

# A Qualitative Focus Group Study to Illuminate the Lived Emotional and Social Impacts of Cancer and Its Treatment on Young Adults

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**Purpose:** Among the many challenges that exist among young adults with cancer, those that intersect psychosocial domains have only begun to be addressed by medical, research, and advocacy communities. While some have attempted to empirically document the psychosocial burden of adolescents and young adults (AYAs), there is a paucity of research exploring this phenomenon from the perspective of AYAs themselves. The purpose of this study is to better understand the lived experiences of young adult cancer survivors and the psychosocial impacts that cancer has had on their lives.

**Methods:** We used qualitative focus group methodologies to elicit positive and negative psychosocial impacts of the cancer experience in a young adult cancer sample.

**Results:** We conducted three separate focus groups ( $n=16$ ). The average age of participants was 33 and majority were female (75%), Caucasian (50%), and married (44%). The most common cancer diagnoses were breast (38%), colon (13%), and acute myeloid leukemia (13%). Participants reported experiencing multiple emotional and social impacts such as stress, sadness, and fear; identity changes; utilizing different coping strategies; challenges discussing cancer; feeling pressure to be better; feeling abandoned, misunderstood, or invisible; and experiencing role reversals with family members.

**Conclusions:** Participants reported experiencing several emotional and social impacts of cancer on their lives, both negative and positive. Our findings are important for oncology clinical practice and survivorship research activities with young adults, especially given the presence of these impacts over the long term.

**Keywords:** cancer survivorship, emotional well-being, social well-being, qualitative methods

## Introduction

ADOLESCENTS AND YOUNG ADULTS (AYAs) diagnosed with cancer experience myriad psychosocial<sup>1</sup> and medical challenges<sup>2</sup> from time of diagnosis through survivorship.<sup>3</sup> These challenges can adversely affect AYAs' health, resulting in age-related disparities in care.<sup>4</sup> Recent empirical studies suggest that significant proportions of AYA cancer survivors have unmet health care and psychosocial care needs.<sup>5-7</sup> In fact, a growing body of research has begun to unpack the psychosocial impact of cancer among AYAs who are post-treatment survivors.<sup>1,8-10</sup>

The National Cancer Policy Board and Institute of Medicine have suggested that the phase of cancer following primary treatment is particularly important for survivors.<sup>11</sup>

Post-treatment AYAs are at increased risk of cancer recurrence and second primaries,<sup>12</sup> and have clinically significant levels of cancer-related distress.<sup>13,14</sup> AYAs' psychosocial needs are greater due to emotional, developmental, and social changes and transitions. Understanding the challenges for AYA survivors as they transition from the end of treatment to the stage of active monitoring (i.e., the re-entry period) is critical to facilitate healthy psychosocial adaptation. Unfortunately, limited information exists for understanding this transition, especially from the perspectives of AYAs themselves.<sup>15</sup>

A handful of studies have begun to document the psychosocial impact of cancer among AYAs who are post-treatment survivors.<sup>1,8-10</sup> However, a gap still exists in our understanding of how AYA survivors explain and describe

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what they believe are the emotional and social challenges, impacts, or even assets to navigating re-entry during survivorship. To address this, we used a qualitative focus group methodology to elucidate the lived psychosocial experiences of post-treatment AYAs, in their own words.

## Methods

This study was approved by the governing internal review board at the Midwestern comprehensive cancer center where this research took place. We used a purposive sampling approach consistent with qualitative research methods.<sup>16</sup> Eligible participants (0–5 years post-active treatment) were identified through the recruiting hospital's clinical enterprise data warehouse and called by a research assistant with the Clinical Research Office. Interested participants were mailed a cover letter, consent form, and self-addressed stamped envelope and asked to provide their availability. Dates and times for focus groups were determined by the study team, conference room availability, and participant availability. Once focus group times were confirmed, each participant was mailed a packet containing a confirmation letter and a sociodemographic form to be completed before coming. All participants were called 1–2 days before the group to remind them of the focus group location and time and to answer any question about the sociodemographic form. While recruitment for focus groups targeted a diverse mix of races and ethnicities, a separate study wave of semistructured interviews was conducted exclusively with racial and ethnic minorities to assure representation. At this stage of the process, a primary focus was to achieve a mix of gender and cancer type diversity within each post-treatment strata (1-year, 2-years, and 3–5 years).

