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Cancer–Peer Connection in the Context of Adolescent and Young Adult Cancer: A Qualitative Exploration

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Purpose: This qualitative study examined experiences and attitudes related to cancer–peer interactions among adolescent and young adult (AYA) cancer survivors.

Methods: Twenty-six survivors, aged 16–24 years who were diagnosed with cancer between the ages of 14 and 18, completed one-on-one semistructured interviews as part of a larger study. Interviews were coded and analyzed using an iterative consensus and data-driven approach.

Results: The data for this study revealed three main themes related to cancer peers, including the unique aspects of shared illness experience (i.e., personalizing of support from lived experience, inspiration from upward comparisons, space to be scared and to joke about cancer), benefits of providing support to other patients/survivors (i.e., giving back, healing after cancer, and incorporating cancer into life as a survivor), and considerations and concerns when connecting with cancer peers (i.e., exposure to adverse outcomes, ‘‘ignorance is bliss'': blocking cancer out, guilt and cancer imposter syndrome).

Conclusion: Study findings demonstrate the importance of cancer–peer connection and support in AYA cancer care, both during treatment and in survivorship. Future research should explore the ways in which peer-to-peer support programs could be tailored to best serve the AYA population in the context of cancer care.

Keywords: adolescence, young adult, cancer, psycho-oncology, social support, peer support

Introduction

Adolescents and young adults (AYAs) report insufficient social support during and after cancer, despite adolescence and young adulthood being a time when independence from parents is often sought and relationships with peers are strengthened.[1–7] For AYAs, peer-driven interventions may have more influence in altering their behavior than adult-driven approaches, and AYA peers can serve as role models by reinforcing social and behavioral norms, prosocial behaviors, and providing well-being strategies.[8–12] A possible contributor to the efficacy of peer support is the universality of shared experiences, which has been reported as an enabler in mentor/mentee relationships among young people.[12–15] Previous studies among AYAs with cancer have demonstrated relationships between social support and psychosocial outcomes, including psychological and physical health.[16–20]

Peer support between patients and/or survivors in health care contexts involves the provision or exchange of support by a social network member with experiential knowledge of a behavior or stressor.[21] Older patients and survivors have reported high levels of interest in becoming a cancer–peer mentor/mentee.[22–30] Further, research demonstrates high satisfaction with cancer–peer support for patients, survivors, and their families, and numerous benefits including improved psychological and physical health, perceptions of social support, self-perception, and cancer-related knowledge.[23–36]

Peer programming among AYAs with chronic pain has demonstrated feasibility, acceptability, and quantitatively significant improvements.[9,37,38] AYA cancer–peer connection during treatment and survivorship is frequently mentioned as an unmet need; while support received from family, friends, and medical staff is critical, additional support exchanged with cancer peers through receiving/providing

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mentorship or engaging with cancer peers may offer unique benefits.[1,39–45] Indeed, past research suggests that cancer–peer engagement may provide opportunities to address uncertainty, dependency and autonomy, social exclusion, body image concerns, intimacy issues, and fertility.[45]

In contrast to research identifying potential benefits of AYA cancer–peer support, research among older cancer populations has elucidated possible concerns with structured programming,[46] and suggests that some methods of support received from AYA cancer peers may be perceived as unhelpful.[47] Existing studies exploring AYA cancer peers have often queried directly about specific benefits of cancer–peer support in structured programs, thus may fail to capture less formal support and may miss negative experiences to inform the ways cancer–peer connection can be facilitated to address and mitigate associated risks.

Qualitative research that omits program-specific inquiries is necessary to gain a more comprehensive picture of how casual and formalized cancer–peer support can be tailored to meet the needs of the AYA cancer population. Given the demonstrated benefits and interest from AYAs, cancer–peer support programs that are informed by both positive and negative experiences and attitudes will improve the promise of cancer–peer support as a feasible, efficacious, low-cost intervention approach that relocates support from the health care system to community settings.[36]

The aim of this article was to explore AYA cancer survivors' perceptions about cancer-peer–related experiences and attitudes during treatment and in survivorship spontaneously discussed in interviews. A characterization of perceived benefits and concerns is the next step in determining broadly what components and considerations are necessary to tailor existing and future cancer–peer support opportunities within and outside structured program environments. Further, this understanding will help support clinicians and oncology care providers when determining appropriate peer support opportunities for AYAs with cancer.

