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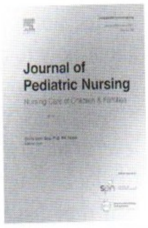

Unmet needs in adolescents and young adults with cancer: A mixed-method study using social media

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ABSTRACT

Purpose: The purpose of this study is to identify and compare the unmet needs of adolescents and young adults (AYAs) with cancer by age and gender.

Design and methods: This is a mixed-methods study to analyze textual data from blog posts on AYAs' unmet needs. Themes were identified using a qualitative descriptive method with content analysis, and a quantitative method was used to compare themes by age and gender.

Results: The findings from blog posts of 100 AYAs showed that AYAs with cancer expressed somewhat different needs by age and gender. Young adults (26–39 years) with cancer tended to describe significantly more feelings of fear ($p = .043$) and parenting needs ($p < .001$) and significantly fewer educational needs ($p < .001$) than did emerging adults (18–25 years) with cancer. Female AYAs with cancer described significantly more feelings of guilt ($p = .020$), sexual needs ($p = .003$), fertility issues ($p = .023$), and social needs ($p = .013$) than did male AYAs with cancer. There were no statistically significant differences in the remaining themes between age and gender groups, although how they described unmet needs differed qualitatively.

Conclusions: AYAs with cancer have various unmet needs and their unmet needs were different by age and gender.

Practice implications: Nurses should proactively provide integrated systematic screening by offering a safe, non-judgmental environment to encourage AYAs to express their needs across their cancer journey. Nurses also should respond with developmentally appropriate support, resources, and referrals based on these expressed needs.

Introduction

The National Cancer Institute (NCI) defines adolescents and young adults (AYAs) as people between the ages of 15 and 39 (NCI, 2018). It has been estimated that in the U.S., approximately 89,500 of AYAs will have been diagnosed with cancer by the end of 2021 (Miller et al., 2020); and in 2018, their 5-year relative survival rate was 85% (NCI, 2018). Consequently, the number of AYA survivors with cancer is growing substantially in the U.S. At the same time, AYAs are more likely to experience delays in diagnosis because of a lack of emphasis on prevention and early detection (Noone et al., 2018).

The age range of AYAs comprises three distinct time periods: middle to late adolescence (15–17 years), emerging adulthood (18–25 years), and young adulthood (26–39 years) (Arnett, 2000). Adolescents (15–17 years of age) usually live with their parents, are completing education, and are largely influenced by their peers. Emerging adults (EAs) (18–25 years of age) can experience a variety of developmental patterns. Often, EAs explore various possible life directions in love, school, work, and worldviews in between the dependency of adolescence and the responsibilities of adulthood. Compared with adolescents and EAs, young adults (YAs) are more likely to be married or partnered, to become parents, and to have started on a long-term career path (Arnett, 2000).

The achievement of these milestones is significantly challenged by cancer diagnosis, treatments, and long-term side effects, which result in various unmet needs in every aspect of AYAs' lives. The unmet needs include medical late effects (Choi et al., 2021), physical symptoms (Jones et al., 2020), emotional concerns (Jones et al., 2020), practical issues (Jones et al., 2020; Salsman et al., 2021), cognitive concerns (Guy Jr et al., 2014; Jones et al., 2020), and fertility issues (Alander et al., 2021). However, these previous studies have tended to aggregate data and have not reported AYA's psychosocial outcomes separately by age or by gender, even though these age groups (adolescents, EAs, and YAs) have fundamentally different needs based their different developmental tasks and cancer journey (Arnett, 2000; Bibby et al., 2017). The

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limited, nonspecific nature of this literature does not permit conclusions about how to address unmet needs and HRQOL among these specific, yet diverse population groups.

About 90% of AYAs use social media (Perrin & Kumar, 2019), and the level of social media usage among AYAs with cancer is likely comparable to that among AYAs without cancer. AYAs with cancer have reported that they began social networking through social media because it was difficult to find age-appropriate survivorship resources and offline support groups (Walton et al., 2017). The online community for AYAs with cancer is thriving, with many AYAs exchanging information and sharing their cancer stories (Perales et al., 2016; Walton et al., 2017). Analyzing these textual data from social media can enable researchers to discover unmet needs among AYAs with cancer and complement the information available from other data sources such as interviews or surveys.

About 30 studies of AYAs with cancer have analyzed their textual data from social media. These studies have been qualitative, using content analysis of posts on online cancer forums, personal blogs, or social media platforms such as Facebook and Twitter. In addition, these studies have tended to treat AYAs as one age group rather than report their outcomes separately by age. Some studies have investigated AYAs' experiences of cancer of the reproductive system separately by gender, but cancer experiences by both genders have not been compared within a single study. Thus, the examination and comparison of age-specific and gender- or sex-specific results among AYAs with cancer have yet to be discussed.

Therefore, the purpose of the present study was to specifically explore and describe AYAs' unmet needs as expressed through social media, and to identify and compare their perceived needs by age and gender. This information can help healthcare providers and researchers to better understand AYAs' cancer experiences and develop age-appropriate treatment and services—in short, to determine what support can facilitate this population's well-being.

Methods

All the methods and results have been reported based on Consolidated Criteria for Reporting Qualitative Research guidelines (Tong et al., 2007).

