk to them, to talk to you and say, **“This is what happens most of the time or with a lot of patients’ or whatever. ‘If you’re experiencing this, it’s normal.’** That’s what you feel like. You feel like it’s not normal, like you need to be different, because you don’t ever hear of it. No one ever talks about that stuff. You talk about it between cancer patients, but you don’t talk about it publicly. No one knows truly what’s going on” (23 y/o female)*
- Empower patient advocates

Implications and Future Directions

- By soliciting advice, oncologists and hospital programs can also learn about some of AYA patients' biggest stressors/disruptions/uncertainties/unmet needs – useful for training? Engage AYA advisory groups?
- Who should be giving this advice to other AYAs? Peer-to-peer support programs?
- Toxic positivity – does this expectation make it even more difficult to speak up if you feel sad, hopeless, angry, etc. and need help?
- AYAs have to be ready to accept advice/support, even when it's frustrating – important to distinguish between what's helpful and unhelpful
- Is all advice appropriate for AYAs at the start of treatment? Information overload?
- Need a nationally representative sample? SES, racial, gender, sexual orientation disparities? Just a small collection of AYAs participating in this...

THANK YOU!

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