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### Title

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### Permalink

<https://escholarship.org/uc/item/8x33x3nr>

### Journal

Journal of Adolescent and Young Adult Oncology, 10(6)

### ISSN

2156-5333

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### Publication Date

2021-12-01

### DOI

10.1089/jayao.2020.0200

Peer reviewed

# The Role of Social Media in Providing Support from Friends for Adolescent and Young Adult (AYA) Patients and Survivors of Sarcoma: Perspectives of AYA, Parents, and Providers

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**Purpose:** The aims of the current study were to better understand, from the perspective of adolescents and young adults (AYAs) with sarcoma, parents, and providers, the friendship support needs of AYAs with bone and soft tissue sarcoma and the role of social media in facilitating social support for AYAs with sarcoma.

**Methods:** Semistructured interviews were conducted with 21 participants. AYA ( $n=10$ ) ranged in age from 14 to 23 years (mean 19.3, standard deviation 3.4 years; 50% female). All AYAs reported a current or past diagnosis of sarcoma, except for one patient who had another cancer diagnosis but was receiving treatment through the sarcoma clinic. Five parents of the adolescent participants were interviewed, as well as six health care providers. Data analysis was conducted using theory-driven immersion/crystallization, incorporating the Resilience in Illness Model as a framework to guide interpretation of the data.

**Results:** Four main themes associated with social support from friends and social media were identified: (1) Social media provides a way to feel normal and connected to friends; (2) Social media accentuates the frustration of being left behind; (3) Social media facilitates the need to be understood by peers who have experienced sarcoma, and (4) Social media can lead to despair, and also provide hope for the future.

**Conclusions:** Connecting with peers through social media can play an important role in providing support for AYAs with sarcoma, but it may also amplify feelings of frustration and anxiety. Future work is needed to determine intervention components that can maximize the benefits of social media for social support of AYAs with sarcoma. Clinical Trial Registration number: NCT03130751.

**Keywords:** cancer, sarcoma, social support, social media, adolescent, young adult

## Background

THERE IS AN emerging interest in identifying and meeting the unique needs of adolescents and young adults (AYAs) with cancer.<sup>1</sup> Bone (e.g., Osteogenic and Ewing) and soft tissue sarcomas are among the most common malignancies in AYA patients. Most patients receive aggressive multimodality therapy with intensive chemotherapy and limb

salvage and/or amputation surgery, with or without high dose radiation.<sup>2</sup> These treatments are associated with symptoms (e.g., pain, nausea, fatigue) that substantially impact quality of life.<sup>3-5</sup>

The demands of cancer treatments often conflict with normative AYA developmental needs, such as increased independence and peer-focused interactions.<sup>6,7</sup> Such conflicts may be magnified among AYAs with sarcomas due to the

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high symptom burden and invasive treatments. Social support can be crucial for helping AYAs cope with cancer,<sup>8–10</sup> but AYAs report difficulties maintaining or making new relationships.<sup>7</sup> Qualitative studies indicate that young adult survivors of childhood cancer have difficulty fitting in with friends and experience loneliness.<sup>11</sup>

Social media can play an important role in facilitating social support for AYAs and enabling AYAs to overcome barriers associated with traditional, in-person support groups (e.g., transportation, time, energy).<sup>12,13</sup> Social media can also connect patients with similar diagnoses or help maintain friendships formed during treatment.<sup>12</sup> Some AYAs with cancer report that they established new and deeper connection with peers they met through this medium, and the support felt less stigmatizing.<sup>13</sup>

While less is known about the role of social media in providing social support to AYAs with sarcoma specifically, patients and relatives reported joining a Ewing Sarcoma awareness Facebook group to receive mental and emotional support,<sup>14</sup> and a focus group with sarcoma survivors revealed openness to social media as a source of emotional/psychological support.<sup>15</sup>

While these findings suggest that AYAs with sarcoma may be open to using social media to access peer support, given the unique experience of AYAs with sarcoma, understanding more about the role that social media plays in peer support is important. The goal of the current study was to better understand, from the perspective of AYAs, parents, and providers, the role of social media in the friendships of AYAs with sarcoma.