Enrolled individuals participated in one of three audio-recorded focus groups. Focus groups are considered an appropriate qualitative data collection method for a Grounded Theory approach,<sup>17</sup> as they encourage dynamic group interaction, exchange, and reflection. We based the number of groups needed to reach saturation on recommendations set forth by Guest et al.<sup>18</sup> Groups were co-moderated by experienced PhD-level moderators (D.V., S.G., and J.S.) using a semistructured interview guide (Appendix A1). Questions were open ended and elicited responses related to participants' psychosocial experiences with cancer. All audio recordings were transcribed verbatim and analyzed using the software NVivo<sup>®</sup>.

## Analysis

Using an interpretive phenomenological approach<sup>19</sup> based on principles of grounded theory<sup>20</sup> and Guba and Lincoln's naturalistic inquiry,<sup>21</sup> we sought to identify personally meaningful constructs directly from the perspectives of young adults with cancer. These perspectives may lead to the development of a larger theoretical understanding of their challenges and contribute to an idiographic body of knowledge grounded in data from their lived experiences.<sup>20,21</sup> A key axiom of naturalistic inquiry is that multiple, interdependent, value-bound realities exist between participants, as well as between researchers and participants.<sup>22</sup> Therefore, our approach applied multiple strategies to ensure credibility, dependability, confirmability, and transferability, including triangulation of data sources; thick, rich description; inter-rater reliability

checks; establishment of coding rules (including procedures to arbitrate disagreement); and evaluation of data saturation (point at which no new codes are being applied). Our analytic approach entailed multiple coders participating in data analysis (D.V., J.S., and S.G.), which included the following: (1) familiarizing ourselves with the data; (2) establishing coding rules; (3) creating an initial code book (e.g., open coding); (4) establishing inter-rater reliability agreement thresholds of 70% or greater before subsequent coding; (5) applying initial codes to the other transcripts; (6) reviewing and discussing codes to determine relationships (e.g., axial coding); and (7) engaging in a similar process with categories to identify core themes that cut across categories and codes (e.g., selective coding).

## Results

Sixteen individuals participated (Group 1 = 6; Group 2 = 6; and Group 3 = 4) and represented different types of cancer, times since diagnosis (0–12 months post-treatment, 13–24 months, or 25–60 months), and socio-demographic characteristics (Table 1).

Participants reported an average age of 33 years (range 28–39) and majority were female (75%), Caucasian (50%), and married (43.8). The most common cancer diagnoses were breast (37.6%), colon (12.5%), and acute myeloid leukemia (12.5%). In total, we applied 53 unique codes 744 times across three focus groups. Inter-rater agreement was >90% between coders. Regarding saturation, 92.5% of all codes were applied in at least two different focus groups (35.8% were applied in two groups and 56.6% were applied in three groups), suggesting that a majority of comments were heard on more than one occasion. A small number of codes (7.5%) did not reach saturation and were only mentioned in one group (Table 2).

Participants highlighted a variety of experiences related to physical, practical, emotional, and social aspects of their diagnoses and treatment on their lives. In the ensuing report, we highlight codes and reflections related to participants' perceived psychosocial impacts. Each theme is represented by several subcategories, with specific codes populating each one.

### *Theme 1: emotional impacts*

Emotional impacts were characterized by four unique categories: (1) stress, sadness, and fear, (2) identity changes, (3) coping and self-care, and (4) transcendence. Each is described below.

**Stress, sadness, and fear.** Most participants commented on how feelings of stress and sadness fluctuated as a result of their cancer diagnosis. One participant (#1105, FG 1) stated, *"I think I'm more stressed now than anything. I've never been a worrisome person, but I think I'm more stressed now and more cautious."* Another participant (#1201, FG 2) became tearful during the focus group and stated, *"As you all can see, I'm depressed, so I'm, uh...not all there right now. I know it's been a while, but I don't know why it's just not leaving me."* One participant (#1102, FG 1) added, *"I've been told there's supposedly no cancer detectable in my body, but I still feel like I have it. I still feel like every day I'm*

TABLE 1. SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS (N=16)