Methods

Participants

Participants were patients at a large urban cancer center, age 15–25 at the time of consent and interview administration, diagnosed with cancer between the ages of 14 and 21, and had completed treatment ~6 months before study participation. Participants were English speaking, and provided written informed consent or assent to participate in the study.

Data collection

After Institutional Review Board approval at Memorial Sloan Kettering Cancer Center (Protocol No. 09-001), 26 semistructured 90-minute one-on-one interviews were conducted by a trained member of the research team as part of a larger study exploring the impact of cancer on survivor identity.[48,49]

Data analysis

Interviews were audio-recorded, transcribed, and analyzed using ATLAS.ti software. Analysis efforts were guided by grounded theory; a methodology used in social science research that outlines a systematic process for evaluating qualitative data and formulating theoretical propositions emerging from data, and thematic analysis.

A subset of transcripts were coded, and consensus meetings were held during which coding differences were resolved, and code names, definitions, and interview subset assignment were established.[51]

Analyses were conducted by four trained coders who independently completed interview coding and identified high-level domain areas relevant to the aims of the larger study.[48–53] Excellent inter-rater reliability was demonstrated (>80%). Through rigorous review and interpretation of our transcripts, a thematic text analysis approach was conducted to deductively develop key themes.

Questions pertaining to experiences with and attitudes about cancer–peer interactions were not specifically queried as part of the interview battery but arose as a prominent theme across all 26 interviews, producing codes that captured benefits and concerns related to cancer–peer interaction from diagnosis through survivorship: ''response to survivorship: become a cancer advocate'' (i.e., involvement in cancer-related volunteering and fundraising), ''response to diagnosis/treatment: connection'' (i.e., connection to cancer peers during diagnosis/treatment), and ''response to survivorship: connection'' (i.e., connection to cancer peers during survivorship).

Results

Interviews were conducted with 26 AYA survivors. Approximately two-thirds of the sample were female (61.5%) and white (65.4%). Participants were between the ages of 16 and 24 at the time of data collection with a mean age of 19.6 (standard deviation [SD] = 2.8), and diagnosed with cancer between the ages of 14 and 18 with a mean age of 15.6 years (SD = 1.3). Half of the sample had been off treatment for 2–5 years at the time of the interview (50%). The most prevalent cancer diagnoses included lymphoma (30.8%), sarcoma (19.2%), and leukemia (11.5%), and a majority of the sample received multimodal treatment (65.4%). A majority of participants were students (84.6%) and employed part- or full-time (61.5%). Full demographic information is located in Table 1.

All participants discussed cancer–peer connections spontaneously, and discussions pertained to both experiences with cancer peers and/or attitudes about what experiences with cancer peers might be like. Over half of the sample (65.4%) reported interacting with a cancer peer during treatment and/or survivorship, and no significant demographic differences were observed between those who did and did not report cancer–peer experiences. Nineteen participants (73.1%) reported interactions with cancer peers as an unmet need during their time as a patient (53.8%), and/or now in survivorship (61.5%).

Twenty-two participants (84.6%) reported positive associations with cancer peers, while 21 participants (80.8%) reported concerns related to cancer–peer interaction. A majority of cancer–peer interactions described did not occur through programs or support groups, but casually: facilitated by family, health care providers, or peer networks. Examples of positive and negative associations with cancer peers were heterogeneous, and produced three themes and nine subthemes. Below, we identify themes and subthemes identified, and provide representative quotes and endorsement rates for the entire sample (Table 2).