Research design

A mixed-methods study design was used to analyze AYA's unmet needs as expressed on an online cancer community. Initially, a qualitative research method was utilized to identify themes and subthemes using content analysis. A quantitative method was then utilized to compare identified themes between age and gender groups.

Conceptual framework

This study is based on the Supportive Care Framework for Cancer Care (Fitch, 2008), which comprises seven domains: physical, social, emotional, practical, informational, spiritual, and psychological. Healthcare providers and survivorship programs use this framework as a tool to conceptualize types of support people with cancer might need and how plans for care and service delivery can be developed. The concepts within the framework have been validated in qualitative research (Herrmann et al., 2020; Primeau et al., 2017). A supportive care needs survey with content derived from this framework has demonstrated good validity and reliability (Bonevski et al., 2000).

Sample

This study utilized convenience sampling and analyzed pre-existing textual data from blogs posted on an online cancer community. Eligible blogs were (1) written by AYAs aged 15–39 years when they were initially diagnosed with cancer and (2) between 15 and 39 years o age when they published blog posts, and (3) written in English, regardless of race/ethnicity, nationality, regions, or types and stages of cancer Blogs were excluded if they were written by people other than AYA with cancer such as family members, friends, healthcare provider and cancer-related organizations. This was determined by checking the profiles of bloggers on the online cancer community, which includ each user (blogger)'s ID, gender, current age, year of cancer diagnosis cancer type and stage, geographic region (city and/or country), an whether the user is a patient/survivor, caregiver, or supporter.

Procedure

The study protocol was exempted by the researchers' Institutiona Review Board because the data included no personally identifying information. However, social media research methods are not free from ethical challenges. There are potential issues such as quality of information informed consent, and confidentiality (Golder et al., 2017; Moreno et al 2013). Considering these ethical concerns, we did not present direc quotations from the blogs in this study because they could be potentially searched to identify bloggers. In order to confirm whether or no the blogger was an AYA with cancer, the profile of each blog post was checked by the first author (E.C.). Once the first author extracted al blogs written by AYAs with cancer, the posts were sorted by blogger's ID and posts' publication dates in order to prevent the inclusion of multiple posts by the same bloggers and adequately represent unmet needs by age and gender. After sorting the posts, if more than one post was written by the same blogger, the most recent post was selected using proportionate stratification (considering age and gender). Using more recent blogs allows for a more socially relevant analysis. Also, using multiple blogs from the same bloggers could overemphasize certain bloggers' cancer experiences in the analysis, and it could violate one of the assumptions underlying the inferential statistical analyses, the assumptions of independent data point. Thus, the number of blog posts for analysis equals the number of bloggers' posts.

Data analysis

The qualitative descriptive analysis process was completed as per Miles, Huberman, and Saldana (2018). First, a codebook was created deductively based on the domains in the Supportive Care Needs Framework (Fitch, 2008). To create codes under the domains of this Framework, the content was analyzed until data saturation occurred (Guest et al., 2006). After reviewing the pattern of codes created from the preliminary codebook, the emotional domain and psychological domain were merged because those two domains covered similar concepts. Also, a new domain, sexual needs, was added. A sexual need domain was needed to stand independently rather than be included within the other domains in order to highlight sexual and fertility issues among AYAs with cancer. Next, the first and third authors (E.C. and S.K.) independently coded the entire data set based on the completed codebook, using the qualitative data analysis software program, ATLAS.ti version 9.1. Inter-rater reliability between the two coders was 89%. The authors discussed discrepancies in coding until agreement was reached. Following review of codes and counts, the codes were then grouped and developed into themes and subthemes, which were reviewed with the second author (H.B.).

The SPSS version 26.0 was used for quantitative analysis. Descriptive statistics, including range, means, standard deviations, frequencies, and percentages were used to describe the characteristics of bloggers and provide a description of themes. Chi-square tests were used to examine relationships between theme frequencies and background characteristics. Statistical significance for the research questions comparing themes by age or gender was set at $p < .05$. According to assumptions for the chi-square test, if any expected values for a cell reflecting a theme in the contingency tables were less than 5, the test was not calculated.

Results

Demographic and clinical characteristics of the bloggers

A total of 100 blogs published between April 25, 2015 to February 13, 2020 were included in the analysis. In terms of the age groups, blogs were divided into two groups based on ages at posting a blog such as EAs (age range, 18–25 years) or YAs (age range, 26–39 years). Because only 6 posts were written by adolescents aged 15–17 years, these blogs were not included in the analysis. The mean word count for each blog post was 955.36 words ($SD = 387.93$), and the posts ranged from 484 to 3206 words. Table 1 shows bloggers' age, gender, cancer type, and geographic area. The mean age at diagnosis was 25 years (range, 15–38 years), and the average age at posting was 29 years (range, 18–39 years). The mean time since diagnosis appeared to be about 4 years.

Unmet needs of AYAs with cancer by age and gender

Table 2 shows the prevalence of need domains by age and gender. The frequency of needs reflects the number of bloggers reporting specific needs in that domain. The percentage of needs is the number of bloggers who reported the specific need divided by the total number of bloggers times 100. Emotional/psychological needs were the most prevalent need ($n = 94$, 94.0%); spiritual needs were reported by only 6 bloggers (6.0%). There were no significant age group differences in the frequency of discussion about needs in these domains. With regard to gender differences, female AYAs were significantly more likely to discuss sexual ($p = .003$) and social ($p = .013$) needs than were male AYAs with cancer. There were no significant gender differences in the frequency of discussions about remaining need domains.

