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Seeking Virtual Support: Digital Technology Use in Adolescent and Young Adults with Advanced Cancer

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Abstract

Background: A cancer diagnosis, especially advanced cancer, interferes with adolescent/young adult (AYA) peer relationships. AYAs increasingly use digital technologies (i.e. social media, video games) as a social instrument; little is known about the role of digital technologies in the AYA cancer experience. The objective of this analysis was to describe the use and impact of digital technologies among adolescents and young adults with advanced cancer.

Procedure: As part of the "Exploring the Concept of a 'Good Death'" study, semi-structured interviews were conducted with 32 English-speaking AYAs (14–25 years) with advanced cancer (relapsed/refractory disease, estimated survival <50%). Interviews were audio-recorded, de-identified, and transcribed verbatim. Questions focused on communication and sources of psychosocial support. Directed content analysis was used for codebook creation. Three reviewers completed transcript coding and reconciled discrepancies. Thematic analysis identified hierarchical themes. The present analysis focused on the specific theme of "digital technologies as a support mechanism."

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Results: When asked about sources of support, social media and multi-player online games were most often recognized by AYAs. Three themes emerged regarding the role of digital technologies: distraction, maintaining existing peer support, and connecting with peers with cancer. Two AYAs acknowledged negative consequences of social media.

Conclusions: AYAs with advanced cancer cite digital technologies as a mechanism for maintaining and seeking peer support. Digital technologies may be leveraged to provide psychosocial support for AYAs with advanced cancer.

Keywords

adolescent and young adult; cancer; social media; digital technology

Introduction

Peer relationships are a defining feature of adolescence and young adulthood.[1, 2] Moreover, peer support plays a critical role in how adolescents and young adults (AYAs) with cancer cope with their diagnosis and influences decisions about treatment. However, AYAs with cancer experience challenges maintaining and establishing peer relationships. For AYAs facing advanced cancer, these challenges are compounded by frequent or prolonged hospitalizations, travel to referral centers to seek experimental therapies, and the psychological impact of navigating a life-threatening disease.[3]

Digital technology use, including social media, text messaging, and video games, is ubiquitous among AYAs. A recent systematic review of young adults with life-limiting conditions suggests that AYAs turn to social media to connect with peers with a shared illness experience.[4] Social media is a well-established mechanism for AYAs to collect diagnosis-related information.[5] AYA survivors of cancer cite the importance of recreational video game use in both creating/maintaining social connection and distraction from reality.[6] Digital technologies have long been utilized for psychosocial intervention delivery, especially for skill development or education about a diagnosis.[7–12] However, the world of digital technologies is rapidly evolving; frequent change complicates how these platforms may be used for research or clinical care.[13] Understanding how AYAs with cancer recreationally use digital technologies, especially when facing the social challenges of advanced disease, may elucidate how digital interventions could be tailored to their specific needs.

The “Exploring the Concept of a ‘Good Death’” study aimed to examine the experiences of AYAs with advanced cancer and those who care for them.[14–17] While conducting the primary qualitative analysis for this study, we found many participants disclosed, without prompting, the role digital technologies played in their ability to cope. Thus, the objective of the present analysis was to describe recreational digital technology use among AYAs with advanced cancer.

Methods

Design, Setting, and Participants

The "Exploring the Concept of a 'Good Death'" study was a prospective, mixed methods study involving four cohorts of participants recruited from a single pediatric specialty center, including health care providers (pediatric oncologists and advanced practice providers, nurses, chaplains, and social workers),[14] bereaved caregivers of AYAs with cancer,[16] caregivers of AYAs currently living with advanced cancer,[17] and AYA patients.[15] This analysis focused on the AYA cohort. Local IRB approval was granted for study completion.

AYA cohort eligibility criteria included age 14–25 years and receiving treatment for advanced cancer (defined as relapsed/refractory disease, eligible for a phase I clinical trial, enrolled in hospice, or anticipated prognosis of survival <50%). Participants were excluded if not fluent in English, cognitively/physically unable to participate, or parent refusal in a minor-aged patient. AYAs were enrolled into two strata based on age (14–17 and 18–25). Study staff reviewed clinic schedules to identify eligible participants. AYAs were recruited in-person with a parent caregiver; parental study participation was not required for AYA participation. Written informed consent (≥18 years)/written assent with parental permission (<18 years) was obtained by a trained clinical research coordinator prior to enrollment.

