

A qualitative study of adolescent and young adult cancer survivors' perceptions of family and peer support

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Abstract

This qualitative study examined adolescent and young adult survivors' perceptions of support from family and peers. A total of 26 survivors, aged 16–24 years, who had been diagnosed with cancer between the ages of 14 and 18, participated in semi-structured interviews. Three themes emerged for support: practical support, emotional support, and new sense of closeness. For lack of support, two themes emerged: absence during treatment and lack of understanding about appearance changes. These findings emphasize the perceived importance of family and peer support throughout adolescent and young adults' cancer trajectories and indicate a need for interventions to help adolescent and young adult develop and maintain support networks throughout treatment and survivorship.

Keywords

adolescence, cancer, health psychology, qualitative methods, social support

Social support from family and peers has been linked to psychosocial outcomes in adolescents with cancer. Among a sample of adolescents with cancer, those who were depressed reported significantly worse relationships with family and others than those not depressed (von Essen et al., 2000). Similarly, in a sample of adolescent and young adult (AYA) survivors, loneliness was significantly related to lower physical functioning and higher adverse outcomes, such as depression, anxiety, fatigue, and pain (Huang et al., 2017). Conflict with mothers has been associated with distress among adolescents with cancer (Manne and Miller, 1998). Family functioning has been found to predict overall mental health, self-esteem, and perceptions of competence in a sample of adolescent survivors

of pediatric cancer (Rait et al., 1992). In addition, a systematic review has indicated that support, particularly from mothers, has been identified as helping adolescents cope with a cancer diagnosis (Decker, 2007). One study of AYA survivors in Italy found that survivors reported lower perceived social support than healthy peers, but reported higher health-related quality of life (HRQoL; Tremolada et al., 2016).

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However, this study did not examine social support as a predictor of HRQoL, thus limiting the conclusions that can be drawn about the potential relationship between these variables.

A modest qualitative literature has also highlighted the importance of family and peer support for adolescents and young adults (AYAs) with cancer. In a sample of Swedish adolescents with cancer, participants indicated that parents were their greatest support, while relationships with peers tended to fade after an initial period of intense support. These adolescents expressed ambivalence about parental support, acknowledging its necessity yet indicating a desire for more privacy and independence (Enskär et al., 1997). Similarly, a sample of AYA survivors emphasized that social support allowed them time to recover, while a lack of social support created stress and hindered their healing process. In addition, AYAs have indicated a desire for support from a variety of sources, and described a sense of overprotection from their parents and abandonment by their friends (Kent et al., 2012). This population's description of intense support from parents while peer support fades over time is notable given that adolescence and young adulthood are generally times when people seek independence from their parents and develop closer relationships with peers (Arnett, 2000; Erikson, 1959; Steinberg and Morris, 2001).

Although the extant literature points to the importance of family and peer support in the context of AYA cancer, there are limitations that restrict understanding of AYA survivors' experiences. Most of the literature in this area focuses on adolescents undergoing cancer treatment. Little is known about how the experiences of this group develop as they enter off-treatment survivorship and young adulthood, or how their perceptions of their cancer experiences may change as they move beyond active treatment. This literature has generally examined whether AYAs feel supported by family and peers and whether that support is associated with psychological adaptation following a cancer diagnosis. Little attention has been paid to specific behaviors that are perceived as supportive or unsupportive by AYA survivors.

Only one qualitative study conducted in Germany (Breuer et al., 2017) has examined these behaviors. This study, which explored young adult (YA) survivors' perceptions of support, found that while family and friends generally provided both instrumental and emotional support throughout the cancer experience, some people distanced themselves from participants during treatment or behaved in ways that participants considered to be inappropriate. It is important to extend this research to assess generalizability to other cultures, and to expand the developmental scope to include adolescents, as the process of seeking independence from parents and closer peer relationships that is observed in young adulthood generally begins during adolescence (Erikson, 1959; Steinberg and Morris, 2001). In addition, while Breuer and colleagues' study provides foundational knowledge about the types of support YA survivors received, they did not identify if particular people (e.g. parents, siblings, friends, etc.) tended to be the primary providers of various types of support. Thus, further qualitative research is appropriate to determine what actions AYA survivors consider to be supportive or unsupportive and who fills these roles.