Emotional/psychological needs

Emotional/psychological needs are the need to feel a sense of comfort, reassurance, and understanding to deal with distress, the need to achieve optimal personal control, and the need to experience positive self-esteem in dealing with the cancer experience and its consequences. Six themes were identified in this domain: negative emotions, illness identity, uncertainty about the future, post-traumatic stress disorder (PTSD), cognitive concerns, and suicidal ideation. Table 3 provides the number of bloggers found for each of the 6 themes and subthemes under each theme.

Negative emotions included subthemes such as feelings of fear, anxiety, depression, guilt, anger, and grief. There were no significant differences between age groups in frequencies of the theme and subthemes of negative emotions except the subtheme of fear. Among the subthemes for negative emotions, *fear* was the most prevalent. YAs were significantly more likely to express fear than EAs. The most common cause of fear was the fear of recurrence or fear of infertility. Fear of recurrence was evident across age groups, but the fear of infertility was salient among YAs with cancer. AYAs with cancer experienced feelings of *anxiety*. Because anxiety about scans is common, people in the cancer community use the term *scanxiety* to describe their nervousness around the time of these tests. AYAs with cancer felt *guilty* because of being a burden on their caregivers or because of the loss of a fellow cancer survivor (*survivor guilt*). Especially, YAs with cancer discussed guilt about the amount of time and energy invested in them by family because they were typically the caretaker of others in their family. AYAs with cancer expressed feelings of *depression*. The frequency of posts about feelings of depression did not differ significantly between the two age groups, but YAs were more likely to express feelings of depression than EAs with cancer ($p = .095$). AYAs with cancer often ask, "Why me?" and they can be *angry* at the cancer. Some AYAs with cancer felt offended or angry when people compared their own disease to cancer or made comparisons between different types of cancers. AYAs with cancer who expressed sorrow felt *grief* because of loss. Some of their losses were tangible, such as losing hair or losing breasts, and some were more intangible, such as the loss of trust in their bodies or loss of friendship or fertility.

In terms of the gender differences, there were no significant differences in frequencies of the theme and subthemes of negative emotions except the subtheme of guilt. Female AYAs were significantly more likely to describe feeling *guilty* than male AYAs with cancer ($p = .020$). Female AYAs tended to express more guilt about their existing children or future children because of their cancer experiences. Although there were no significant differences between gender groups in how frequently feelings of *depression* and *grief* were discussed, the patterns of blog contents were different for those two subthemes. Female AYAs tended to write more about long-term/late feelings of

Table 1
Demographic and clinical characteristics of bloggers by age and gender ($N = 100$).

Characteristics	All Bloggers ($N = 100$)	Age: Emerging Adult ($n = 41$)	Age: Young Adult ($n = 59$)	Gender: Male ($n = 50$)	Gender: Female ($n = 50$)
	n (%), *M* (*SD*)	*n* (%), *M* (*SD*)	*n* (%), *M* (*SD*)	*n* (%), *M* (*SD*)	*n* (%), *M* (*SD*)
Age at cancer diagnosis	25.32 (6.70)	19.76 (2.40)	29.88 (4.58)	25.10 (7.39)	25.54 (6.00)
Age at posting a blog	29.22 (6.71)	22.39 (2.07)	33.97 (4.25)	29.60 (7.53)	28.84 (5.84)
Gender					
Male	50 (50.0%)	21 (51.2%)	29 (49.2%)	–	–
Female	50 (50.0%)	20 (48.8%)	30 (50.8%)	–	–
Cancer type ($n = 98$)					
Testicular	32 (32.7%)	7 (17.1%)	25 (43.9%)	32 (64.0%)	0
Leukemia	19 (19.4%)	15 (36.6%)	4 (7.0%)	13 (26.0%)	6 (12.5%)
Breast	12 (12.2%)	0	12 (21.1%)	0	12 (25.0%)
Lymphoma	10 (10.2%)	8 (19.5%)	2 (3.4%)	0	10 (20.8%)
Cervical	5 (5.1%)	0	5 (8.8%)	0	5 (10.4%)
Sarcoma	5 (5.1%)	2 (4.9%)	3 (5.3%)	1 (2.0%)	4 (8.3%)
Thyroid	3 (3.1%)	1 (2.4%)	2 (3.4%)	1 (2.0%)	2 (4.2%)
Melanoma	3 (3.1%)	3 (7.3%)	0	0	3 (6.3%)
Colorectal	2 (2.0%)	1 (2.4%)	1 (1.8%)	1 (2.0%)	1 (2.1%)
Other	7 (7.1%)	4 (9.8%)	3 (5.3%)	2 (4.0%)	5 (10.4%)
Country ($n = 94$)					
U.S.	56 (55.4%)	11 (28.2%)	45 (81.8%)	28 (58.3%)	28 (60.9%)
Australia	27 (27.0%)	25 (64.1%)	2 (3.6%)	18 (37.5%)	9 (19.6%)
Canada	8 (8.0%)	3 (7.7%)	5 (9.2%)	1 (2.1%)	7 (15.2%)
England	2 (2.0%)	0	2 (3.6%)	1 (2.1%)	1 (2.2%)
South Africa	1 (1.0%)	0	1 (1.8%)	0	1 (2.2%)

Table 2
Prevalence of needs by age and gender.