Procedures

Quantitative Data Collection—AYAs completed surveys at baseline (after study enrollment, prior to interview completion) and 12 weeks. The survey included demographics plus age-validated measures of health-related quality of life (HRQOL) (Pediatric Quality of Life Inventory; PedsQL[18–20]) and anxiety/depression (Hospital Anxiety and Depression Scale; HADS[21]). The PedsQL Generic Form and Cancer Modules include 50 questions querying perceived wellbeing in both generic and disease-specific domains (internal consistency 0.75–0.92).[18–20] A total score is transformed on a scale of 0–100, with higher scores representing "better" HRQOL.[19] The HADS includes seven items querying anxiety and seven items querying depression.[21] Total subscale scores range from 0–21.[21] Higher scores represent worse anxiety or depression; scores ≥8 are clinically significant.[21] Additional demographic and treatment-related information were obtained by medical record review.

Qualitative Data Collection—The Standards for Reporting Qualitative Research (SRQR) guidelines were used to guide qualitative data collection and analysis. All AYA interviews were conducted one-on-one with a trained qualitative methodologist (K.S.B.) with no professional relationship to the caregivers or AYAs between December 2017 and September 2018. Semi-structured interviews used a pre-defined interview guide with open-ended questions and optional probes. The interview guide did not include any questions addressing AYA use of digital technologies, recreational or otherwise. Interview timing (during hospitalization vs outpatient) and location (in-person versus telephone) was subject to AYA preference/availability. Interviews were attempted in one session; a second session was offered if needed. Interviews were audio-recorded and averaged 37 minutes in duration

(range 20–75 minutes). A $20 gift card was offered following completion of each survey and interview.

Data Analysis

Qualitative Analysis—To comprehensively describe the AYA advanced cancer experience, we used a combination of directed content analysis for codebook creation followed by thematic networks analysis for deeper analysis. The analysis team included psycho-oncology researchers with experience in qualitative methods and additional training in pediatric oncology (A.S., A.R.R), psychology (N.L., K.M.F., J.P.Y.F.), social work (C.A.W.), and health services (A.R.R., K.S.B.). Interviews were transcribed verbatim, deidentified, and imported into Dedoose for analysis (Dedoose Version 7.0.23 (2016). Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com).

Directed content analysis was used to guide codebook development and coding structure. Two reviewers (C.A.W., A.S.) independently reviewed five transcripts in entirety and then used open coding to cross-reference with an existing codebook developed from the provider and caregiver cohorts. Additional AYA-specific codes were developed deductively (addition of parent code “adolescent development” with sub-codes “interference/disruption to life goals,” “decision-making capacity,” and “physical change/losses;” addition of sub-code “avoidance/distraction” under parent code “response to advanced cancer;” addition of sub-code “peers” under parent code “relationships”), and revisions (broadening codes “acceptance” and “societal perceptions” to include declining health status or other change in the illness trajectory) were made to generate a final codebook.[24] Three coders reviewed every transcript; C.A.W. was the primary coder, A.S. was the secondary coder, and K.S.B. was a tertiary and tie-breaking coder. Discrepancies were discussed and reconciled during a series of consensus meetings.

After coding was complete, thematic networks analysis was selected to systematically structure and organize themes about the AYA advanced cancer experience based on excerpts from code categories with common points of reference that unified the idea. For the primary analysis, three global themes were identified, each with three organizing themes. For this secondary analysis, we explored the code category” mechanisms for coping with advanced cancer,” not explored in the primary analysis. We abstracted themes from the coded text, including distraction, maintaining relationships with peers during treatment away from home, and identifying similar-aged AYAs with cancer to build informal support groups. Selected themes were iteratively arranged, and basic themes were refined. We then rearranged basic themes into the organizing theme of “purpose of digital technology use.” We next deduced a common global theme of “digital technologies as a support mechanism.” This thematic network was iteratively reviewed by the analysis team until final consensus was reached (Final thematic matrix described in Table S1).