The aim of this study was to describe AYA cancer survivors' perceptions of family and peer support during and after cancer treatment. Qualitatively examining AYA survivors' experiences is the first step in understanding the role family and peer relationships play in AYAs' psychosocial adjustment following a cancer diagnosis. A more complete understanding of AYAs' experiences will aid in developing interventions to help AYAs with cancer maintain and utilize supportive relationships to help them navigate their cancer experiences.

Method

Participants

Participants were aged 15–25 at the time of consent, had been diagnosed with cancer between the ages of 14 and 21, had completed treatment at least 6 months prior to study participation,

were English-speaking, and were able to provide informed consent or assent. Participants were patients at a large metropolitan cancer center. All potentially eligible individuals who lived within 1-hour of the cancer center ($n=90$) received recruitment letters. (Letters were sent to parents for adolescents.) Of the potentially eligible individuals, 28 percent ($n=25$) were unable to travel (e.g. scheduling conflicts, at college), 28 percent ($n=25$) were lost to follow-up, and five were found to be ineligible. Of the eligible and available individuals, 26 percent ($n=9$) refused, leaving a 74 percent participation rate. All participants provided written consent to take part in the study.

Data collection

Following Institutional Review Board approval at Memorial Sloan Kettering Cancer Center (Protocol # 09-001), 26 semi-structured 90-minute individual interviews were conducted by a trained research assistant between March and June of 2009 as part of a larger study exploring identity development. Semi-structured interview guides were developed based on themes identified in the literature and in the clinical practice of the principal investigator (J.S.F). Probes were pilot-tested and refined with five non-participant AYA survivors. See Appendix 1 Supplementary file for the detailed interview guide. Interviews were conducted until thematic saturation was reached.

Data analysis

Interviews were audio-recorded, transcribed, and imported into ATLAS.ti (Friese, 2014). Analyses were guided by thematic content analysis with an inductive data-driven approach (Creswell, 2013; Friese, 2014; Miles et al., 2014; Murphy and Dingwall, 2003). Analyses were conducted by four trained coders who independently reviewed selections of interviews to identify high-level domain areas relevant to the aims of the larger study. The coding team subsequently independently coded a subset of transcripts creating descriptive and interpretive

codes that represented the underlying meaning of the content of the selected quotations, followed by consensus meetings to reach agreement on code names, meanings, and assignment to the content (inter-rater reliability > 80%). Through this process a foundational codebook was developed (Miles et al., 2014). Once the subset of transcripts had been independently and consensus coded, coders resolved coding differences, merged similar codes, simplified code names/definitions, and ensured mutually distinct and inclusive coding (inter-rater reliability > 80%). Multiple codes could be applied to a quotation to allow for inherent overlap among themes. Analyst triangulation was used to assess thematic salience and evaluate the degree to which thematic findings recurred across the sample (Patton, 1999, 2002). This iterative, consensus-driven approach was used because it enhances the quality and credibility of qualitative findings (Barbour, 2001).

In total, 88 codes were identified for the larger study. Although social support had not been specifically queried during the interviews, it arose as a prominent theme, producing five codes for the supportive and unsupportive actions of family and peers throughout participants' cancer trajectories. The relevant codes included others' response to diagnosis/treatment (support from family, support from peers), others' response to survivorship (support from family, support from peers), and others' response to diagnosis/treatment/survivorship (lack of support from others). Identified themes were compared by gender using chi-square analysis.

Results

Interviews were conducted with 26 AYA survivors. Approximately two-thirds of the sample was female (61.5%) and/or Caucasian (65.4%). The mean age at the time of study was 19.6 years (standard deviation (SD)=2.8; range, 16–24), and participants were a mean age of 15.6 years (SD=1.3) at the time of diagnosis. Half the sample had been off treatment for 2–5 years ($M=3.2$ years). The most

prevalent cancer diagnoses were lymphoma (30.8%), sarcoma (19.2%), and leukemia (11.5%). In all, 65.4 percent of the sample received multimodal treatment. Most participants were students at the time of the interview (84.6%) and were employed at least part-time (61.5%). See Table 1 for detailed demographic information.

All participants reported receiving some support from their family and 20 participants (76.9%) described supportive reactions from peers. Five participants (19.2%) described instances in which they did not feel supported by their family and eight participants (30.7%) described a lack of support from peers. With regard to support from family and peers, three themes and nine subthemes emerged: practical support (managing medical care, encouraging healthy behavior, tasks of daily living, and navigating school), emotional support (spending time together, coping, nice gestures, supporting survivors' choices, and helping survivors maintain a sense of consistency), and new sense of closeness and appreciation. For lack of support, two primary themes emerged: absence during treatment and lack of understanding about change in appearance. One gender difference emerged in chi-square analyses, such that female survivors were more likely than male survivors to describe others' absence during treatment as a source of feeling unsupported ($\chi^2(1, N=26)=4.9, p=.04$). It is notable that most quotes about family members were about parents. Representative quotes and theme/subtheme endorsement rates for support and lack of support are provided in Table 2.