		Age			Gender		
	All Bloggers ($N = 100$)	Emerging Adult ($n = 41$)	Young Adult ($n = 59$)	p	Male ($n = 50$)	Female ($n = 50$)	p
	n (%)	n (%)	n (%)		n (%)	n (%)	
Emotional/Psychological	94 (94.0%)	38 (92.7%)	56 (94.9%)	0.687	45 (90.0%)	49 (98.0%)	0.204
Physical	63 (63.0%)	23 (56.1%)	40 (67.8%)	0.293	31 (62.0%)	32 (64.0%)	0.836
Social	61 (61.0%)	25 (61.0%)	36 (61.0%)	0.997	24 (48.0%)	37 (74.0%)	0.013*
Practical	36 (36.0%)	15 (36.6%)	21 (35.6%)	0.919	17 (34.0%)	19 (38.0%)	0.835
Sexual	35 (35.0%)	10 (24.4%)	25 (42.4%)	0.088+	10 (20.0%)	25 (50.0%)	0.003**
Informational	24 (24.0%)	7 (17.1%)	17 (28.8%)	0.235	8 (16.0%)	16 (32.0%)	0.061+
Spiritual	6 (6.0%)	3 (6.4%)	3 (5.1%)	N/A	5 (10.0%)	1 (2.0%)	N/A

Note: Statistical comparisons not computed when n for the category was 10 or fewer persons.
*** $P < .001$, ** $p < .01$, * $p < .05$, + $p < .10$.

depression after completing treatment and tended to describe not only survivor guilt but also grief resulting from loss of relationships or loss of fertility more than did male AYAs with cancer.

The theme of *illness identity* was found in 42 AYAs with cancer. The theme of illness identity included self-identity issues, self-consciousness, and self-esteem. When AYAs are diagnosed with cancer, they experience changes in self-image and self-esteem because of the negative impacts of cancer on their physical and emotional status. They begin to feel self-consciousness about themselves and self-blame about a cancer diagnosis. Some may even experience feelings of embarrassment or shame about side effects and long-term effects after treatments. The theme and subthemes of illness identity also showed no significant age and gender differences. However, male AYAs did tend to describe low self-esteem resulting from questioning self-worth or losing independence. Female AYAs tended to have low self-esteem because of changes in appearance and loss of fertility, which affected their sexuality and romantic relationships. Some of the female AYAs described themselves as "not a good romantic investment," "a damage good," or "feeling an incomplete woman."

The uncertainty that cancer can cause was identified by AYAs wit cancer and did not always end with treatment. AYAs with cancer are uncertain about their future such as their health status, how long they wil live after treatment, their careers, relationships, and family planning. There were no significant differences between age and gender groups in how frequently uncertainty were discussed. However, females were more uncertain about their fertility and romantic relationships.

The theme of *PTSD* emerged in AYAs with cancer. YAs described more PTSD than did EAs with cancer ($p = .056$). Aspects of the cancer experience that might cause PTSD included 1) the diagnosis, 2) physical issues including cancer-related pain, 3) cancer treatment and tests, 4) waiting for test results, 5) long hospital stays, and 6) cancer recurrence or fear of recurrence. Although the difference was not statistically

Table 3
Prevalence of emotional/psychological, physical, and social needs by age and gender.