Table 1. Demographics and Medical Characteristics

Variable	n	%	*M*	*SD*	*Range*
Age (years)	26		19.6	2.8	16–24
Sex					
Female	16	61.5			
Male	10	38.5			
Marital status					
Single	26	100.0			
Married or partnered	0	0			
Ethnicity					
White	17	65.4			
Hispanic	2	7.7			
African American	5	19.2			
Asian/Pacific Islander	2	7.7			
Level of education					
Partial high school	7	26.9			
Partial college	12	46.2			
Completed college	1	3.8			
Not indicated/unsure	6	23.1			
Currently a student	22	84.6			
Currently employed	9	34.6			
Part-time	5	19.2			
Full-time	4	15.4			
Cancer diagnosis					
Lymphomas	8	30.8			
Sarcomas	5	19.2			
Leukemias	3	11.5			
Neuroblastoma	2	7.7			
Thyroid	2	7.7			
Age at diagnosis (years)			15.6	1.3	2–5
15–19	15	57.7			
20–24	11	42.3			
Treatment type					
Chemotherapy	18	68.2			
Radiation	11	42.3			
Surgery	17	65.4			
Multimodal treatment	17	65.4			
Time since treatment ended (years)					
<2	8	30.8			
2–5	13	50.0			
>5	5	19.2			

M, mean; SD, standard deviation.

Unique components of shared illness experience

Nearly all participants reported positive experiences and associations with cancer peers due to shared experiential knowledge of cancer, benefit from upward comparisons, and space to be scared and to joke while talking about cancer.

Personalizing of support from lived experience. Over half of the participants reported receiving and/or providing customized support based on their personal experiences during cancer treatment and survivorship. One participant discussed coping tools provided by a survivor, ‘‘When I was sick I had somebody come to me and say … when you get nauseous to smell an orange peel, or suck on a certain flavored candy … [those are] things that you learn along the way, but it helps to know them from the beginning.’’

Inspiration from upward comparisons. About half of the participants discussed the positive impact of upward comparisons related to physical appearance, physical ability, and emotional resilience on coping during treatment and survivorship. Participants expressed that while many support persons verbally communicate that they will ‘‘be okay’’ during their cancer experience, seeing a survivor in a healthy state firsthand was a more deeply impactful and believable way to communicate this sentiment. One participant shared the impact of meeting a survivor peer, ‘‘He [survivor peer] was like fit and he had just run the New York Marathon … he did not look like a cancer survivor at all. So it was like, ‘I can get back from this, and I can be just like I was before’.’’

Space to be scared and to joke about cancer. Nearly half of the participants reported cancer–peer interactions as a unique opportunity to be scared and/or light hearted about their cancer experience. As AYA cancer patients may try to ‘‘be okay’’ for their parents and peers, cancer–peer relationships may create space for emotions, which are not as readily and appropriately received by other social support outlets. One participant described this during treatment, ‘‘[Patient peer] and I did a lot of crying together, just to let it out. We were scared, and we were so young.’’ Another peer spoke about the joy of having a cancer-peer to joke about cancer with, ‘‘We joke about it [cancer treatment] all the time, I'm like, ‘You're gonna glow in the dark', and all this fun stuff.’’

Benefits for those providing support

Many participants spoke about their personal benefits of providing support to others both experienced and predicted, often driven by their positive peer experiences during cancer. Participants discussed emotional healing and the incorporation of survivor identity into life after cancer.

Giving back. Nearly half of the participants referenced a desire to give back to the cancer–peer community, driven by positive experiences during treatment and/or survivorship. One survivor described his motivation to interact with cancer patients, ‘‘I mean it felt like what [cancer-peer] had done for me, it was good to try to pass it on as much as I could … it just sort of felt like what I should be doing at that point because someone had helped me through it, so I should help other people through it.’’

Healing after cancer and incorporating cancer into life as a survivor. About half of the participants discussed supporting cancer peers as a method of processing fears and trauma, and affirming cancer as part of one's identity after treatment has ended. One participant explained, ‘‘I guess part of [supporting cancer-peer] is overcoming my fear of [cancer] in a way too, if I'm dealing with it, helping others deal with it, then I'm overcoming my fear of being around it.’’ Another participant described experiences of purpose and meaning when supporting a cancer peer through treatment, ‘‘I was there for [cancer-peer] a lot, and I was just like, wow, like things come around full circle, and so I was like this is probably like another reason why [cancer] happened to me.’’