Support

All survivors reported experiencing support throughout their cancer trajectory. This support took practical and emotional forms, and survivors described a new sense of closeness and appreciation with regard to their friends and family resulting from the support they received. Participants emphasized the importance of support for coping with diagnosis and treatment. For example, one survivor expressed the following

about the support he received from his family: "And I-I probably would not have gotten through any of this without my family. I have a loving-very, very loving and supporting family. And they were everything for me."

Practical support. Almost all survivors reported receiving practical support from family and peers throughout treatment and survivorship. Generally, family members were the primary source of practical support during treatment, while peers helped survivors navigate their return to school. Family and peers both offered practical support in terms of encouraging survivors to maintain healthy lifestyles, particularly during survivorship.

Managing medical care. Half the sample shared that family members offered practical support with regard to managing treatment and follow-up care. Survivors reported that family members arranged for them to have the best possible medical care, came to medical appointments with them, kept track of medications, and did research about treatments and resources. One participant noted her father's help in this area, "We had seen some kids in the hospital who had amputations and prosthesis, ... So my dad researched a couple different places, but I went to go see the place ... [and] I decided even before I had my amputation to [get a prosthesis]."

Encouraging healthy behavior. Half of the sample reported that both family and peers offered support by encouraging them to maintain healthy lifestyles, particularly during survivorship. Generally, survivors' family and peers reminded them to wear sunscreen and eat healthy foods, as well as regularly checking in with survivors about their health and well-being. One participant described her friends' reminders to use sunscreen, "[My friends] are always on top of me about like putting sunscreen on my scar so that it doesn't burn."

Tasks of daily living. Almost half the sample reported receiving help with activities of daily living such as eating, bathing, etc. This support

Table 1. Demographic and medical characteristics (n=26).

Variable	n	%	M	SD	Range
Age (years)	26		19.6	2.8	19–20
Gender					
Female	16	61.5			
Male	10	38.5			
Marital status					
Single	26	100.0			
Married or equivalent	0	0			
Ethnicity					
White	17	65.4			
Hispanic	2	7.7			
African American	5	19.2			
Asian/Pacific Islander	2	7.7			
Highest education level completed ^a					
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			
Other ^b	6	23.1			
Sarcomas	5	19.2			
Thyroid	2	7.7			
Age at diagnosis (years)			15.6	1.3	2–5
15–19	15	57.7			
20–24	11	42.3			
Type of treatment					
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.

^aAs per self-report.

^bCraniopharyngioma, germ cell cancer, gestational trophoblastic disease, melanoma, pancreatic cancer, and teratoma tumor.

Table 2. Representative participant quotations.