Quantitative Analysis—To describe patterns in digital technology use for the purpose of guiding future hypothesis development, quantitative analysis was completed. Participants were then categorized into two groups: those who independently referenced digital technology use during their interviews and those who did not. Excerpts were searched for

terms including “social media,” “Facebook,” “Instagram,” “YouTube,” “Twitter,” “Caring Bridge,” “video game,” “videogame,” “game,” “text,” “text message,” “message,” “chat,” “phone.” More contemporary social media platforms (e.g. “Discourse,” “TikTok”) were searched but interviews pre-dated their widespread use. Demographics (age at enrollment, sex, and whether the AYA relocated for treatment) were compared in each group using numbers and proportions. Baseline PedsQL and HADS scores were compared using medians and interquartile ranges. Baseline scores were used because of their proximity to interview completion. Hypothesis testing was not performed in this exploratory analysis.

Results

In total, N=39 (of 44 eligible) AYAs were approached, N=37 provided informed consent/assent, and N=32 completed interviews (Table 1). The mean age at diagnosis was 13 years (range 6–20 years). The mean age at study enrollment was 18 years (range 14–25 years). Most participants were male (59%) and identified as non-Hispanic, white race (56%). Leukemia/lymphoma was the most common diagnosis (71%). Video games and social media were the most commonly discussed digital technologies. In examining themes for the role of digital technologies in coping with advanced cancer, we identified three basic themes: distraction, maintaining existing peer support, and connecting with peers with cancer (Table 2).

Distraction

AYAs referenced video games and social media as a distraction from unwanted thoughts, to pass time, and to feel connected to the outside world. About social media, one AYA shared:

> “I see what my friends and family are doing that I don’t get to see a lot, and I usually find some humorous stuff, and, “Oh hey, this is happening.”… So, if I’m having a bad day, I could find some good things.”
>
> [14-year-old, Male]

About video games, another AYA shared how they use video games to maintain normalcy:

> “[We do] Regular friends stuff… You know, just hanging out, talking, playing games together. Stuff like that. [We talk about] regular stuff, just whatever we feel like talking about.”
>
> [14-year-old, Male]

They also identify video games as a distraction from symptoms, such as pain, nausea, or fatigue. Regarding how they cope with especially difficult days, one AYA shared:

> “Just playing video games or whatnot, just taking my mind off of it for an hour, and usually that does the trick.”
>
> [23-year-old, Male]

Another shared: “I usually just stay in bed and play videogames and try not to do anything.”*[19-year-old, Female]*

Maintaining Existing Peer Support

To maintain existing peer relationships, AYAs referenced using social media, video games, and text messaging. AYAs reported social media as a constructive means for seeking out encouragement:

> "If I've posted updates on Facebook, there are people … I have friends, mostly all from high school … that I've known for many years, I haven't been close to necessarily, that comment unbelievably sweet and uplifting comments."
>
> [25-year-old, Female]

This played a role for AYAs traveling for treatment. About overcoming the challenges of being away from home, one AYA shared:

> "Social media has played a really big role too, because I was able to keep in contact with all my friends from high school 'cause of it."
>
> [18-year-old, Male]

Others share that they use video games to facilitate communication with their peers about challenges they experience during treatment:

> "It's kind of weird to say, but when I go home or when I'm home, I talk with people on my game, and like they know my situation. I kind of just play games with them and talk to them about like where I am stuck. I guess that helps a lot 'cause it like takes my mind off things. Yeah, that did help a lot actually."
>
> [15-year-old, Male]

Another AYA shared how video games allowed them to re-connect with childhood friends:

> "We're close again, and it's just amazing 'cause one of my friends was friends with him on the PlayStation. And I was like, "oh hey, what's up" and then we've caught up and everything. And he still knew everything that was happening with me. But we were able to talk more because of a video game platform."
>
> [18-year-old, Male]

Text messaging also played an important role in how AYAs were able to update peers and to find emotional support:

> "I have also kept in touch with my best guy friend through high school, but we haven't been able to visit a lot closely, but he's always been there via phone and text, whatever, even though he was in [another state] during college and stuff. If I ever needed any help or just wanted to update him on what was going on, he was always there."
>
> [25-year-old, Female]

Connecting with Peers with Cancer

AYAs with advanced cancer acknowledged the challenge of identifying peers with shared experience. Social media was referenced as a tool for identifying other AYAs with cancer. One AYA shared:

> "She had gotten in contact with me through one of my friends who like shared a photo of me on her Facebook… I guess you know [friend's name] the girl who had cancer, she saw it and texted the girl, "Hey like can you give me her contact info? Like I'd love to just text her and like you know be there for her." So my friend gave her the phone number and [friend's name] texted me one night and she was like, "We should meet up and like talk about all this stuff.""

[21-year-old, Female]

Text messaging, however, was referenced as the primary tool for maintaining communication with other AYAs they met during treatment. One AYA shared:

> "They keep checking up on you… And since I'll be in the area getting treatment, we want to definitely get together and catch up. And we talk sometimes over text. We're not super close, but it's cool to have someone else that you can share same experiences with and have a good laugh over different things that happen in the hospital, about that kind of stuff, without offending people. You know? It can be uncomfortable if you're talking about cancer to someone because they want to feel bad, but at the same time you want to share kind of the light-hearted memories as well."

[19-year-old, Male]

> Another AYA shared: "You meet someone who is your age and is going through the same thing and is away from home. She's from [another state], and meeting her was extremely uplifting… So we text everyday. Sometimes she's here, so we'll see each other in the hall. But yeah, we talk and we vent and we are excited about good news."

[17-year-old, Female]

Potential Negative Consequences

Finally, two AYAs referenced negative psychological consequences, primarily of social media. One AYA shared:

> "The whole social media aspect kind of makes it harder. 'Cause, while its like entertaining and helpful for me to pass the time, its hard to see, you know, people just living their lives and, you know, going to bars and being able to do normal things."

[21-year-old, Female]

This AYA also disclosed how social media played a role in negative body image:

> "It's just kind of the beauty standard now… its just hard for me to fit that standard right now and I'm hard on myself when I shouldn't be."

[21-year-old, Female]

Group-specific Participant Characteristics

Most of the AYAs interviewed independently referenced recreational digital technology use (N=19; 60%) (Table 3). Those who shared their digital technology use were more likely to

be male (74% versus 38%), older (63% versus 54%), and to have relocated for treatment (74% versus 62%) compared to those who did not. Recreational video game use was reported by 10 AYAs, 9 of which were male, and 6 of which were in the older age group (18–25) (Table 4). Social media use was referenced by 9 AYAs, 6 of which were male, and 6 of which were in the older age group. Text messaging was referenced by 8 AYAs, 4 of which were male, and 7 of which were in the older age group. There was no difference in depression and anxiety based on digital technology use (HADS score median [IQR]: Yes: 12 [7–18]; No: 11 [10–14]). HRQOL scores were also similar between groups (PedsQL score median [IQR]: Yes: 71 [66–78]; No: 67 [62–69]).

Discussion

In this mixed-methods study, we aimed to describe digital technology use among AYAs with advanced cancer. We found that AYAs reference using digital technologies (including social media, video games, and text messaging) for the purposes of distraction, maintaining peer support, and connecting with AYAs with a shared experience. AYA males and those who have relocated for treatment more often independently referenced using digital technologies. Psychological distress scores were similar between those who referenced digital technology use and those who did not.

Digital technologies may be a helpful distraction from symptoms and other disease-related stressors. Previously, video games have been found to be an important distractor from symptoms of post-traumatic stress disorder. Recreational video game use also has a positive impact on psychological symptoms in children with cancer during and after treatment. The AYAs in our cohort recognized the role of both video games and social media use for distraction. However, video games seemed to play a larger role in symptom control. The value of play therapy and distraction in symptom management is well-recognized. Interactive interventions may be more effective in symptom management. This may account for why AYAs in our cohort referenced interactive video game use, rather than other digital technologies, in providing distraction from symptoms. Further research is needed to explore the potential role in clinical care.