Table 2. Representative Participant Quotations

Theme and subtheme	*Endorsement* *Total* n *(%)* *Male* n *(%)* *Female* n *(%)*	Quotation
Unique Components of Shared Illness Experience	18 (69.2) 8 (80.0) 10 (62.5)	
Specializing of Support from Personal Experience	14 (53.8) 6 (60.0) 8 (50.0)	I have spoken to kids who were either just diagnosed or in the process of it, to try to help them and … say, “Well, I was in your position and, trust me, it gets much, much better.” … it makes me happy that I'm able to help… because when I was sick I had somebody come to me and say … “Well, this is what it's gonna feel like, and if you have any questions, if you have any concerns let me know. I went through it, you know, I did the same thing that you're doing right now.” … that was very comforting … And even just small tips that I had, when you get nauseous to smell an orange peel, or suck on a certain flavored candy … things that are helpful, and that you learn along the way, but it helps to know them from the beginning. (18-year-old white male diagnosed with Hodgkin's Lymphoma at age 14)
		[Survivor peer] would say, “How are you feeling,” and I would say, you know, describe it to him and he'd be like, “Oh yeah, I remember that part.” … And he'd be like, you know, “Dude, here's what you can do for this,” or, you know, like, “Here's a food, like, try yogurt maybe if you can't have the crunchy foods.” (16-year-old white male diagnosed with Burkitt's Lymphoma at age 14)
		[Patient peer] was like really uncomfortable coming back to school, and like if she could do school and all this stuff, and like I was going through her priorities and like what she was like looking forward to do next year, and I was like, “That all has to change,” like, “You can't do everything now anymore.” You know, like she was like gonna take this head leadership role, and I was like, “Well, you can't really do that, because now you have to focus on this,” and it's kind of hard to see that because you're still in the mindset of like being that person and making that your identity, but like it changes so quickly when you have something like that come up … it helped her a lot. Like I sent her like—I used to send her things, like I sent her like a survival kit, like, okay, things that, you know, you can do, and so I would just give her my two cents about things. (20-year-old black female diagnosed with non-Hodgkin lymphoma at age 16)
Inspiration from Upward Comparisons	11 (42.3) 5 (50.0) 6 (37.5)	When I was sick I had [a survivor peer] come to me and say, you know, “Well, I had this.” … I went through it, you know, I did the same thing that you're doing right now.” And she was—at that time she was out of treatment, her hair was growing back, she looked fantastic. She's absolutely gorgeous. And she's like, “I had it two years ago, and look at me. You know, I'm back to normal, I'm fine, I'm healthy, you know, and so will you.” And that was very comforting, you know, just to see somebody that … Because you could tell me over and over again, “You're gonna be fine, you're gonna be fine, you're gonna be fine,” and it helps to know that. But to actually see it is a different thing. (18-year-old white male diagnosed with Hodgkin's Lymphoma at age 14)
		[A survivor peer], he's 22 or 23 now, but he had had the same type of cancer that I had three years before I did … And he would come and visit me in the hospital. … So I would see him, and that sort of, that was what inspired me … I think the biggest part, not even like him talking to me, was just seeing him and he was like fit and he had just run the New York Marathon … he did not look like a cancer survivor at all. So it was like, “I can get back from this, and I can be just like I was before.” (16-year-old white male diagnosed with Burkitt's Lymphoma at age 14)
		[Patient peer] was like, you know, I guess a good role model. She was so strong and so positive, and although she had gone through what I was going through, and then she had to do it again, and still, you know, so positive. It was—that was something to really admire.” (17-year-old white male diagnosed with Hodgkin's Lymphoma at age 14)

(*continued*)

TABLE 2. (CONTINUED)