	M (SD)
Age	33.1 (3.7)
	N (%)
Ethnicity	
Hispanic	1 (6.3)
Race	
White	8 (50.0)
Black	5 (31.3)
Asian/Pacific Islander	2 (12.5)
Mixed	1 (6.3)
Sex	
Female	12 (75.0)
Marital status	
Single, never married	6 (37.5)
Married	7 (43.8)
Divorced	1 (6.3)
Separated	1 (6.3)
Living with partner	1 (6.3)
Education completed	
Some college	6 (37.5)
College	4 (25.0)
Some graduate school	3 (18.8)
Graduate school	3 (18.8)
Employment	
Full time	9 (56.3)
Part time	2 (12.5)
Self-employed	1 (6.3)
Not employed, but looking for work	1 (6.3)
Not employed, and not looking for work	3 (18.8)
Stopped working or going to school due to Dx	12 (75.0)
Total household income	
\$24,999 or less	2 (12.5)
\$25,000–\$74,999	6 (37.5)
\$75,000–\$149,999	5 (31.3)
\$150,000 or greater	2 (12.5)
Declined to answer	1 (6.3)
Primary cancer diagnosis	
Breast	6 (37.5)
Leukemia	3 (18.8)
Colon	2 (12.5)
Hodgkin Lymphoma	1 (6.3)
Ovarian	1 (6.3)
Sarcoma	1 (6.3)
Thyroid	1 (6.3)
Uterine	1 (6.3)
Treatment received	
Chemotherapy	13 (81.3)
Surgery	12 (75.0)
Radiation	8 (50.0)
Time post-treatment	
0–12 months	6 (37.5)
13–24 months	6 (37.5)
25–60 months	4 (25.0)
ECOG performance status	
0 - Normal activity	9 (56.3)
1 - Symptomatic & ambulatory; cares for self	5 (31.3)
2 - Ambulatory >50% of time; occasional assistance	2 (12.5)

(continued)

TABLE 1. (CONTINUED)

	M (SD)
Past or current history of	
Back pain	5 (31.3)
Anxiety	4 (25.0)
Insomnia	4 (25.0)
Acid reflux	3 (18.8)
Migraine/Headache	3 (18.8)
Depression	1 (6.3)
Anemia	1 (6.3)
Asthma	1 (6.3)
Other	3 (18.8)

ECOG, Eastern Cooperative Oncology Group.

*fighting just to get to the next day. Because I always feel like I'm carrying it with me."*

Many participants discussed the uncertainties related to cancer. One participant (#1202, FG 2) stated, *"I was diagnosed with stage IV, so there is definitely always a lot of uncertainty and anxiety."* This was directly related to participants' reported fear of recurrence. One participant (#1201, FG 2) said, *"It's always in the back of your head, 'is it gonna come back?'"* Another (#1101, FG 1) added, *"When I was going through treatment I felt like this is going to protect me? I'm not going to get it...because I'm putting toxins in my body so it's not going to attack me. Once I stopped treatment, everything came back; the nervousness, the fear, the frustration."*

Some participants reported experiencing symptoms consistent with trauma, such as hypervigilance, intrusive experiences, and feelings of dread. One person (#1102, FG 1) stated, *"I'm more cautious about the smallest things. Someone can cough down the street and I feel like I'm [snaps finger] sick in a second. I'm constantly washing my hands. I won't even touch door knobs."* Another participant (#1304, FG 3) added, *"One of my big ones is rubbing alcohol...that smell, it just brings me back to the port draw room."* Other participants described a feeling of foreboding that something bad is yet to happen. One participant (#1106, FG1) commented, *"There's always this waiting for the other shoe to drop. Is something gonna crack at some point? Am I dealing with this too well?"*

**Identity changes.** Several participants shared a sense of personal loss and disconnect from themselves as a result of chemotherapy and radiation, at times describing it as "traumatizing" and "devastating." One participant (#1104, FG1) elaborated,

*"You look in the mirror every day and you see somebody...but you're not the person you were yesterday, at all. And as you continue treatment...your skin color changes; with steroids, you get bloated, you get red, red, red cheeks; you're irritated and angry and you're not sleeping and every day you wake up and you are like, 'who is this person?' Cause that's not me."*

Another participant (#1101, FG 1) described feeling "less of a woman," stating *"here I have one breast, my hair is gone, my nails are turning black..."* She continued sharing