## Methods

### Design

This study consisted of semistructured interviews. Our Phenomenological qualitative approach<sup>16</sup> was informed by the Resilience in Illness Model (RIM),<sup>17,18</sup> developed to examine how psychosocial factors (i.e., social integration, family environment, courageous coping, derived meaning, illness-related distress, and defensive coping) influence resilience outcomes in AYAs with cancer. Interviews were conducted as a part of a larger online psychosocial intervention study.<sup>19</sup>

### Participants

AYAs aged 13–25 years, diagnosed with sarcoma and either undergoing active treatment or within 5 years of transitioning to survivorship care, and fluent in English were eligible to participate. The inclusion age range is consistent with pediatric development literature<sup>20</sup> and AYA cancer literature within the limits of the patient population at the study site. To capture a range of perspectives, we purposefully recruited a diverse sample of AYAs in terms of age, gender, and treatment history (e.g., on and off treatment, limb-salvage procedure, and amputation), reviewing participant characteristics at weekly meetings. Parents were eligible if they had a child under 18 years enrolled in the study and were fluent in English. Health care providers currently providing care to AYAs with sarcoma were eligible. We purposefully recruited providers representing a range of treatment care roles (see Table 1 for characteristics of all participants).

### Procedure

**Recruitment.** The AYA and adolescents' parents were recruited from a pediatric sarcoma clinic in Los Angeles, CA. Research team personnel distributed flyers in clinic and screened patients or parents by phone. Author N.C.F. emailed study invitations to providers in his network, and research personnel contacted interested providers. Eligible participants provided online (AYA and parents) or phone (providers) assent or consent.

**Development of interview guides.** We developed three semistructured interview guides for AYA, parents, and health care providers. To facilitate the comparison of multiple perspectives on the same topics, the parent and provider interview guides mirrored the patient interview guides as much as possible. Informed by the RIM,<sup>17,18</sup> the interview guide first focused on the psychosocial factors associated with resilience, to facilitate exploration of themes pertaining specifically to AYA with sarcoma. Other questions focused on development of the intervention as part of the larger study.<sup>19</sup> Author E.D. created the interview guides, revising them with input from the research team, including researchers and clinicians with AYA oncology experience. Interview guides are included as Supplementary Material.

**Interviews.** Two female team members with qualitative research experience, and no relationship with interviewees, conducted the 45–90-minute interviews. One team member conducted all the patient and parent interviews, in-person or by phone. The other team member conducted all the health care provider interviews, by phone. Participants were offered gift cards of US\$25 (AYA and parents) or US\$100 (providers) as compensation. We collected interview data until 10 AYAs, 5 parents of adolescents, and 6 providers had been interviewed. After these interviews were completed, the team reached thematic saturation consensus and no further interviews were conducted. Interviews were audio recorded and transcribed. Interviews were conducted from December 2016 to March 2017 and were approved by the institutional review board (reference no.16-000766).

**Data analysis.** Data analysis was conducted using theory-driven immersion/crystallization, which involves examining, and reflecting on, data until interpretations are reached.<sup>21</sup> This approach is both deductive and inductive in that it allowed for detection of emerging themes within the RIM framework.<sup>16,17</sup>

Author E.D. created a coding structure,<sup>22</sup> with each RIM factor represented. Three trained team members applied codes to the interview transcripts in duplicate, and discrepancies were resolved with discussion. Coded transcripts were entered into NVivo software.<sup>23</sup> Two team members (backgrounds in developmental psychology and social work) independently reviewed data and discussed emerging themes for each code during weekly meetings. Themes, supporting quotes, and exceptions were noted, and overarching themes were determined. A research team member with AYA oncology experience reviewed the findings, which, in combination with including data analysts with different backgrounds, served to reduce bias resulting from a single perspective.<sup>24</sup>