Theme and subtheme	*Endorsement* *Total* n *(%)* *Male* n *(%)* *Female* n *(%)*	Quotation
Space to be Scared and to Joke About It	11 (42.3) 4 (40.0) 7 (43.8)	We [Participant and patient peer] like joke about it like all the time, like I'm like, ''You're gonna glow in the dark,'' and like all this like fun stuff. (17-year-old white female diagnosed with thyroid cancer at age 14) [Patient peer] like told me, she's like, ''I couldn't like tell this to like anyone really, because no one would understand that.'' And, you know, and like times where we'd meet up and she's like, ''I just can't meet up,'' like I wouldn't push her. I'd be like, ''That's fine,'' like, ''Just let me know, because like I understand.'' (20-year-old black female diagnosed with non-Hodgkin lymphoma at age 16) We [Survivor peers] buy each other drinks at a bar, we don't really talk about it. That's about it. Like there's a little bit of understanding, like a mutual thing going on but we don't really talk about it. (21-year-old white male diagnosed with Hodgkin's Disease at age 17) I feel like her [Patient peer] and I did a lot of crying together, just to let it out. We were scared, and we were so young. (22-year-old white Hispanic female diagnosed with Melanoma of the skin at age 18)
Benefits for Those Providing Support	15 (57.7) 3 (30.0) 12 (75.0)	
Giving Back	11 (42.3) 3 (30.0) 8 (50.0)	I mean it felt like what [Survivor peer] had done for me, it was good to try to pass it on as much as I could … it just sort of felt like what I should be doing at that point. … Because, you know, someone had helped me through it, you know, so I should help other people through it at the same time. (21-year-old white male diagnosed with Ewing's Sarcoma at age 17) It's not like a hassle or a chore, but it's like something that I want to do … Almost like backwards karma, like they did good things for me first so I have to pay it back … pay it forward. (21-year-old white male diagnosed with Ewing's Sarcoma at age 17) I probably credit [Cancer-peer interaction] the most with my, quote/unquote, good recovery, like because just being able to do that and like give other people some perspective … So that was probably—yeah, I definitely credit that with like saying my sanity for the past couple years. (24-year-old white female diagnosed with Hodgkin's Lymphoma at age 14) When you need it someone's willing to come and help you and then it's time to give it back, you have to do what's right. (17-year-old white female diagnosed with Hodgkin's Lymphoma at age 14)
Healing After Cancer and Incorporating Cancer into Life as a Survivor	11 (42.3) 2 (20.0) 9 (56.3)	I think that with somebody who's gone through [cancer] it's either, ''I don't want to have anything more to do with it,'' which I totally get, or it's—I guess part of it is overcoming my fear of it in a way too, if I'm dealing with it, helping others deal with it, then I'm overcoming my fear of being around it. (16-year-old white female diagnosed with Osteogenic Sarcoma at age 14) I could kind of see myself in [patient peer's] shoes … I was having like flashbacks like here and there, and I was like telling her these stories … I felt like I was kind of like reliving like those moments and those experiences like talking to her … it's so funny how like similar experiences you can go through with people like that and like how much closer it could bring people like us together. (20-year-old black female diagnosed with non-Hodgkin lymphoma at age 16) I mean it just sort of felt like what I should be doing at that point … I think I saw myself in him [patient peer], and then at that point I was getting better, so it was like, oh … He's gonna get better. (16-year-old white male diagnosed with Burkitt's Lymphoma at age 14) I was just telling [patient peer], like, you know, like giving her a piece of my story as like strength to like, you know, ''You can get through this, and you will be fine.'' … so I was there for her a lot, and I was just like, wow, like things come around full circle, and so I was like, oh well, you know, this is probably like another reason why this happened to me, because I've come in contact with this person and whatnot. (20-year-old black female diagnosed with non-Hodgkin lymphoma at age 16)

(*continued*)

Table 2. (Continued)