TABLE 2. FOCUS GROUP CODES, FREQUENCIES APPLIED, INTER-RATER AGREEMENT, AND DEFINITIONS

<i>Theme</i>	<i>Category</i>	<i>Code</i>	<i>% coded compared to all codes</i>	<i># of times codes applied</i>	<i>Average % agreement across 3 groups</i>	<i>FG1</i>	<i>FG2</i>	<i>FG3</i>	<i>Code definition</i>
Emotional impacts	Stress, sadness and fear	Chronic stress habituation	0.40%	3	99.9	x	x		Being used to chronic burden of illness in lives.
		Dealing with uncertainty	4.03%	30	98.1	x	x	x	Unknowns/uncertainties of cancer experience.
		Emotional distress (general)	7.26%	54	98.3	x	x	x	Emotionality and stress as it relates to cancer and its impact.
			Fear of recurrence	2.69%	20	99.3	x	x	Feelings of anxiety, worry, and fear related to their cancer coming back after treatment are completed.
			Feeling lonely	1.08%	8	99.6	x	x	Feeling isolated or lonely because of cancer.
			Hard getting back to normal	1.61%	12	98.8	x	x	Challenges of getting back to normal once treatment has ended.
			Helpless frustration	0.40%	3	99.8	x	x	Inconsistencies of who gets cancer and who does not, and the role of lifestyle.
			Hypervigilance	3.23%	24	98.6	x	x	Purposefully feeling more vigilant about symptoms, aches, pains, etc., thinking it could be their cancer coming back.
			Intrusive experiences	3.09%	23	99.3	x	x	Cognitive or affective cancer-specific intrusions
			Precognition of cancer	0.40%	3	99.8	x	x	An intuitive "knowing" that they had cancer or something seriously wrong with their health.
		Stir crazy	0.94%	7	99.6	x	x	Because of their cancer experience, they are provided with more time to contemplate their situation	
		Surprised	1.88%	14	99.6	x	x	Surprise of something that occurred during the cancer experience (e.g., diagnosis, not being a BRCA 1 carrier)	
		Treatment decision-making	4.30%	32	96.7	x	x	Discuss treatment decision-making, including the cognitive and affective components.	
		Waiting for the other shoe to drop	0.27%	2	99.4	x		Feelings of a foreboding sense of something bad that is yet to happen.	
Identity changes		Body image	1.88%	14	96.4	x	x		Changes in their body image as a result of their cancer treatment.
		Describing success	2.15%	16	96.8	x	x	x	Ways in which they feel "successful" as a cancer survivor.
			Growth ambivalence	0.27%	2	99.9	x	x	Ambivalence about ways they have grown or changed because of cancer.
			Losing a part of yourself	0.40%	3	99.6	x	x	Losing a sense or part of themselves as a result of cancer treatment or changes from it.
			New normal	2.02%	15	98.8	x	x	When participants discuss their new normal.
			Rarity of situation	0.27%	2	99.6	x	x	Unique nature or rarity of their cancer situation
			Survival instinct	0.81%	6	99.7	x	x	When participants make comments about their drive to survive.
			Survivor identity	6.32%	47	95.4	x	x	How they perceive themselves as a person with cancer.

(continued)

TABLE 2. (CONTINUED)

Theme	Category	Code	% coded compared to all codes	# of times codes applied	Average % agreement across 3 groups	FG1	FG2	FG3	Code definition
Coping and self-care		Adherence	1.88%	14	99.6	x	x	x	Doing the things they are supposed to do to comply with treatment & lifestyle recommendations.
		Avoidant coping	1.48%	11	99.8	x	x		Using escape/avoidant ways of dealing with cognitive/affective aspects of their cancer.
		Engaging in health behaviors	3.09%	23	98.7	x	x		Wanting to or re-engaging in health behaviors.
		Genetic testing	1.08%	8	99.5	x	x		Discuss their experience with genetic testing
		Inconsistent lifestyle guidelines	0.40%	3	99.7	x	x		Inconsistencies of what they have been told by medical professionals or other sources.
		Proactive cancer disclosure	0.13%	1	99.6	x			Proactively disclose aspects of their cancer experience with others.
		Pushing through	2.82%	21	98.9	x	x		Needing to see past their problems and push through for others (e.g., kids).
		Religious coping	1.61%	12	99.4	x	x		Using prayer, God, or spirituality to cope with their situation.
		Self-care	4.03%	30	97.5	x	x		Comments about their need to take care of themselves.
		Self-coaching	1.61%	12	99.3	x	x		Self-talk or coaching messages they give themselves to cope.
Transcendence		Status Quo	3.76%	28	98.7	x	x		Not making any significant lifestyle changes as a result of their cancer
		Use of humor	2.69%	20	99.0	x	x		Comment on using or benefiting from humor as a way of coping.
		Use of supportive care	1.08%	8	99.4	x	x		Comment on their use of supportive care from medical professionals, organizations, etc.
		Appreciation	1.08%	8	99.3	x	x		Appreciating life more because of their cancer diagnosis.
		Higher purpose	0.27%	2	99.6	x	x		How their cancer diagnosis and situation fall into a larger cosmic plan.
		Letting go (re-prioritizing)	2.96%	22	99.2	x	x		When they have been able to let things go that were bothering them
		Positive transformation	2.96%	22	98.1	x	x		How their lives and outlooks have been positively transformed by the cancer experience.
		Slowing things down	2.42%	18	98.5	x	x		Trying to slow the pace of their life down and not sweat the small stuff as a result of their cancer experience