		Age			Gender		
	All Bloggers ($N = 100$)	Emerging Adult ($n = 41$)	Young Adult ($n = 59$)	p	Male ($n = 50$)	Female ($n = 50$)	p
	n (%)	n (%)	n (%)		n (%)	n (%)	
Emotional/Psychological							
Negative emotions	79 (79.0%)	29 (70.7%)	50 (84.7%)	0.133	38 (76.0%)	41 (82.0%)	0.624
Fear	44 (44.0%)	13 (31.7%)	31 (52.5%)	0.043*	24 (48.0%)	20 (40.0%)	0.546
Feelings of anxiety	33 (33.0%)	10 (24.4%)	23 (39.0%)	0.138	17 (34.0%)	16 (32.0%)	0.832
Guilt	25 (25.0%)	9 (22.0%)	16 (27.1%)	0.642	7 (14.0%)	18 (36.0%)	0.020*
Feelings of depression	24 (24.0%)	6 (14.6%)	18 (30.5%)	0.095+	9 (18.0%)	15 (30.0%)	0.241
Anger	22 (22.0%)	7 (17.1%)	15 (25.4%)	0.462	9 (18.0%)	13 (26.0%)	0.470
Grief	14 (14.0%)	5 (12.2%)	9 (15.3%)	0.774	5 (10.0%)	9 (18.0%)	0.388
Illness identity	42 (42.0%)	15 (36.6%)	27 (45.8%)	0.414	20 (40.0%)	22 (44.0%)	0.840
Self-identity	20 (20.0%)	8 (19.5%)	12 (20.3%)	0.919	10 (20.0%)	10 (20.0%)	1.000
Self-Consciousness	17 (17.0%)	7 (17.1%)	10 (16.9%)	0.987	7 (14.0%)	10 (20.0%)	0.595
Self-Esteem	15 (15.0%)	5 (12.2%)	10 (16.9%)	0.580	7 (14.0%)	8 (16.0%)	0.779
Uncertainty about the future	39 (39.0%)	16 (39.0%)	23 (39.0%)	0.997	16 (32.0%)	23 (46.0%)	0.218
PTSD	16 (16.0%)	3 (7.3%)	13 (22.0%)	0.056+	11 (22.0%)	5 (10.0%)	0.171
Cognitive concerns	7 (7.0%)	2 (4.9%)	5 (8.5%)	N/A	3 (6.0%)	4 (8.0%)	N/A
Suicidal ideation	6 (6.0%)	2 (4.9%)	4 (6.8%)	N/A	4 (8.0%)	2 (4.0%)	N/A
Physical							
Pain	25 (25.0%)	8 (19.5%)	17 (28.8%)	0.352	16 (32.0%)	9 (18.0%)	0.165
Hair loss	20 (20.0%)	6 (14.6%)	14 (23.7%)	0.316	9 (18.0%)	11 (22.0%)	0.803
Fatigue	17 (17.0%)	6 (14.6%)	11 (18.6%)	0.788	9 (18.0%)	8 (16.0%)	0.790
Sleeping problems	14 (14.0%)	6 (14.6%)	8 (13.6%)	0.879	9 (18.0%)	5 (10.0%)	0.388
Weight changes	13 (13.0%)	5 (12.2%)	8 (13.6%)	0.842	6 (13.0%)	7 (14.0%)	0.998
Nausea/vomiting	9 (9.0%)	4 (9.8%)	5 (8.5%)	N/A	3 (6.0%)	6 (12.0%)	N/A
Social							
Lack of awareness in society	17 (17.0%)	6 (14.6%)	11 (18.6%)	0.788	8 (16.0%)	9 (18.0%)	0.790
Friends and peer	15 (15.0%)	8 (19.5%)	7 (11.9%)	0.394	5 (10.0%)	10 (20.0%)	0.262
Romantic relationship	13 (13.0%)	4 (9.8%)	9 (15.3%)	0.551	5 (10.0%)	8 (16.0%)	0.554
Family communication	9 (9.0%)	4 (9.8%)	5 (8.5%)	N/A	3 (6.0%)	6 (12.0%)	N/A

Note: Statistical comparisons not computed when n for the category was 10 or fewer persons.
*** $P < .001$, ** $p < .01$, * $p < .05$, + $p < .10$.

significant, male AYAs with cancer wrote more frequently about PTSD than females did.

The theme of *cognitive concerns* (commonly, referred to as chemo brain) was noted in AYAs with cancer. Examples of chemo brain symptoms included forgetting things that they usually had no problem remembering, trouble concentrating, difficulties with remembering details, troubles with multitasking, taking longer to complete things, difficulties in learning new things, or difficulties in remembering common words (unable to find the right words to complete a sentence). Because of the small number of posts about the theme of cognitive concerns, no statistical tests are reported.

Six AYAs with cancer experienced *suicidal ideation* perhaps because cancer diagnosis and treatments were stressful and overwhelming. They experienced suicidal ideation even after cancer treatment, because although they had been declared "cancer-free," life after cancer might not be quite what they expected. The suicidal ideation might overlap with other effects of cancer and cancer treatments such as feelings of depression and anxiety, fatigue, pain, and sleep disturbance. Because of the small number of posts about the theme of suicidal ideation, no statistical tests are reported.

Physical needs

Physical needs are needs for physical comfort, optimum nutrition, freedom from pain, and functional ability to perform one's daily activities. Six themes were identified in this domain: pain, hair loss, fatigue, sleeping problems, weight changes, and nausea/vomiting (Table 3). No statistically significant differences between age and gender groups were found for physical needs. However, YAs were more likely to discuss pain and hair loss than were EAs and male AYAs were more likely to discuss pain than were female AYAs. Twenty-five AYAs with cancer reported various *pains*, including headache, chest pain, bone pain, joint pain, and pain related to neuropathy. AYAs with cancer expressed that they experienced *hair loss*. Among females, losing hair especially tended to have a more negative impact on psychological issues such as self-esteem and body image. The theme of *fatigue* was noted in AYAs with cancer. Contributing factors to cancer-related fatigue reported by participants were cancer itself, cancer treatment, anemia, pain, emotions, insomnia, lack of exercise, and hormone changes. Thirteen AYAs with cancer reported that they experienced *weight changes* (weight loss or gain). The weight changes can affect body image or self-esteem.