Digital technologies play an instrumental role in how AYAs socialize and connect with the outside world. In both AYA cancer survivors and others facing social isolation, video games improved mental health by providing virtual socialization and cultivating a sense of accomplishment. Social media is another outlet for AYAs with cancer to navigate peer relationships, reclaim independence, preserve normalcy, and seek out encouragement. This is particularly relevant as COVID-19 exacerbated feelings of social isolation for AYAs with cancer, especially during hospitalization. Digital technologies are likely an important complementary platform to provide AYAs with psychosocial support. Our results suggest this remains true in the setting of advanced disease.

Whereas social media, video games, and text messaging all appear to facilitate communication with well peers, video games seem to provide AYAs an interactive method to facilitate conversations about their diagnosis and treatment with well peers. Alternatively, social media and text messaging appear to be the primary means of connecting with other

AYAs with cancer. Further, although social media was referenced as a means of identifying other AYAs with cancer, text messaging was referenced as the primary mechanism for maintaining contact. Efforts should be made to explore how to integrate digital technologies in the care of AYAs with advanced cancer to promote social connection with both healthy peers and those with shared disease experiences. Given the rapid pace of digital technology evolution, partnering with existing support communities and patient advocates will be necessary to tailor clinical and research interventions to the needs of AYAs.[13]

The negative psychological impact of social media is well documented among AYAs. For AYAs with cancer, social media may exacerbate feelings of negative body image. Other AYAs acknowledge the emotional toll of seeing healthy peers participate in “normal” activities and reaching milestones while their own lives are interrupted by their diagnosis. Our findings suggest that these challenges do not change in the setting of advanced cancer. Despite these consequences, AYAs who referenced digital technology use did not report worse anxiety or depression and many described digital technologies, including social media, as a positive coping instrument.

AYAs with cancer report impaired social functioning compared to their well peers, especially early in treatment. Certain AYAs may be more likely to turn to digital technologies for social connection, based on their risk of social isolation. For example, although our cohort included a large proportion of AYAs who relocated for treatment, our findings suggest that digital technologies may be especially useful for maintaining social connection when navigating physical separation from one’s peers. Our results may also suggest gender and age differences in preferences for specific digital technology modality and application. However, given the small sample size and exploratory nature of this analysis, future research querying digital technology preference is warranted. Ultimately, psychological screening that includes a discussion about digital technology use and preferences may be helpful in both identifying individuals at risk for social isolation and providing preventative interventions.

Several limitations of this analysis must be noted. Primarily, our interview guide did not specifically address digital technology use, nor did it ask AYAs to reflect on how their digital technology use influenced their psychosocial wellbeing or symptom control. Thus, we can only speculate the potential implications for research and clinical care. Although we were unable to draw qualitative conclusions about the perspectives of AYAs in our cohort who did not reference digital technologies, we hope this may be investigated in future research. Interviews were completed more than two years prior to this analysis and may not account for technology evolution incurred in that time. Our sample was relatively small, especially for the evaluation of quantitative measures. This prevented hypothesis testing in our quantitative analysis and limits sub-group comparisons. Quantitative analyses were used to help describe patterns and are important for informing future research. Our sample was recruited from a single, pediatric health care center. Although a large proportion of our participants relocated for care, our findings may not completely reflect the experience of AYAs treated elsewhere. Similarly, participants were English-speaking and predominantly white. Thus, their experiences may not reflect those of individuals from different cultural

backgrounds. Finally, the experience within a pediatric center may be unique. Our findings may not reflect the experience of older AYAs who seek treatment at adult cancer centers.

Digital technologies play an influential role in the lives of AYAs. Recreational use of digital technologies may provide AYAs with cancer a mechanism to socialize and to mentally escape the circumstances of treatment. Exploring how we can include recreational digital technology use into research and clinical care the potential to improve the social and emotional wellbeing of AYAs with advanced cancer.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability Statement:

Research data are not shared.

Abbreviations:

AYA	Adolescent and young adult
HADS	Hospital Anxiety and Depression Scale
PedsQL	Pediatric Quality of Life Inventory

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TABLE 1

Participant Demographics.