(continued)

TABLE 2. (CONTINUED)

<i>Theme</i>	<i>Category</i>	<i>Code</i>	<i>% coded compared to all codes</i>	<i># of times codes applied</i>	<i>Average % agreement across 3 groups</i>	<i>FG1</i>	<i>FG2</i>	<i>FG3</i>	<i>Code definition</i>
Social Impacts	Introducing cancer to the social network	Received support	5.78%	43	96.9	x	x	x	Discuss support they received
		Social limitations	1.34%	10	99.3	x	x		Being socially limited because of how cancer has impacted their lives.
		Work impact	2.28%	17	97.9	x	x		How their cancer experience has affected their ability to work.
	Pressure to be fine	Being OK for others	1.61%	12	99.2	x	x	x	When they keep up good appearances for others to help them feel better about their (patient's) cancer situation.
		Support ambivalence	2.69%	20	98.5	x	x	x	Ambivalence they felt toward the support they received (or did not receive) as it related to their cancer.
	Feeling abandoned, misunderstood, or invisible	Feeling let down by others	1.21%	9	98.8	x	x		How they felt let down by those they thought were their friends when they were diagnosed.
		Nobody gets it	0.94%	7	99.5	x	x	x	Feeling misunderstood or not understood by others after treatment ends.
		Survivor support	0.81%	6	99.1	x	x		Support that they received specifically from other cancer survivors.
	Role reversals	Wanting others to see through it	0.54%	4	99.8	x	x		How they wish their friends and family would see through the facade of being well.
		Caregiver coping	0.67%	5	99.5	x	x	x	Ways in which their family and/or friends are coping with this.
Caregiver stress		0.13%	1	100.0	x			When family members and supportive others felt helpless to be able to help	
Foregone conclusion Role changes		0.13% 0.81%	1 6	99.8 99.0	x x			How others treated them as if they were already dead. Ways in which their social roles have been changed because of the cancer experience.	

the challenge of not appearing “sick enough” on the outside to reflect the reality of her situation, stating, “*My job is not supportive of this [cancer] at all. I don’t appear to be sick. [I] appear to be ok. This is a hindrance to me because they feel like I can function as normal as...you know?*”

When the term “new normal” was brought up to represent this new reality, several people commented that while they hear this being used, the phrase was somewhat off-putting, with one participant (#1204, FG 2) stating, “*I know what my new normal is, but I know it is going to be different from person to person and that makes it hard to put a label on it and feel like it’s fair.*” Some participants felt that the label “survivor” did not accurately fit with their sense of identity as a person with cancer and stated, “*I don’t feel comfortable saying I’m a survivor. I don’t know if ‘cancer survivor’ will...ever fit (#1102, FG 1).*” Another participant (#1106, FG 1) added, “*I like it because I think it really raises awareness. It isn’t like you just had cancer and it is done.*”

**Coping and self-care.** Some participants discussed ways in which they coped with their treatment through using distraction and avoidance. One participant (#1202, FG 2) commented, “*During treatment the name of the game was distraction. ...whether it was on purpose or completely unconscious, distraction was probably, like, the only way to really cope with things, for me.*” Another participant (#1201, FG 2) added, “*Forcing to numb myself...emotionally, physically sometimes. Some stuff I don’t remember that my mom has told me... while I was there, I don’t remember. I don’t even recall any of it, so that’s good.*”

One participant (#1204, FG 2) described using supportive self-talk, stating, “*You have your moments where you get up, you look at yourself in the morning and you’re like, ‘I will get through this day. I will.’*” One participant (#1106, FG 1) reported using self-talk during moments where she felt she had no other choice: “*Fortunately and unfortunately, I have two small children so I’d say to myself, ‘okay, I have these kids, I gotta do this.’ You can’t feel bad.*”