TABLE 1. PARTICIPANT CHARACTERISTICS

	AYA (n=10)	Parents (n=5)	Providers (n=6)	Total (n=21)
Age	19.3 (3.4)			
Sex				
Male	5 (50.0)	1 (20.0)	3 (50.0)	9 (42.9)
Female	5 (50.0)	4 (80.0)	3 (50.0)	12 (57.1)
Ethnicity				
Hispanic/Latino	4 (40.0)	1 (20.0)	1 (16.7)	6 (28.6)
Non-Hispanic/Non-Latino	5 (50.0)	4 (80.0)	5 (83.3)	14 (66.7)
Unknown	1 (10.0)	0 (0.0)	0 (0.0)	1 (4.8)
Race				
White	6 (60.0)	3 (60.0)	5 (83.3)	14 (66.7)
Black/African American	1 (10.0)	1 (20.0)	0 (0.0)	2 (9.5)
Asian	0 (0.0)	0 (0.0)	1 (16.7)	1 (4.8)
Multiracial	2 (20.0)	1 (20.0)	0 (0.0)	3 (14.3)
Unknown	1 (10.0)	0 (0.0)	0 (0.0)	1 (4.8)
Treatment status				
On treatment	2 (20.0)			
1–3 months post-treatment	2 (20.0)			
4–8 months post-treatment	1 (10.0)			
1–2 years post-treatment	3 (30.0)			
3–6 years post-treatment	2 (20.0)			
Providers' specialties				
Oncologist			3 (50.0)	
Nurse or medical assistant			2 (33.3)	
Child life			1 (16.7)	

Data are presented as mean (standard deviation) for continuous variables and *n* (% of group) for categorical variables.

## Results

### Participant characteristics

Twenty-one participants, ranging in age from 14 to 23, were interviewed. All five adolescents (<18 years) and parents screened were eligible and enrolled. Of the six young adults screened, six were eligible and five enrolled; one was lost to follow-up. Seven providers were approached, and six were screened. One provider declined indicating being too busy. Participant demographic data are presented in Table 1.

### Main themes

**Theme 1: Social media provides a way to feel normal and connected to friends.** Many AYAs described wanting to stay connected to old friends. Whether hearing about friends' day-to-day lives, reminiscing about past interactions with friends, or focusing on something other than sarcoma with friends online, patients described that experiences that had nothing to do with cancer were important for their identity and their role as a friend.

One AYA described using private messaging to connect with old friends.

I want to hear about what's is going on in your life. Because I want to still feel connected to you. I don't want this to take away that friendship for me...I had a few friends that were like, "I'm having problems with my boyfriend, can I talk to you about it?" I'd be like, "Thank god." I actually want to know what was going on—PA01.

For some AYAs, social media provided a reassuring record of their previous social existence.

I would go back into my Instagram and I would find posts about myself before cancer, and I'd try to go back and think about myself like, how things were at that time, and how things were happening to me at that moment. I would kind of think to myself, like, "oh, it's okay, like, I'll be able to get back into that once I'm done with treatment"—PA02.

Another described comfort from not revealing their diagnosis to friends online.

The best parts of my day I'd say are the end of the day. I always get on Overwatch and I have a bunch of online friends and we always end up hanging out. Which is really nice to talk to people online for me. Because I've never told any of them about my situation, so they see me as just another normal person—PA05.

**Theme 2: Social media accentuates the frustration of being left behind.** While many AYAs described the desire to stay connected to old friends, they also reported that this often led to frustration, anger, and sadness, as they watched others move on with their lives.

When you look at other people's Instagram over spring break, I had some moments where I just was just; It was a mixture of just complete, utter sadness and being so angry. I wanted to throw my phone across the room.—PA07.

Another AYA described taking steps to avoid seeing images of old friends' daily lives.

I follow people from school. So I always make sure never to look at the [Instagram] home page. Because I know if I do, I'll see them from school. And I'll see them doing normal things. And I'll see them out with friends doing these things. In the beginning I didn't really understand that. And I'd end up making myself sad.—PA05.

One provider echoed the AYAs' experience of valuing the connection that social media provides while feeling distress when seeing friends move on with their lives.

I think having some sort of online support or social media that's geared toward them or geared toward connecting with other patients can be really powerful. I've had kids that will say, "I'm done with Facebook, I won't even go on Facebook anymore because I'm so tired of seeing so-and-so graduating, or you know, the family trip that I'm not a part of."—PR02.

**Theme 3: Social media facilitates the need to be understood by peers who have experienced sarcoma.** All three groups of interviewees described how social media made possible important connections to peers who had also experienced sarcoma. Most AYAs described comfort from connecting with peers who had navigated similar challenges. Some providers also commented that these connections can take time to develop.

One AYA summed up the value of connecting with other AYAs with sarcoma.

Well, there's a level of camaraderie that you can't get anywhere else. It's like you know exactly what the other person did without having to tell them. It's so much less energy and effort to spend time with a person like that.—PA07.