Social needs

Social needs are those related to participation in social support and social roles. Four themes emerged under social needs domain: lack of awareness in society, peer support and relationships, dating and romantic relationships, and family relationships (Table 3). There was no significant difference between age groups in how frequently themes under social needs were discussed. One of the most prevalent social needs among the AYAs concerned the *lack of awareness in society* about men's health, mental health, and long-term effects of cancer. AYAs with cancer described the need for *friends and peer support*. Although there were no significant differences between the two age groups, the nature of the blogs about friends and peer support needs did differ. The EAs with cancer were more likely to write that they were losing friendships because they could not spend time with their existing friends as much as they used to, owing to absence from school or activities during and after cancer treatment. They compared their lives with those of their friends, and they felt that sometimes their friends treated them differently after their cancer diagnosis, which negatively influenced maintaining connection and communication with friends throughout treatment. The YAs with cancer were more likely to state that they needed peers living with cancer for mutual support. However, they said that it was rare to see people of a similar age with cancer in hospitals. In addition, despite the fact that feeling connected was important to AYAs with cancer, some were reluctant to tell other people that they had cancer, or they did not know how to share emotions and feelings with their friends and coworkers because they felt scared and insecure; they feared that people would judge them, or they did not want to be a burden on others. Not telling other people about their cancer made these AYAs with cancer feel isolated and lonely. They described a need for more support from peers with cancer because they felt more comfortable and connected when they talked with peers who had similar medical conditions about their cancer experience. The AYAs with cancer said that cancer made a difference in relationships, which included *dating and romantic relationships*. The EAs with cancer tended to worry or be uncertain about dating and romantic relationships or about starting their own family in the future. The YAs with cancer were more likely to discuss how to maintain their current romantic relationships, breaking up with their loved ones, or how and when to disclose a cancer experience such as infertility to their loved ones in the future. The AYAs with cancer stated that they had needs related to *communication with family*. Some AYAs with cancer tried to deal with or discuss their cancer with their families, but some discovered quite different coping strategies. AYAs who described issues in family communication reported that family members tried to discuss issues with them, but the AYAs did not wish to do this and instead tried to avoid the conversation, or vice versa. Also, some AYAs with cancer desired to protect their family members from things they worried about, because they felt guilt about what their family members were undergoing or just because they saw how emotional and upset family members were. Those who had these issues tended to hide their emotions and felt guilty, isolated, and lonely. The YAs with cancer felt guilty especially toward their children and did not know how to explain their cancer to their young children or how to express their feelings.

Significant differences in posts about social needs between males and females were not found. Most males who blogged about *lack of awareness in society* described a lack of awareness about testicular cancer or about men's health in comparison with breast cancer or women's health. Regarding *needs for friends or peers*, male AYAs hoped to spend time with their friends because they could not do so as much as they used to, owing to their physical and emotional health; but female AYAs said that their friends were disappearing, which resulted in their feeling betrayal, anger, and loneliness. Female AYAs were more likely to have issues in *dating new partners or in maintaining romantic relationships* due to altered body image, self-esteem, and infertility, and they did not know when or how to disclose their cancer history to new people.

Practical needs

Practical needs refer to any needs relating to seeking direct aid in order to accomplish an activity or task and thereby decrease the demands on a person. Five themes related to practical needs domain were identified among the participants' texts: education, parenting, career development and employment, financial issues, and help with daily tasks (Table 4). One of the practical needs among AYAs with cancer involved *education*. Between the two age groups, EAs with cancer discussed educational challenges significantly more than did YAs with cancer ($p = .001$). The EAs with cancer who reported educational challenges were either high school students or college students ($n = 12$). YAs with school issues were in graduate programs ($n = 3$). The educational issues were related to attendance and missed exams during cancer treatment, as well as difficulties in keeping up with schoolwork during and after treatment. Some AYAs with cancer reported *parenting* needs. Compared with EAs, YAs discussed childcare significantly more ($p < .001$). Being a parent while living with cancer was often physically and emotionally exhausting. Parenting was especially more challenging for a single parent. Although there was no statistical difference in the theme of *career development and employment issues*, the EAs with cancer tended to worry about possibly altered employment opportunities in the future, because cancer and treatment interrupted their education and the YAs with cancer were more likely to report their current employment and career issues such as searching for new jobs,

Table 4
Prevalence of practical, sexual, informational, and spiritual needs by age and gender.

	All Bloggers ($N = 100$)	Age			Gender		
		Emerging Adult ($n = 41$)	Young Adult ($n = 59$)	p	Male ($n = 50$)	Female ($n = 50$)	p
	n (%)	n (%)	n (%)		n (%)	n (%)	
Practical							
Education	15 (16.0%)	12 (29.3%)	3 (5.1%)	0.001**	10 (20.0%)	5 (10.0%)	0.262
Parenting	13 (13.0%)	0	13 (22.0%)	<0.001***	3 (6.0%)	10 (20.0%)	0.071^{+}
Career and employment	10 (10.0%)	4 (9.8%)	6 (10.2%)	N/A	4 (8.0%)	6 (12.0%)	N/A
Financial	9 (9.0%)	3 (7.3%)	6 (10.2%)	N/A	3 (6.0%)	6 (12.0%)	N/A
Help with daily tasks	5 (5.0%)	2 (4.9%)	3 (5.1%)	N/A	1 (2.0%)	4 (8.0%)	N/A
Sexual							
Body image change	23 (23.0%)	8 (19.5%)	15 (25.4%)	0.630	8 (16.0%)	15 (30.0%)	0.153
Fertility issue	15 (15.0%)	4 (9.8%)	11 (18.6%)	0.266	3 (6.0%)	12 (24.0%)	0.023*
Premature menopause	7 (7.0%)	2 (4.9%)	5 (8.5%)	N/A	0	7 (14.0%)	N/A
Sexual function	5 (5.0%)	0	5 (8.5%)	N/A	1 (2.0%)	4 (8.0%)	N/A
Informational							
Symptom management	10 (10.0%)	4 (9.8%)	6 (10.2%)	N/A	3 (6.0%)	7 (14.0%)	N/A
Communication with healthcare professionals	8 (8.0%)	1 (2.4%)	7 (11.9%)	N/A	3 (6.0%)	5 (10.0%)	N/A
Long-term survivorship	8 (8.0%)	1 (2.4%)	7 (11.9%)	N/A	3 (6.0%)	5 (10.0%)	N/A
Spiritual							
Existential despair	4 (4.0%)	3 (7.3%)	1 (1.7%)	N/A	3 (6.0%)	1 (2.0%)	N/A
Spiritual crisis	3 (3.0%)	0	3 (5.1%)	N/A	3 (6.0%)	0	N/A