Other participants reported drawing from spiritual practices and beliefs as a means of coping. One participant (#1105, FG 1) stated, “*I just pray about it. That is about all I can do, is just pray.*” Another person added, “*After I finished treatment I went out to a yoga ashram. I went looking for spiritual enlightenment.*” Some participants commented on getting used to living with cancer over time. One participant (#1205, FG 2) commented, “*Eventually you start to get over it, like if you have to put down your cat, eventually you get over it.*” Trying to find ways to see the lighter side of things emerged throughout discussions. One participant (#1301, FG 3) shared, “*I had a sense of humor about going through treatment and everything, and I don’t feel embarrassed about sitting naked in front of a doctor anymore. I’m just like ‘pssht’, you know?*”

Beyond specific coping styles and strategies, participants also reflected on the importance of self-care, despite how uncomfortable advocating for oneself can sometimes feel. One participant (#1106, FG 1) stated, “*When you’re sick, you learn that if you do not take care of yourself you will die*” and another (#1102, FG 1) added, “*You need that time for yourself; you need that time to relax. But, I do feel like I’m being selfish and I feel guilty for it.*”

Self-care also manifested through being more adherent to health care recommendations and engaging in positive health behaviors. One participant (#1102, FG 1) stated, “*I showed up to treatments, I did everything I had to do. I ate well—when I could eat—you know, I did everything my doctors told me to do.*” Another person (#1205, FG 2) added, “*I had my last cigarette the day before I went in for my treatment at like 11 o’clock at night. I smoked for about 12 years. I may still be a smoker today if I hadn’t gotten cancer.*”

**Transcendence.** While a good deal of focus group conversations centered on the negative life impacts of cancer, woven throughout were, at times, positive and even transformative reframes or reflections that had the potential to transcend some of these challenges. One participant (#1103, FG 1) commented, “*When it is nice outside, I pay more attention to it. And you know I really enjoy that.*” Another (#1206, FG 2) added, “*I spent too much time at work and now it’s five o’clock—‘Who, see you later!’ [laughs] ‘I’m out!’*” Sometimes comments focused on a newfound ability to let go of things that previously seemed important. One participant (#1202, FG 2) stated,

*“Before my life was about saving money and going to work six days a week. But now I go. Like this weekend we decided to go to Hawaii. I would never do stuff like that before and now I do stuff like that all of the time. I don’t really care about the future per se.”*

Others commented on paying more attention to their “bucket list” and following through with intended plans. Some participants made comments about how their lives and outlooks have been positively transformed by their cancer diagnosis. One participant (#1105, FG 1) stated, “*I’ve always been a loner, and not much of a people person. But now it’s, go talk, go have a conversation, speak whatever, go party.*” Finally, some participants referred to slowing things down in their lives as a result of cancer and not sweat the small stuff as much. One participant (#1102, FG 1) commented, “*I’m more present in what’s going on in the moment. I don’t make plans ahead of time anymore. If things happen, things happen.*” Others talked about not worrying about being late for appointments and meetings as much as they were before treatment, and instead stating to themselves, “*I’ll make it*” (#1102, FG 1) and “*let it go (#1104, FG 1).*”

#### *Theme II: social impacts*

Hand in hand with emotional impacts were several social impacts that participants reported, including (1) introducing cancer to the social network; (2) pressure to be fine; (3) feeling abandoned, misunderstood, or invisible; and (4) role reversals. Each is described below.

**Introducing cancer to the social network.** Some participants discussed disclosing aspects of their cancer experience with others, which varied according to individual preferences and circumstances. One participant (#1101, FG 1) shared, “*I finally decided to sit down and tell my ten year-old son what I was going through. That was the hardest thing in my life. I was like, ‘Do I keep it from him? Do I tell him? How do I tell him? Do I have somebody else tell him? What to do?’*” In

contrast, other participants decided not to disclose their cancer status. One person (#1104, FG 1) stated,

*“A lot of people [in the office] had no clue. I wore a wig that was very similar, you know, the way my hair looked.... I showed up [to work] and they’re like, ‘Ah, you cut your hair!’ And I’m like, ‘Mhmmmmmm, yeah... cut my hair.’”*

Pressure to be fine. Others reported feeling pressure to keep up good appearances for others as one participant (#1105, FG 1) stated, *“I don’t care how sick I was or whatever, I just felt like I didn’t want them to see me down. And if they didn’t have to worry about me, then everything else is ok.”* He continued to talk about the weight of needing to reassure family members that things were fine and stated, *“Making your family feel like, ‘I’m okay, I’m alright, I’m ok,’ knowing that I’m not—it was pretty heavy.”* Others expressed feelings of frustration with the pressure to make others feel as if they were okay, with one participant (#1303, FG 3) stating, *“When people weren’t seeing me as sick, they wanted to hear that I was better.”* She continued, *“I got tired of feeling like I had to make them feel good about trying to help me and I would get defensive about it and then people would be like, ‘oh they’re just trying to help’ and I’m like ‘I’m sorry, it’s not helping.’”*