Theme and subtheme	Endorsement		Quotation
	Total <i>n</i> (%)	Female <i>n</i> (%)	
Practical support	25 (96.2%) 10 (100.0%) 15 (93.8%)		
Managing medical care	13 (50.0%) 5 (50.0%) 8 (50.0%)		<p>... anything that the doctors did, "Oh, what's the name of that drug, what's the name of this drug?" [My mom] wrote everything down. (18-year-old Caucasian male diagnosed with Hodgkin's lymphoma at age 14)</p> <p>We had seen some kids in the hospital who had amputations and prosthesis, ... So my dad researched a couple different places, but I went to go see the place ... [and] I decided even before I had my amputation to [get a prosthesis]. (19-year-old Caucasian female diagnosed with osteosarcoma at age 16)</p>
Encouraging healthy behavior	13 (50.0%) 6 (60.0%) 7 (43.8%)		<p>[My friends] are always on top of me about like putting sunscreen on my scar so that it doesn't burn. They're just like, "Make sure you put sunscreen on your scar." (19-year-old Caucasian female diagnosed with pancreatic cancer at age 17)</p> <p>... [my mom] told me to eat more tomatoes and fruits and things like that, and like organic foods. (17-year-old bi-racial man diagnosed with thyroid cancer at age 14)</p> <p>I kind of gave up on a lot of stuff and then my friends were like, "What are you doing right now?" So they made me go [to a therapist]. (21-year-old Caucasian male diagnosed with Hodgkin's lymphoma at age 17)</p>
Tasks of daily living	12 (46.2%) 5 (50.0%) 7 (43.8%)		<p>... my parents got, you know, like an intercom-yeah, they got an intercom ... so if I needed anything to press it, and we'd talk through the house ... I mean of course they were always attentive and always there. I mean, why wouldn't they be? I remember I came out of the bath one time and I fainted, so like why wouldn't my mom always be around me, taking care of me? That's what she's supposed to do when I'm sick. But, you know, it was just hard not having your strength and not being able to just be with yourself, you know, be alone with yourself. (19-year-old Caucasian female diagnosed with osteosarcoma at age 16)</p> <p>I was just sort of ... figuring things out on my own ... And then- and then that ... brick wall just said, "No, you do need [your parents]. Get back to bed. They're going to do everything for you." (24-year-old Caucasian male diagnosed with acute lymphoblastic leukemia at age 16)</p>
Navigating school	4 (15.4%) 2 (20.0%) 2 (12.5%)		<p>I was walking with crutches when I went back to school. It was still pretty painful, because, you know, the amputation was still not perfectly healed, just because chemo prevented it from getting completely healed. So, yeah, I went back to school with my crutches and my prosthesis. And, you know, some kids would help me get around, they would carry my bag for me and take the elevator with me. (19-year-old Caucasian female diagnosed with osteosarcoma at age 16)</p>
Emotional support	26 (100.0%) 10 (100.0%) 16 (100.0%)		

Table 2. (continued)

Theme and subtheme	Endorsement		Quotation
	Total <i>n</i> (%)	Female <i>n</i> (%)	
Spending time together	21 (80.8%) 9 (90.0%) 12 (75.0%)		[Friend 1] doesn't live in [state], but she came in to see me a couple times. And they were both there the day of my amputation, you know, and came in afterwards and ... They were in the waiting room and [Friend 2] was just bawling, she just wanted to see me to make sure I was okay, and- she's a really, really good friend and I'm really lucky to have her as a friend. (19-year-old Caucasian female diagnosed with osteosarcoma at age 16) [My brother] and his girlfriend were always hanging out with me through everything ... both of them were always there playing board games with me, cards with me, video games with me, anything to keep me busy and take me out ... they were just always there for me. They would watch like three movies a day with me, just to stay with me, and go to the pool, anything they could possibly do to stay with me and keep me busy and keep my mind off everything that was going on. (17-year-old Caucasian male diagnosed with Hodgkin's lymphoma at age 16) My dad doesn't show emotions. And he actually [stayed] with me ... and laid in the bed with me, and that was the first time I'd ever seen him pray. And we fell asleep on the bed, and that was my greatest memory because me and my dad never, ever shared a moment like that. So it was- it was pretty awesome, you know. It touched me. And that memory will forever be with me ... it showed me that he actually loved me and cared for me, and so that like- that stuck with me for life. (18-year-old Hispanic female diagnosed with non-Hodgkin's lymphoma at age 15)
Coping	22 (84.6%) 8 (80.0%) 14 (87.5%)		[My friend] would call, but if I didn't want to talk she'd say, "Okay talk to you later." And as soon as I came back [to school] she was there. She didn't ask any questions ... She was like, "If you want to talk about it you tell me." I did because she's my best friend ... But she was like "I'm there when you want me to be there," so her and I have been really close and we've been extremely close since ... she's just been there whenever I needed her. (17-year-old Caucasian female diagnosed with Hodgkin's lymphoma at age 14) I remember like one time specifically, [my mom] ... like grabbed my face and she was like, like she was like an inch away from my face and she was like- like, "You're gonna be fine," like, "Trust me." ... And like we'd just talk about like everything. (19-year-old Caucasian female diagnosed with pancreatic cancer at age 17) ... it's not that [my dad] would stay away, but he'd stay, you know, a little more quiet. He would let me be. Like if I wanted to be alone or he'd just let me do my own thing, didn't try to butt in. (17-year-old Caucasian female diagnosed with Hodgkin's lymphoma at age 14)
Nice gestures	12 (46.2%) 5 (50.0%) 7 (43.8%)		I thought it was great. I just felt like everyone really supported me. Apparently, they told me that like, "We didn't order enough shirts" ... I didn't realize I was that popular. (19-year-old Caucasian male diagnosed with a germ cell tumor at age 17)

(continued)

Table 2. (continued)