Theme and subtheme	*Endorsement* *Total* n *(%)* *Male* n *(%)* *Female* n *(%)*	Quotation
Considerations and Concerns	21 (80.8) 9 (90.0) 12 (75.0)	
Exposure to Adverse Outcomes	11 (42.3) 3 (30.0) 8 (50.0)	I think I saw myself in him [cancer-peer], and then at that point I was getting better, so it was like, oh … He's gonna get better … It might've been different if he was a more serious case … where he wouldn't have recovered … or even wouldn't have—you know, if he was a terminal patient. Then that would've been a lot different. (16-year-old white male diagnosed with Burkitt's Lymphoma at age 14) I cleared first and then … they found something in his [patient peer's] lungs right after. He went back and then he was cleared and then they found something again and he actually passed away and I was like oh my God. Because he was younger than me. I was, I think at that time I was probably 17, I think he was 15–16. And I just didn't realize that this could happen … it hit me like a—I got pretty scared but it passed. (19-year-old Asian American female diagnosed with Osteosarcoma at age 5) He [patient peer] was in really bad shape … he had to have his leg amputated and he was a track runner so it was sad. And I think he was a year older than me, too, and he would up having his other leg amputated. He was a nice kid … he died … It was really sad. That was a like a shocker … That was tough because then of course I think what if that happens to me, but after talking to everybody they said it's different. And it is, it was entirely different, the kid was, I mean he was really, really sick … Yeah and it was really bad. My doctor said don't worry about it. (17-year-old white female diagnosed with Hodgkin's Lymphoma at age 14) I was just like expecting to relapse, like that's just the way I thought. I was always like just expecting to just have to go through treatment again. And I knew so many people who were doing that, you know, who one day were great and the next day I'd speak to them, like, ''Oh yeah, he's relapsed.'' Like—why was I any different, you know? (21-year-old white male diagnosed with Ewing's Sarcoma at age 17)
Ignorance is Bliss, Blocking Cancer Out	13 (50.0) 7 (70.0) 6 (37.5)	Ignorance is bliss. Like, the fact that I didn't know what I was getting myself into is in a way helpful, because if I would've known, I would've been scared like shitless, like I would've been freaking out. (21-year-old white male diagnosed with Ewing's Sarcoma at age 17) The whole thing with understanding how post-cancer life is not gonna be what pre-cancer life was. It's going to be post-cancer life … I don't know if anybody should've told me that. Would it have been helpful if they'd said, like, ''Oh, your life's gonna suck in two years.'' … ''Don't get your hopes up.'' (21-year-old white male diagnosed with Ewing's Sarcoma at age 17) The people I've been in touch with that have cancer, which is a lot … I feel usually they're just like, they take the approach of like they don't—they like hide, they like keep it out of their life. Like they block it out of their head, like it's not reality. (21-year-old white male diagnosed with Ewing's Sarcoma at age 17) I'm not trying to completely ignore it. It's just I would like to live as normal a life as possible—The less I think about it the more I guess normal my life kinda, you know, seems. (19-year-old white male diagnosed with Leukemia at age 15)

(*continued*)

TABLE 2. (CONTINUED)

Theme and subtheme	*Endorsement* *Total* n *(%)* *Male* n *(%)* *Female* n *(%)*	Quotation
Guilt and Cancer Imposter Syndrome	15 (57.7) 7 (70.0) 8 (50.0)	I've been lucky that like all the tests have come back fine … and my doctor, like she's very particular about like doing all these tests, so—I think it's also like coming back and just going through the process again and just knowing—I mean every time I'm like, ''Andrea, you're not gonna get upset about this,'' but then you do get upset. And then you see, I don't know, coming back and then you see like sick patients and stuff like that and just like remembering that you were one of those patients, and like how lucky you are to come back and, you know, be fine and healthy. So there's like a lot of emotions I go through, like whenever you come back for a checkup … But they're good emotions to go through, just reminders. (20-year-old black female diagnosed with non-Hodgkin lymphoma at age 16) I can't really empathize with what [patient peer] is going through because she's in so much more pain than I ever experienced. She's in chemo right now, I mean I almost feel guilty for not having to go through chemo when I think about it. Because, I mean why me? Why didn't I have to go through chemo? What made me different? (19-year-old white male diagnosed with Germ Cell Tumor at age 17) I feel like I would feel bad almost talking to like someone my age who's like gone through like chemo and things, because I feel like I didn't go through that and I can never understand that, because that I feel like is so much worse than what I had to go through. So I would feel almost bad like trying to connect with that person. Because I just feel like they're on a whole different level … I would like feel bad almost like comparing myself to them, because like I feel like what they had to go through is like inspirational and heroic. What I had to go through I feel like isn't. I don't know why. (19-year-old white female diagnosed with Pancreatic Cancer at age 17)
Lack of Compatibility	8 (30.8) 3 (30.0) 5 (31.3)	I learned from [Cancer camp] and from kids that I met who were sick, that we constantly feel like we're in like our own world, we're in like a bubble, and no one understands us. That's—that I agree with like 100% and I really feel that way … And even people who do understand, a kid who's the same age as me who had the same thing, but they're not me. They understand—so there's like one level that's like of people who were never sick—And then there's a level of people who are sick, but they still aren't you … just because we had the same cancer, and even the same problem with your arm, but to you, you like to sew a lot and I like to—you can't appreciate I lost hockey or I lost sports. Everyone's their own person, everyone has their own deal … Every cancer is different, every treatment is different … Like people don't—people who don't know anything about cancer, it's like, ''Oh, you have cancer, you have cancer,'' like it's the same thing. (21-year-old white male diagnosed with Ewing's Sarcoma at age 17) A person with leukemia should talk to someone who had leukemia. They shouldn't be talking to a person who had a different cancer because everything is different. Every protocol is different. Every medicine is different, every way you react is different. (17-year-old white male diagnosed with Hodgkin's Lymphoma at age 14) I haven't spoken to [survivor peer] in a while … she was more depressed than I was. So she would think about so many negative things, and it would make me think more negative. So, like now when my mom asks me to talk to [cancer-peers] it's like I don't want to talk to that person if they're sick, because then they're gonna make me more depressed, and I don't want to be depressed anymore. (18-year-old Hispanic female diagnosed with non-Hodgkin lymphoma at age 15)