One provider commented that it can take time and creativity to form those connections.

A lot of the responses that I've gotten is they don't want to... Maybe they don't want to meet someone who doesn't have the exact same experience, or they feel like they don't want to be a part of this cancer world, like they want to just stay with their regular friends because that'll keep them more normal, but like I said, once they meet and once that connection is made, it's almost always really, really beneficial. I think it's just that barrier of figuring out how to connect in an organic-feeling way, or in a way that makes sense to teenagers.—PR02.

Another provider expanded on why social support from peers who have experienced sarcoma is so important.

There are a large percentage of these patients who will require multiple rounds of therapy and many of these patients will not be cured and they will succumb to their disease. I think that this population would benefit from a social networking or peer-to-peer type of outreach to help them sustain them through this journey. It's a little bit different for other diseases where there is a very high cure rate and so we just bring the patient through that and even if they're a little bit down at the end, we can expect them to be cured.—PR01.

One parent described witnessing the value of the connections her daughter had formed with AYAs with sarcoma through social media.

If she has an emotionally difficult day, if something goes bad as far as hearing from the doctor, she doesn't usually want to talk to me or her dad. She has a friend who walked through cancer. They bonded in the hospital, and that's who she talks to and she tells me that unless you had walked it you just can't really understand, and so I respect that space for her.—PAR105.

**Theme 4: Social media can lead to despair, and also provide hope for the future.** Many AYAs described the

anxiety associated with the uncertainty of the disease and potential recurrence. They identified social media as a way to find hope through patients' stories, but also described fear and devastation associated with learning of an AYA's recurrence.

One AYA described the fear of receiving discouraging news on social media.

As I progressed through treatment, I ended up realizing that I didn't really like receiving notifications from the [Facebook] group. The reason being was because some people were posting up, oh, I have a recurrence of this type of sarcoma, or a recurrence of this type... You're just kind of like the audience, just kind of seeing how they're going after, how they're reacting to after treatment, how are their scans coming back after treatment? That's something that I just, I kind of just want to, like, steer away from. I kind of wish that there was a page dedicated for all sarcoma patients that, like, to break them up in groups, like maybe sarcoma patients that are going through treatment, sarcoma patients that have relapsed, sarcoma patients that are currently off of treatment, you know?—PA02.

The same AYA described the relief and hope she experienced from meeting online a survivor.

I ended up finding a girl on YouTube, actually. She had a different type of sarcoma, but I actually found her after treatment, and I actually found out that even though she had radiation near, almost like a site where I had mine, because she had her radiation near the abdomen and pelvic region, and mine's like in the pelvic region, and I was told, unfortunately, I wouldn't be able to have children, for the reasons of that I probably couldn't, I wouldn't, I'd lose my fertility because of radiation and chemo. She went through radiation and she had very low dosages of chemo and radiation, and she ended up having twins.—PA02. Please see Table 2 for a summary of themes, example quotes, and associated codes.

## Discussion

The goal of this study was to understand the role that social media plays in the friendships of AYAs with sarcoma. Other studies have highlighted unmet social needs of AYAs with cancer.<sup>7</sup> The current findings extend this body of literature by describing the unique experiences of AYAs with sarcoma and the role of social media in facilitating and maintaining friendships.

Themes from our interviews suggest that social media plays an important role in social support, potentially amplifying the ups and downs of relationships with both old friends and peers with sarcoma. Consistent with other studies,<sup>25</sup> the AYAs we interviewed described how social media amplified the tension between the desire for comfort from connections with old friends and the frustration and pain of no longer fitting in. Social media facilitated communication and provided a record of the old "normal." However, social media also provided a constant reel of friends' lives, which was painful for AYAs to witness.