Theme and subtheme	Endorsement Total <i>n</i> (%) Male <i>n</i> (%) Female <i>n</i> (%)	Quotation
Supporting survivors' choices	8 (30.8%) 3 (30.0%) 5 (31.3%)	... if I'm not with anybody within the next two years or so ... I have talked to my mom about it. I have talked to other people about it, and they all agree that I should do it. I mean, maybe artificial insemination. I do want to have a child. (24-year-old Caucasian female diagnosed with osteosarcoma at age 17) [My dad]'s like, "Get a job. Get out there and do your thing." Yeah, so now it's like, you know, we're at that point where- where them taking care of me and me needing them is- is fading in a big way. (24-year-old Caucasian male diagnosed with acute lymphoblastic leukemia at age 16)
Helping survivor maintain a sense of consistency	6 (23.1%) 2 (20.0%) 4 (25.0%)	... my friends never really changed. They were always cool. They always maintained who I was, which was good. (24-year-old Caucasian male diagnosed with acute lymphoblastic leukemia at age 16) I mean, my sister pretty much didn't change about anything. Her attitude towards me when I was diagnosed was still the same, which I was really happy about because I didn't want anyone seeing me any different. (19-year-old Asian female diagnosed with osteosarcoma at age 15)
New sense of closeness and appreciation	18 (69.2%) 6 (60.0%) 12 (75.0%)	I definitely feel much more connected to [my mom], which I definitely think is a product of having spent pretty much an entire, you know, half a year to a year of my life just with her. (24-year-old Caucasian female diagnosed with Hodgkin's lymphoma at age 14) I just feel like I'm more close with everyone, especially my best friend. I guess that was the point when I realized that she was my best friend was when she- she called me every day when I was in the hospital. (19-year-old Caucasian male diagnosed with a germ cell tumor at age 17)
Absence during treatment ^a	6 (23.1%) 0 (00.0%) 6 (37.5%)	... I lost every single friend I had. That was probably the hardest ... I mean, yeah, I didn't have a whole lot of friends to begin with. I was really shy ... And so now looking back ... I can sort of understand why, like one more thing onto the pile. Well, you know, like adding something on, like having a friend who's like seriously ill, people can't handle that. And I mean I really, honestly don't begrudge anybody at this point. (24-year-old Caucasian female diagnosed with Hodgkin's lymphoma at age 14) ... a lot of them were 17, and, you know, a lot of them, I didn't really want them to see me like that ... it would have been nice for them to just come anyway, you know, just be there anyway ... I really didn't think of it until afterwards, and I was just like, you know, "Wow, where was everybody?" (24-year-old Caucasian female diagnosed with osteosarcoma at age 17)
Lack of understanding about change in appearance	3 (11.5%) 1 (10.0%) 2 (12.5%)	People would say, "Oh, you look like a zombie." (23-year-old Black female diagnosed with craniopharyngioma at age 16) ... the day I came in after- I was gone for a while, and I came back with no hair and a couple of kids in my class though it was a joke or something, so they were laughing about it ... I didn't care. Like, I was kind of used to being made fun of sometimes when I was younger so I was like okay with that and they figured it out. (21-year-old Caucasian male diagnosed with Hodgkin's lymphoma at age 17)

Table 2. (continued)

Theme and subtheme	Endorsement	Quotation
	Total <i>n</i> (%)	
	Male <i>n</i> (%)	
	Female <i>n</i> (%)	
		I mean, to be honest, I grew up in a house where my dad told me I was worthless. He told me that I was ugly, that I was fat, when I was on treatment. (24-year-old Caucasian female diagnosed with Hodgkin's lymphoma at age 14) ... he's a health freak. So he was constantly pushing me, you know, exercise more or eat less. So it came to a point where in my mind I was like, "Oh, I'm fat. I can't eat. I can't eat." (18-year-old Hispanic female diagnosed with non-Hodgkin's lymphoma at age 15)

*Females were significantly more likely than males to endorse this theme ($\chi^2 [1, N=26]=4.9, p=.04$).

was offered exclusively by family members, including parents, siblings, aunts, and grandparents. Mothers were the primary source of support for tasks of daily living, followed by fathers. While survivors expressed understanding of the necessity for such intense care while they were receiving treatment and appreciated their families' willingness to care for them, many survivors also expressed some frustration about the resulting lack of independence and privacy. For example, one survivor stated, "... why wouldn't my mom always be around me, taking care of me? That's what she's supposed to do when I'm sick. But, you know, it was just hard not having your strength and not being able to just be with yourself."