Feeling abandoned, misunderstood, or invisible. Many participants reported feeling let down by others they thought were their friends when they were diagnosed. One participant (#1102, FG 1) commented, *“You really find out who cares about you and who doesn’t.”* Another participant (#1205, FG 2) added, *“I lost some friends through the process that I thought would always be there for me and they weren’t, and then I gained some new friends, too. But no matter what happens, as good as your support is, I just still feel alone...It’s my own world, [and] it’s a different world.”* In addition, comments regarding lack of trust seemed to resonate throughout the group as one participant (#1102, FG 1) stated, *“I trust no one.”* emphasizing the disappointment and relationship fallouts that were commonly experienced. Others reported feeling misunderstood on multiple levels and isolated by others after their treatment ended. One participant (#1102, FG 1) commented, *“Nobody gets it. My friends don’t get it. My family doesn’t get it. And I don’t expect them to completely, ‘cause they didn’t go through it like I did. But—at the same time it irritates me.”* Another person (#1205, FG 2) stated, *“Sometimes I’m offended if they don’t ask [about cancer] and sometimes I’m sick of hearing it. Depending on your mood, sometimes you want...call it attention. Or you feel like explaining or talking about your feelings, but sometimes you just wanna keep it to yourself.”* Finally, some participants spoke about how they wished friends or family would see through their façade of being well. One participant (#1106, FG 1) commented on her family’s inability to be observant and notice how she was really feeling, stating, *“I wish they could just get past themselves and see me.”*

Role reversals. Sometimes participants commented about ways in which their social roles have been changed because of their cancer experience. One participant (#1102, FG 1) stated, *“My parents pretty much broke down when*

*they found out I was sick. I felt like I was taking care of them.”* She continued feeling as if her family took the diagnosis worse than she did. She said, *“it was almost like they were treating me as if I was already dead. They were having a harder time dealing with it than I was. And of course, I was the one taking care of them throughout the whole entire thing.”* Another participant (#1203, FG 2) commented on her relationship with her grandmother stating, *“I’m thinking I should be checking on you, not the other way around. You know? She’s healthier than I am!”*

## Conclusions

The purpose of this study was to use qualitative methodologies to elicit the lived experiences of young adult cancer survivors on the psychosocial impacts of cancer on their lives. For most participants, their cancer diagnosis and treatment levied significant emotional distress and disrupted the achievement of formative social developmental milestones, both personal and professional. This in turn lead many participants to report feeling misunderstood, isolated, and alone, or incapable of actively engaging or being open to new relationships. Some young parents reported struggling that they could no longer attend to their children’s needs in the same way, while others reported role reversing altogether and experiencing pressure to take care of others, at least emotionally. Many stated they had to take time off or quit their jobs, halting their professional development at a critical time.

Because their cancers emerged during a period of critical development and transition, many young adult participants reported experiencing manifold cancer-related psychosocial impacts amid tremendous normal developmental-psychosocial capriciousness. For most, young adulthood is a time characterized by significant social development, both through close personal relationship formation as well as professional development; and their cancer diagnosis and treatment disrupted the achievement of these milestones. Peer and romantic relationships had been negatively impacted by cancer, leading many participants to report feeling misunderstood, isolated, and alone, or feeling incapable of actively engaging or being open to new relationships. Some participants were also young parents and reported struggling with the fact that they could no longer attend to their children’s needs in the same way as previously. Alternatively, some reported role reversing altogether and experienced a pressure to take care of their parents, at least emotionally. Similar challenges were discussed in participants’ abilities to work. Many stated that they had to take time off or quit their jobs, halting their professional development at a critical time in their career. The unique timing of cancer for AYA survivors has a critical impact on their lived experience and of the social and emotional impacts on their lives.