Interviews also revealed conflicting experiences with connecting with other AYAs with sarcoma through social media. As reported by others,<sup>25</sup> AYAs described the ease and relief that came with connecting and communicating with peers who had similar cancer experiences. Providers and parents emphasized the painfully unique experience of sarcoma and the need for AYAs to have connections with peers who understood. Yet, social media was also described as a source of anxiety. Although it could provide stories of hope,

TABLE 2. SUMMARY OF THEMES, EXAMPLE QUOTES, AND ASSOCIATED CODES

<i>Main theme</i>	<i>Example quote</i>	<i>Code (informed by RIM<sup>17,18</sup>)</i>
Social media provides a way to feel normal and connected to friends	I do think they use social media as a means of connection and depending on the patient's personality and age, whether or not they're sharing exactly what's going on. I think social media can be really great in keeping people connected—PR02	Social integration Coping
Social media accentuates the frustration of being left behind	I want to hear about what, what's is going on in your life. Because I want to still feel connected to you.—PA01 The frustrations that I've heard from patients, especially with social media is that it can be really hard to see their friends and family continuing on with their life when they're not.—PR01 "Have fun at Copacabana while I'm sitting here in my fancy hospital gown and some nice hairnet things."—PA07	Social integration Coping
Social media facilitates the need to be understood by peers who have experienced sarcoma	Just like knowing that you're not the only one, like actually seeing somebody that's going through something similar to what you're going through, or sometimes even worse. Would kind of help...—PA03. Yeah, I actually met a girl named [name], at my first treatment about half way through, I met this girl named [name] and she went through exactly what I went through. She was a year out and I met her and we're still friends today. She's one of the best things that's happened throughout this. I can talk to her about anything. It's so nice being able to talk to someone who really understands what you're going through. So I can be like, don't you hate it when you have to go in for blood and you have low counts? And she's like yeah they always take so long at the pharmacy and we can go off about these things that none of my other friends would understand—PA05.	Social integration Hope derived meaning Coping
Social media can lead to despair and also provide hope for the future	So I just try to avoid stuff like that [Instagram]. And then I gotta think this isn't what I truly look like. This is making me look this way right now. I'll get to being normal eventually and I just gotta keep thinking of that. Because it's very hard to see all these things and then look in the mirror and then see what you look like. "—PA05..." You would get people on there who ... It would be hard to watch people die on there. ... They're like, "Damn, that could be me."—PA01	Social integration Hope derived meaning Illness distress Coping

RIM, Resilience in Illness Model.

it could also devastate. Facebook use can negatively affect mental health outcomes,<sup>26</sup> and our findings suggest that this may be especially true for AYAs with sarcoma who may be unable to participate in developmental milestones and social events along with their friends, or who are faced with notifications of a peer's cancer reoccurrence or passing.

#### *Clinical implications*

While general social media use may not be helpful, targeted social media interventions may play an important role in providing access to structured social support from old friends and peers with sarcoma. Teachable communication skills may be an important intervention target for AYAs as they seek to maintain friendships. In other populations, competency in communication has been found to predict better Facebook-based social support.<sup>27</sup>

In addition, information about the benefits of connecting with peers with sarcoma online, for example, by providing survivors' stories of hope, may be helpful for those who are reluctant to make these connections. However, pairing this information with tailored education—informed by those who

have experienced sarcoma—around appropriate, positive Facebook use is warranted. Interventions that teach coping skills to help AYAs better navigate the negative thoughts and feelings associated with connecting with peers through social media may be helpful.

#### *Limitations*

We aimed to mitigate limitations associated with qualitative research by following standard qualitative evaluative criteria.<sup>28</sup> To strengthen the internal validity of the findings, researchers with different backgrounds analyzed the data. The inclusion of AYAs with diverse treatment experiences, as well as parents and providers, allowed us to understand the social health of AYAs from a variety of perspectives. Still, the current results cannot be generalized to other AYAs with cancer, or AYAs with sarcoma in other settings. Finally, we attempted to minimize bias by enlisting researchers familiar with the study population, but not involved with analysis, to review the methodological approach and findings.

Connecting with friends and other AYAs with sarcoma through social media can play an important role in providing

support for AYAs with sarcoma, but it may also amplify feelings of frustration and anxiety. Future work is needed to develop interventions that can maximize the benefits of social media for social support for AYAs with sarcoma.

#### Data Availability Statement

Research data are not shared.

#### Author Disclosure Statement

At the time the study was conducted, E.D. was Chief Science Officer at BodiMojo, Inc., and T.M.C. was Chief Executive Officer at BodiMojo, Inc.

#### Funding Information

This research was funded by a grant from National Cancer Institute, grant no. R43CA206666. N.C.F. is supported by the National Institute of Health/NCATS grant no. UL1TR001881.

#### Supplementary Material

Supplementary Data

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