Navigating school. A small portion of survivors reported receiving practical support from their peers with regard to keeping up with academics and navigating their return to school. Peers brought participants' school materials to them when they were absent and helped participants get around school while they were recovering from treatment. A survivor who had been treated with a leg amputation described, "Some kids would help me get around, they would carry my bag for me and take the elevator with me."

Emotional support. The entire sample reported receiving emotional support from family and peers in a variety of forms. Specific patterns did

not emerge with regard to sources of different types of emotional support.

Spending time together. The majority of the sample reported the importance of spending time with their family and friends during treatment. They indicated that family members and friends visited them in the hospital and at home, as well as talking to them on the phone. Survivors described these visits as being very meaningful for them. One survivor described the following about the time he spent with his brother and his brother's girlfriend:

[My brother] and his girlfriend were always hanging out with me through everything ... both of them were always there playing board games with me, cards with me, video games with me, anything to keep me busy and take me out ... they were just always there for me.

It is notable that most of the quotes emphasizing the importance of spending time together referred to peer interactions.

Coping. Most of the sample indicated that their family and friends helped them cope with the challenges of their diagnoses and treatment by talking with them about their experiences, providing encouragement and reassurance, praying together, holding them when they were afraid, staying strong for them, and expressing pride

about participants' strength. Participants also expressed appreciation that people were willing to provide support on their terms. One survivor described how her best friend provided flexible support according to the survivor's needs, "... she was like 'I'm there when you want me to be there.'"

Nice gestures. Almost half the sample described their family and peers making nice gestures that helped them feel supported. Gestures included acts such as gift giving, fundraising, and doing special things for participants such as putting up a canopy so the survivor could swim during treatment without getting sunburned. A survivor whose friends had made tee-shirts in his honor stated, "I thought it was great. I just felt like everyone really supported me."

Supporting survivors' choices. Approximately one-third of the sample reported that family members made efforts to support participants' independence. A young adult participant described his father's support for his career choices: "[My dad]'s like, 'Get a job. Get out there and do your thing.'"

Helping survivor feel maintain a sense of consistency. Approximately a quarter of the sample indicated that they appreciated when people helped them maintain a sense of consistency by treating them similarly to how they had been treated before they became ill. One survivor described her appreciation of her sister's unchanged attitude toward her: "Her attitude towards me when I was diagnosed was still the same, which I was really happy about because I didn't want anyone seeing me any different."

New sense of closeness and appreciation. More than half of the sample described becoming closer with their family and friends as a result of their experiences, and expressed a sense of renewed appreciation for the supportive people in their lives. One survivor reported, "I just feel like I'm more close with everyone, especially my best friend. I guess that was the point when I realized that she was my best friend."

Lack of support

A small group of survivors described experiences with family and peers in which they did not feel supported.

Absence during treatment. Absence during treatment, reported by approximately a quarter of the sample, was the main source of feeling unsupported. Friends were the primary individuals who were not present during treatment, but other figures who were reported as being absent during treatment included significant others, extended family, and a step-sibling. One survivor recalled, "... I lost every single friend I had. That was probably the hardest." Survivors expressed understanding of why their family and peers may not have been present during treatment, but indicated that these people's absence was still hurtful. It is notable that only females described instances of others being absent during treatment.

Lack of understanding about change in appearance. A small portion of survivors also indicated that others were sometimes not understanding about changes in their appearance. For example, one survivor described his peers' reaction when he returned to school: "... I came back with no hair and a couple of kids in my class thought it was a joke or something, so they were laughing about it." Two survivors spoke about the reactions of their peers, and two survivors also indicated that their fathers had difficulty accepting the changes in their appearance.

Discussion

Support from family and peers has been identified as a predictor of psychosocial outcomes in adolescents with cancer (Decker, 2007; Manne and Miller, 1998; Rait et al., 1992; von Essen et al., 2000). Therefore, understanding AYA cancer survivors' experiences with family and peer support is an important step in identifying targets for interventions to facilitate supportive relationships throughout the cancer trajectory. In this study, all participants reported receiving

some form of support from family and peers, and some described actions of others that they found unsupportive. Examples of supportive and unsupportive reactions from family and peers were complex and nuanced, producing five themes and nine subthemes.

Survivors reported a range of ways in which they felt supported by family and peers. Although survivors received support from a variety of people, parents, particularly mothers, were most frequently mentioned as a source of support, a finding that is consistent with previous research (Decker, 2007).