Note: Statistical comparisons not computed when n for the category was 10 or fewer persons.
$^{***}P < .001$, $^{**}p < .01$, $^{*}p < .05$, $^{+}p < .10$.

decreased capacity to work, changes in responsibilities, or job loss. AYAs with cancer discussed various *financial issues*. Regardless of statistical significance, while the EAs tended to struggle with worries about the financial burden on their parents, the YAs were likely to have direct financial challenges, including providing for family members, housing, insurance, and other bills, which could cause increased financial need during and after cancer treatment. A few AYAs with cancer stated that they needed *help with daily tasks* such as daily home help, assistance in daily living activities, and transportation to hospitals. Whereas the EAs with cancer were likely to have needs in activities of daily living such as getting out of bed or getting dressed, the YAs with cancer tended to need help in the home such as cooking, cleaning, or washing laundry.

There was no significant difference in posts about practical needs between males and females. Nevertheless, female AYAs with cancer were more likely to report parenting issues and help with daily tasks and less likely to report educational needs. Female AYAs with cancer who reported practical needs described the demands of parenting children and doing chores at home while taking care of themselves.

Sexual needs

Sexual and fertility needs included themes such as body image change, fertility, premature menopause, and sexual function (Table 4). AYAs with cancer struggled with *body image changes*, which resulted from scars, decreased physical function, weight changes, mastectomy, orchiectomy, or hair loss. The EAs with body image changes were worried about how other people thought about them because of their altered appearance. YAs reported that body image change had a negative impact on sexual functioning in addition to their self-consciousness. AYAs with cancer described a sense of loss because they had already *lost their fertility* or were worried about the chance that they might lose their fertility, regardless of diagnosis, treatment, or prognosis. The YAs were more likely to blog about fertility issues than were the EAs with cancer. One AYA described that even if she was still fertile, she feared that her future child would get cancer because of her own cancer experience. Another AYA with cancer regretted that she missed the opportunity for fertility preservation because she was so young. When she was diagnosed with cancer, fertility was not an immediate concern. So she missed that opportunity because of the timing of treatment. The fertility issue was a problem not only for AYAs without children but also for AYAs who currently had children but wanted to have more in the future. Five of the YAs with cancer described sexual function issues such as erectile dysfunction, vagina dryness, and losing desire and libido: None of the EAs with cance described such concerns.

Overall, female AYAs were more likely to express sexual needs tha were males ($p = .003$) (Table 2). Regardless of statistical significance female AYAs described *altered body image* in their blogs more tha male AYAs did. Male AYAs reported *body image change* itself, but femal AYAs reported sexual and social issues resulting from body imag change. Females described significantly more *fertility issues* than di males ($p = .023$) (Table 4). Decision-making about fertility whil going through necessary surgery or other cancer treatments was considered to be one of the most difficult decisions of their lives. One femal wrote that she regretted that she did not preserve her fertility, an sometimes she felt anger toward her oncologist for not providing information about fertility preservation at the time of diagnosis. Another female stated that she had never previously thought about havin children; then she had to confront the risk of becoming infertile Seven female AYAs said that they went through *premature menopaus* because of the loss of ovarian function or ovarian failure during o after cancer treatment. The premature menopause caused multipl symptoms such as sleep disturbances, sexual function changes, moo swings, and hot flashes, which could cause anxiety about relationship and low self-esteem. Four women expressed sexual function needs.

Informational needs

Informational needs are for information to inform a person's o family's decision-making; to reduce anxiety, confusion, and fear; an to help with obtaining skill. This domain contained three themes needs for symptom management, for communication with healthcare professionals, and for long-term survivorship information (Table 4). Because of the small number of posts about the themes of informational needs, no statistical tests are reported. With respect to the theme o *symptom management*, while male AYAs were more likely to express informational needs about physical symptoms, female AYAs were more likely to express needs about acquiring information about how to dea with mental health and sexual function. AYAs with cancer experienced unmet needs regarding *communication with healthcare professionals* Some of the bloggers regretted that they could not ask questions about medications, prognosis, or lifestyle, because at the moment of diagnosis or treatment, everything was so overwhelming that such thoughts simply stopped. One blogger thought that oncologists did not understand her problem and that oncologists were sometimes unwilling to talk about the issues of side effects of treatment such as losing limbs. AYAs with cancer wrote of a lack of information about *long-term survivorship*. YAs with cancer were more likely to have questions about their life after cancer or new normal after cancer. However, although they could easily access medical information such as survival rates or treatment plans, they had difficulties finding adequate resources and information related to longer term survivorship.