Characteristic	N (%)*
Age (in years) at enrollment [mean (range)]	18 (14–25)
Age (in years) at diagnosis [mean (range)]	13 (6–20)
Sex	
Male	19 (59)
Female	13 (41)
Race	
White/Caucasian	18 (56)
Asian	5 (16)
More than one race	5 (16)
Unknown	4 (12)
Ethnicity	
Not Hispanic or Latinx	22 (69)
Hispanic or Latinx	6 (19)
Unknown	4 (12)
Diagnosis	
Leukemia/Lymphoma	23 (71)
Brain Tumor	6 (19)
Sarcoma	3 (9)
Deceased at time of analysis	
No	24 (75)
Yes	8 (25)

* unless otherwise noted

TABLE 2

Themes and Representative Quotes.

Theme	Technology Modality	Exemplary Quote
Distraction	Social media	"I see what my friends and family are doing that I don't get to see a lot, and I usually find some humorous stuff, and, "Oh hey, this is happening."… So, if I'm having a bad day, I could find some good things."
	Video game	"I'd say going online is pretty satisfying, because I don't really have … Like, playing an online game, I usually don't have to think too hard."
Maintaining existing peer support	Social media	"And if I've posted updates on Facebook, there are people … I have friends, mostly all from high school … Yeah, so there are just a lot of people that I've known for many years I haven't been close to necessarily that comment unbelievably sweet and uplifting comments."
	Video game	"It's kind of weird to say, but when I go home or when I'm home, I talk with people on my game, and like they know my situation. I kind of just play games with them and talk to them about like where I am stuck. I guess that helps a lot cause it like takes my mind off things. Yeah, that did help a lot actually."
	Text messaging	"And I have also kept in touch with my best guy friend through high school, but we haven't been able to visit a lot closely, but he's always been there via phone and text, whatever, even though he was in Louisiana during college and stuff. If I ever needed any help or just wanted to update him on what was going on, he was always there."
Connecting with peers with cancer	Social media	"She texted me out of the blue when I was going through I think like course two or something… And she had gotten in contact with me through one of my friends who like shared a photo of me on her Facebook… I guess you know [friend's name] the girl who had cancer, she saw it and texted the girl, "Hey like can you give me her contact info? Like I'd love to just text her and like you know be there for her." So my friend gave her the phone number and [friend's name] texted me one night and she was like, "We should meet up and like talk about all this stuff."
	Text messaging	"You meet someone who is your age and is going through the same thing and is away from home. She's from [another state], and meeting her was extremely uplifting… So we text everyday. Sometimes she's here, so we'll see each other in the hall. But yeah, we talk and we vent and we are excited about good news."
Negative consequences	Social media	"The whole social media aspect kind of makes it harder. Cause, while its like entertaining and helpful for me to pass the time, its hard to see you know people just living their lives and you know going to bars and being able to do normal things."

TABLE 3 Participant Characteristics by Digital Media Use.

Participant Characteristic	Digital Technology Endorsed?	
	Yes (N=19)	No (N=13)
Sex, N (%)		
Male	14 (74)	5 (38)
Female	5 (26)	8 (62)
Age at Enrollment, N (%)		
14–17	7 (37)	6 (46)
18–25	12 (63)	7 (54)
Relocated for treatment, N (%)		
No	5 (26)	5 (38)
Yes	14 (74)	8 (62)
HADS score [median (IQR*)]	12 (7–18)	11 (10–14)
PedsQL score [median (IQR*)]	71 (66–78)	67 (62–69)

*IQR = interquartile range

TABLE 4

Demographic description of technology purpose, sorted by technology modality.

Theme (Purpose)	Technology Modality	Sex		Age (years)		Relocated for treatment?	
		Male	Female	13–17	18–25	Yes	No
Distraction	Social media	3	1	2	2	3	1
	Video game	7	1	3	5	6	2
Maintaining existing peer support	Social media	2	1	1	2	3	0
	Video game	6	1	4	3	6	1
	Text messaging	3	2	0	5	3	2
Connecting with peers with cancer	Social media	1	1	0	2	1	1
	Text messaging	1	2	1	2	1	1
Negative consequences	Social media	1	1	0	2	1	1