Most of the sample talked about practical support they had received since being diagnosed with cancer. Practical support included help with tasks of daily living, management of medical care, navigating school, and encouraging healthy behavior. Family members, particularly parents, were the primary source of practical support with regard to tasks of daily living and management of medical care, whereas peers helped survivors navigate school during and after treatment. Family members and peers were both supportive with regard to encouraging healthy behavior, such as eating healthy foods and wearing sunscreen, a form of support that primarily occurred during survivorship. Although survivors expressed understanding and appreciation about the need for practical support, they also expressed frustration with the resulting lack of independence and privacy, which is consistent with the prior literature in this area (Enskär et al., 1997). This ambivalence likely reflects conflict between AYAs' developmental stage, which is characterized by seeking greater independence, and the need to depend on others for help with tasks ranging from necessities of daily living to managing medical care.

All participants spoke about receiving emotional support from family and peers, and emphasized the importance of such support. Emotional support was experienced through spending time together, coping (e.g. talking about cancer and praying together), helping survivors maintain a sense of consistency, supporting survivors' choices (e.g. career goals, fertility choices), and nice

gestures (e.g. making tee-shirts in the survivor's honor). Several of these subthemes pointed to a drive to maintain a typical trajectory for psychosocial development, whereas others highlight the need for unique forms of support. For instance, it is notable that quotes about spending time together were primarily about peer interactions, perhaps indicating the importance of maintaining social ties that can aid in the processes of individuation and identity development (Arnett, 2000; Erikson, 1959; Steinberg and Morris, 2001). These findings are consistent with the extant literature in which peer interactions were highlighted as important to the development of autonomy among adolescents with cancer (Dunsmore and Quine, 1995).

Similarly, survivors felt supported when they were given the autonomy to make their own choices and when people helped them maintain a sense of consistency by treating them similarly to how they had been treated before they became ill. Survivors' expressed preference for being treated similarly to how they had been treated before diagnosis should be further examined in the context of prior research indicating that survivors feel that everything has been turned upside down and they need to create a new sense of normalcy after their cancer diagnoses (Love et al., 2012), as these findings indicate complex interactions between wanting to maintain a sense of consistency with their lives before cancer and recognition that their previous sense of normalcy may no longer exist.

Most survivors also discussed a general sense of support from family and peers, often described as "being there." Quotes about this general sense of support emphasized survivors' appreciation for their families' and friends' presence throughout the cancer trajectory. Survivors also reported feeling closer to their friends and family as a result of the support they received during their cancer experiences. The reported sense of increased closeness highlights relationships as an important area of posttraumatic growth, defined as positive change resulting from a highly distressing life event (Tedeschi and Calhoun, 2004). In contrast to codes that

indicated a desire to maintain a typical developmental trajectory, codes about coping together and performing nice gestures indicate a need for emotional support that is unique to the cancer experience. Notably, this sample's prominent description of receiving support from peers differed from prior research in which AYAs reported that peers distanced themselves and were not identified as a primary source of support (Kent et al., 2012).

Although all survivors experienced some form of support from family or peers, there was a subset of survivors that reported unsupportive actions of family or peers. Absence during treatment was the predominant theme for lack of support and it primarily applied to the absence of peers. Survivors also reported family and peers being critical of the changes in their appearance. While lack of support was reported by a minority of the sample, these findings are critical for identifying areas for intervention to promote psychosocial adjustment of AYAs with cancer. In addition, it is important to note that 100 percent of the survivors who spoke about others' absence during treatment were female, perhaps indicating that females prefer more intensive emotional support than males, possibly increasing their risk for psychosocial difficulties if the people around them do not adequately provide such support. Alternatively, this finding could reflect a gender difference in willingness to speak openly about their emotions (Brody and Hall, 2008).

In addition, it is notable that across themes, a small number of survivors described feeling that some support they received was disingenuous. For example, a 19-year-old Caucasian female who was diagnosed with osteosarcoma at age 16 stated that upon returning to school, "Everyone was like happy to see me, you know, 'Oh, [name], we missed you', blah, blah, blah. Half of it was bullshit, but whatever. I mean they were glad I was alive, obviously." While this sentiment was expressed too infrequently to warrant an additional code, it is an interesting topic for further investigation, as it indicates additional complexity to the issue of perceived social support.