As with any phenomenologically based qualitative study, it is understood that findings are affected by the experience and perceptions of the research team as well as the composition and experiences of the group participants themselves. To limit this from jeopardizing the integrity of our results, our team comprised individuals with expertise in qualitative methods and analysis, who followed a systematic process to increase credibility and dependability of findings. The use of purposive sampling in qualitative research, while critical to



assure that proper informants are being interviewed, also places limitations on the generalizability of findings. While generalizability and inference are not stated goals of qualitative research, due to these methodological restrictions, interpretive caution should be taken nonetheless. In addition, the hospital from which patients were recruited serves an urban catchment area, which is diverse with respect to race/ethnicity and socioeconomic status. These factors may also place limitations on the interpretability of our findings. AYA research is burgeoning and has been catalyzed by important collaborative initiatives by the National Cancer Policy Forum of the Institute of Medicine<sup>23</sup> and the National Cancer Institute.<sup>24</sup> Although the majority of AYA research focuses on cancer clinical trials and physical health outcomes,<sup>8,25</sup> there is increasing interest on the emotional and social impact of cancer among AYAs.<sup>1,10</sup> Overall, our findings are important for oncology clinical practice and survivorship research activities with young adults, especially given the presence of these impacts over the long term and the current dearth of attention given to this unique cohort. D'Agostino et al. discuss appropriate psychological care for AYA survivors to include the following: (1) establishing autonomy from parents, (2) personal set of values and identity, (3) strong peer relationships, (4) preparation for work, (5) developing a sense of normalcy, (6) having access to supportive resources, (7) fertility and sexual counseling, (8) help with academic programs, and (9) financial support.<sup>26–28</sup> Future research should examine ways in which the negative psychosocial impacts might be mitigated, and the positive psychosocial impacts might be augmented. Such efforts could include peer-to-peer focused age-appropriate supportive and behavioral interventions to increase self-acceptance and other acceptance related to the struggles of survivorship.

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### Disclaimer

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## Appendix 1

### Focus group interview guide

- I. Welcome and brief study background
- II. Discussion of group rules
- III. Brief participant introductions
- II. Discussion questions and probes
  - A. Assessment of global life changes
    - I. Tell us about how cancer has affected your life?
      1. Probes:
        - A. Please tell me what your life was like before the cancer.
        - B. How is your life different since your diagnosis and treatment?
        - C. Generally probe for details to get a complete narrative account of changes.
        - D. (if valence, not specified) Would you describe those changes as negative or positive?
        - E. (if all QOL domains not included) Did you experience any change in the (physical, emotional, social, spiritual, and practical) aspect of your quality of life? If yes, can you tell me about those changes?
        - F. (if not described) Did you experience any positive change?
        - G. What would you describe as the most significant long-lasting negative change in your life since your diagnosis and treatment?
        - H. What would you describe as the most significant long-lasting positive change in your life since your diagnosis and treatment?
  - B. Life changes, coping strategies, and barriers:
    - I. Looking back, what did you notice about yourself in terms of how you were dealing with the many things you were faced with at that time? What has helped you get through the cancer experience? What changes if any, have remained? What has made it difficult to get through the cancer experience?
      1. Probes
        - A. Generally probe for details to get a complete narrative account of changes
        - B. (if not specified) Were there any personal strengths that helped you get through? Were there other people who helped you get through? How?
        - C. Probe specific behaviors and query
          - I. What specific changes? (f/u with “yes” vs. “no”, “increased” vs. “stayed the same” vs. “decreased”)
            1. Diet
            2. Smoking
            3. Medication
            4. Alcohol consumption
            5. Exercise patterns
            6. Formal stress management strategies (e.g., stress management courses and assertiveness training)

7. Informal coping strategies (e.g., work life, leisure time life, religious activities, and new activities)
  8. Anything else?
- C. Perceptions of “success,” “survivor,” and “new normal”:
- I. Define success since you have stopped treatment?
  - II. Let us talk about some common terms that people use. What does it mean to you to be a cancer survivor?
  - III. Some cancer survivors talk about a “new normal.” Have you heard the term? What does it mean to you?
- D. Direct assessment of growth
- I. Some people report that their perspective or outlook of life has changed because of the experience. How would you respond to that?
    1. Probes
      - A. Generally probe for details to get a complete narrative account of changes.
      - B. Are there ways these changes have impacted your day to day life or health?
      - C. (if not specified) Were your daily activities affected? Your priorities? Your future plans or goals? Your sense of self? “Your relationship with your spouse? Your meaning of life? Your faith?
      - D. Were there people who made it difficult for you to get through? How? Were there specific things you did to help you get through?
- E. Final thoughts/questions
- I. Is there anything else that you think is important for me to know about your experience that I did not ask you about?