Considerations and concerns

Nearly all participants raised concerns related to experiences with or attitudes about cancer–peer interaction, including worry about exposure to adverse cancer–peer outcomes, avoidant coping strategies, guilt, and peer compatibility.

Exposure to adverse outcomes. Nearly half of the participants described possible adverse outcomes as causing concern for their cancer peer and about their personal vulnerability to adverse outcomes or recurrence. One participant described her response to a cancer peer's amputation, ''He wound up having his other leg amputated … I was really sad

… That was tough because then of course I think what if that happens to me.'' Another participant discussed the death of a cancer peer, ''They found something in his lungs right after … he actually passed away and I was like oh my god. Because he was younger than me and I just didn't realize that this could happen … I got pretty scared but it passed.''

"Ignorance is bliss": blocking cancer out.

Half of the participants mentioned a lack of interest or adverse experiences with cancer–peer relationships due to patients' and survivors' avoidance of cancer-related topics. One participant described his avoidance during treatment, ''Ignorance is bliss. Like, the fact that I didn't know what I was getting myself into is in a way helpful, because if I would've known I would've been scared like sh*tless, like I would've been freaking out.'' Another participant described the response among survivor peers when the topic of cancer comes up, ''[Survivor peers] hide, they keep [cancer] out of their life. Like they block it out of their head like it's not reality.''

Guilt and cancer imposter syndrome.

Over half of the participants reported feeling discomfort when interacting with cancer peers due to feelings of guilt or cancer imposter syndrome. Specifically, survivors who felt they experienced easier/milder treatments or positive outcomes compared themselves with peers who had more adverse experiences and experienced consequent discomfort offering advice, support, or insinuating any comparison between their survivorship status or cancer experience. One participant described this guilt, ''[Cancer-peer] [is] in chemo right now, I mean I almost feel guilty for not having to go through chemo when I think about it. Because, I mean why me? Why didn't I have to go through chemo?''

Lack of compatibility.

Less than one-third of the participants expressed their concerns about compatibility between cancer peers, referencing age, gender, diagnosis type, treatment type, treatment outcome, and psychological state. One participant talked about the importance of diagnosis matching, ''A person with leukemia should talk to someone who had leukemia[…] Every protocol is different. Every medicine is different, every way you react is different.''

Another survivor discussed a cancer peer's psychological difficulties during treatment, ''[Cancer-peer] was more depressed than I was. So she would think about so many negative things, and it would make me think more negative. So, like now when my mom asks me to talk to people it's like I don't want to talk to that person if they're sick, because then they're gonna make me more depressed, and I don't want to be depressed anymore.''

Discussion

Cancer–peer support is often an insufficient but important psychosocial resource for AYA survivors.[1,5–15,37–45] Thus, expanding our understanding of AYA experiences, attitudes, and needs related to cancer–peer support can inform the development and refinement of cancer–peer support programs for AYAs. In this study, despite questions pertaining to cancer–peer connection not specifically queried, all participants spontaneously discussed cancer-peer–related experiences, needs, or concerns.