Study strengths and limitations

Study strengths include a robust qualitative sample size, comprehensive in-depth interviews, the use of multiple coders, a thorough coding process, and an age range that spans from adolescents through YAs. In addition, this is the first qualitative study to focus exclusively on AYA survivors' perceptions of social support throughout the cancer trajectory. With regard to limitations, reporting about participants' experiences throughout the cancer trajectory was retrospective, leading to the possibility of recall bias. Another potential limitation is the inability to connect support to other psychosocial outcomes, which were not a primary focus of this study. Finally, this sample may not be representative of all AYA cancer survivors for two reasons: (1) the sample was drawn from one large urban cancer center and (2) although the sample size was adequate for qualitative analysis, it represents a small proportion of the AYA survivor population, which limits the generalizability of our findings to a broader AYA population. It is possible that differences would emerge with regard to age, diagnosis, treatment, and other demographic or medical variables if this topic were explored in a larger and more diverse sample.

Summary

AYA survivors' support needs are complex and nuanced. Participants reported receiving a mix of practical and emotional support from a variety of sources. Practical support was primarily received from parents who assisted with AYAs' care. Emotional support came from both family and peers. Spending time with peers, the desire to maintain consistency in their relationships, and the desire to make autonomous choices pointed to survivors' motivation to remain on a typical developmental trajectory as much as possible. There was a subset of survivors that also reported unsupportive experiences with family and peers, with peers' absence during treatment being the most prominent example of unsupportive experiences.

Clinical implications and future directions

Given the documented relationship between social support and psychosocial outcomes in AYA cancer survivors (Huang et al., 2017; Manne and Miller, 1998; Rait et al., 1992; von Essen et al., 2000), it is important to develop interventions to foster supportive relationships throughout the cancer trajectory. In particular, it is necessary to develop tools to foster peer relationships because spending time with peers emerged as an important source of support for AYAs, yet peers' absence during treatment was the most prominent source of feeling unsupported among this sample. Currently, there is one intervention for AYA cancer survivors that include peer relationships as one of the primary intervention targets. One of the aims of the Recapture Life-AYA program (Sansom-Daly et al., 2012) is to foster survivors' social relationships based on the conceptualization that social support is one of the primary factors that promotes resilience in AYAs with cancer (Haase, 2004). This online group intervention targets social relationships through cognitive behavioral strategies and peer-to-peer survivor discussions about managing social relationships. Although outcome data for this intervention has not yet been published, it may be a promising first step toward addressing the social needs of AYA survivors.

There are no published intervention studies addressing the peer support needs of AYAs on treatment, which may be a critical period for intervention given this sample's experience of peers' absence during treatment. Future research should explore barriers to support in order to inform development of interventions to facilitate psychosocial support during and after treatment for cancer diagnosed in adolescence or young adulthood. For example, an educational intervention for peers to learn about cancer and strategies to support their friend with cancer may be helpful if peers report wanting to help but not knowing how to do so, or if peers endorse fear as a reason for distancing themselves from a friend with cancer. Similarly, there are no published intervention studies addressing AYAs' conflicted feelings about needing to rely heavily

upon their parents as a result of their diagnosis. Family interventions may be useful in helping family members balance the opposing tasks of providing appropriate care for AYAs with cancer and fostering opportunities for independence and individuation. For instance, such an intervention could help families problem-solve to adapt family routines to provide opportunities for AYAs with cancer to have some independence when possible.

It may also be important to provide survivors with communication skills to help them effectively express their support needs and preferences to family and peers, as specific support needs are likely to vary from person to person and may change over time throughout treatment and survivorship. Interventions to promote developmentally sensitive support from family and peers could improve the quality of AYAs' support networks throughout the cancer experience, thereby buffering the risk for psychosocial difficulties. In addition, further investigation regarding the complex nature of survivors wanting to be treated similarly to how they had been treated before cancer while in the process of establishing a new sense of normalcy could provide additional guidance for intervention development.

Although there are no published intervention studies addressing these issues, there are a wide range of support groups that could ameliorate some of the concerns raised by this sample. Thus, it is important for researchers to team with organizations that are doing this work in order to assess psychosocial outcomes and build upon previously laid foundations. In addition, future research should explore potential differences between the support offered by healthy peers and peers with cancer, as peers with cancer likely provide unique support that cannot be offered by healthy peers as evidenced by cancer-specific concerns, such as infertility, hair loss, and dating, that were raised by female AYAs in an online support group (Pounders et al., 2017).

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Supplementary material

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