Discussions included high and nearly equivalent rates of positive and negative experiences and attitudes; thus, positive and negative experiences and/or attitudes overlapped across participants. Although many participants reported interacting with cancer peers at some point during treatment or survivorship, consistent with past research, cancer–peer support was often mentioned as an unmet need.[1,39,41–43]

Benefits of cancer–peer connection, including emotional support, decreased distress, and gaining cancer-related knowledge, were described.[23,25,32] Unique and positive components of cancer-peer–facilitated support included the personalizing of support from lived experiences, including emotional support and advice offered (i.e., tips and resources collected from cancer treatment and survivorship), as suggested by past research.[50]

Survivors found that upward comparison when seeing someone who had survived what they were experiencing was more powerful than being told by other support persons that they would be okay. Uniquely, some participants felt an appreciation for their situation from downward comparisons during treatment and survivorship as well. Support from cancer peers was unique, in that it created space for negative and lighthearted emotions, which may be something that is limited with family, friends, and medical staff in the cancer context.[50]

An often-overlooked component of peer support is the ways in which providing support to cancer peers may help patients and survivors, with research reporting experiences of growth and maturation.[14,15] Among our sample, peer-provider benefits included fulfillment from the sense of giving back, or paying it forward and were incredibly diverse in nature, including descriptions of cancer–peer connection through fundraising, public speaking, or peer mentorship as previously reported.[21]

As past research demonstrating personal growth after cancer–peer mentoring has suggested, participants discussed cancer–peer mentoring as aiding in identity reformation after treatment, overcoming trauma, and meaning making.[30,50] Participants also described decreased distress, a sense of accomplishment/contribution, and gaining new perspectives and closure on their cancer experience, which past research has supported.[23,27,30,54,55,56]

Participants also discussed engaging in calculated risk when connecting with peers due to possible exposure to adverse outcomes (i.e., intense treatments, surgeries, recurrence, death), unwanted knowledge about, reminders of, or exposure to cancer, experiences of guilt and cancer imposter syndrome, or peer incompatibility. Cancer-related avoidance was also described, as some participants coped with cancer during treatment and in survivorship by making their best attempt to live a normal life and not think about cancer. Survivors mentioned experiences of guilt when interacting with patients/peers who experienced more intense treatments or adverse outcomes.

Finally, participants expressed peer compatibility-related concerns (i.e., difference in age, sex, diagnosis/treatment characteristics, psychological state, or personality differences). The importance of considering unique challenges in cancer–peer contexts raised by participants, including a cancer–peer poor prognosis or high levels of negative emotion, has been expressed in prior research.[30,50]

This finding has implications for cancer–peer support facilitation. Specifically, before facilitating cancer–peer support within or outside of structured programs, measures to reduce the risk of negative peer experiences should be considered; preparation for the emotional demands of connection and possible consequences, infrastructure to support for those assuming a supportive role with a cancer peer, and careful conversations with the patient and/or survivor about the optional nature of connection opportunities and decision making about peer-related compatibility-related preferences.

Study strengths include achievement of thematic saturation, the use of multiple coders and excellent intercoder reliability, an iterative and exhaustive coding process, the unprimed nature of cancer-peer–related discussions, and the inclusion of AYAs. Limitations of the study include the retrospective nature of experiences and attitudes described in interviews, the inability to examine relationships between cancer–peer attitudes/experiences and quantitative psychosocial outcomes, minimal information acquired regarding the contexts and facilitators involved, and the possible limitations related to the predominantly urban and suburban AYA population interviewed.

Conclusions

Study findings demonstrate the importance of cancer–peer connection and support in AYA cancer care during treatment and survivorship. Concerns related to cancer–peer connection, and how these concerns could be mitigated, should be examined further. Future research should investigate facilitators and contexts involved in cancer–peer connection to inform cancer–peer support outside of structured programs, and assess, inform, and refine existing and new programming to target unmet needs and psychosocial effects that disproportionately impact the AYA patient and survivor age group.

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