Spiritual needs

Spiritual needs refer to the meaning and purpose of life or the practice of religious beliefs. Few blogs fell into this category, although themes such as existential despair and spiritual crisis were present (Table 4). Because of the small number of posts regarding spiritual needs, no significance testing was conducted for these themes. Three males and one female expressed existential despair, and three males discussed spiritual crisis.

Post-hoc analysis

Since the majority of bloggers lived in the U.S. and Australia, AYA posts about their unmet needs were compared. There were no significant differences in unmet needs between blogger posts from the two countries. Post-hoc analysis for unmet needs differences by cancer types was not conducted because types of cancer were too heterogeneous to compare.

Discussion

To the best of our knowledge, this is the first study to compare unmet needs of AYAs with cancer by age and gender using textual data from social media. A significant number of AYAs with cancer reported unmet needs across the seven domains identified in this study (6.0–94.0%). Although few age and gender differences in numbers of themes that emerged were statistically significant, differences in how these issues were discussed were nonetheless present.

Emotional/psychological needs

Disruption in the lives of AYAs by cancer results in a variety of emotional/psychological needs, and the level of emotional/psychological needs among AYAs with cancer is higher than in cancer-free AYAs and in older adults with cancer (Phillips-Salimi & Andrykowski, 2013). In line with the present study, a prior study reported that 90% of AYAs experienced at least one emotional concern, and 64% expressed three or more (Jones et al., 2020). AYAs with cancer expressed various negative emotions, but in the present study, each negative emotion appeared with other emotions rather than standing alone. These negative emotions also stemmed from other unmet needs—physical, informational, sexual, and social.

Consistent with results of a systematic review (Yang et al., 2019), about half of the AYAs with cancer in the present study reported feelings of fear including fear of recurrence, fear of dying, or fear of losing fertility. Although most of the demographic factors in the prior study, including age, were not significantly associated with fear of recurrence, the YAs with cancer in the present study tended to report more feelings of fear compared with EAs. The reason for this difference between the two studies may be that in the current study, the subtheme of fear included not only fear of recurrence but also fear of dying and fear of infertility. Yet despite the high prevalence of fear among AYAs with cancer, specific interventions to reduce feelings of fear in this age group are lacking.

In this study, about 24% of the AYAs with cancer expressed feelings of depression, and the YAs tended to report depressive feelings more often than did the EAs. Perhaps YAs have higher cognitive capacity to understand the severity and consequences of their cancer (Zebrack & Isaacson, 2012). Despite non-statistical differences by gender in frequency of posts, our study found differences in depressive feelings by gender appeared in content. Female AYAs posted about long-term depressive symptoms or symptoms after completion of treatment, suggesting higher needs for information about psychological aspects of symptom management and survivorship care. In a previous study, female cancer patients showed two to three times higher rates of depressive symptoms than did male cancer patients (Linden et al., 2012).

In the present study, one quarter of AYAs with cancer described guilt. The analyzed blogs showed that cancer often forced AYAs to move back to their family's home and become dependent on parents and/or family members and partners, usually after periods of living independently. This unexpected forced dependence is often a source of emotional distress such as guilt (Zebrack & Isaacson, 2012). In the present study, AYAs with cancer also reported that they felt guilty when other peers were lost to cancer (i.e., survivor guilt). Survivor guilt in the cancer population is common, and surprisingly few studies have directly investigated it, but it may be connected to a sense of helplessness and powerlessness (Glaser et al., 2019). In the present study, while survivor's guilt or the feeling of being a burden on others was similar between the two gender groups, females more frequently discussed guilt because of not being able to take care of family members, especially children, and about not being able to do home chores as much as before.

Uncertainty was related to living with cancer, to the impact of the cancer treatment, and to receiving insufficient knowledge about cancer and its treatment. In line with our study, previous studies have reported that AYAs with cancer experience uncertainty related to medical, personal, and social sources (Donovan et al., 2015), including access to health and life insurance, career and job options, hereditary or genetic risks of cancer passed on to children, and availability of appropriate survivorship care through an attentive and skilled medical staff and system (Parsons & Kumar, 2019).

PTSD, the direct result of trauma resulting from a life-threatening illness or medical disorder, has very specific medical criteria. However, people tend to use the term "PTSD" more broadly than that. We cannot know whether the bloggers who commented on PTSD had been diagnosed with PTSD by a psychiatrist. For these bloggers, PTSD might cover a cluster of simultaneous symptoms, emphasizing how impactful their cancer experiences were. Perhaps the bloggers were referring to posttraumatic stress symptoms (PTSS) rather than actual PTSD. Compared with older and childhood cancer populations, few studies have examined PTSS in AYAs. A prior study found that 39% and 44% of AYAs aged 14–39 years at diagnosis reported moderate to severe levels of PTSS at 6 and 12 months postdiagnosis respectively, but with no significant differences by age and gender (Kwak et al., 2013). Regardless, in the present study, PTSD was described more frequently among the YAs with cancer, perhaps simply because PTSD is a big word for EAs. Also, the higher usage of PTSD among males (22.0%) than among females (10.0%) might be due to a preference among males to describe various negative emotions together by calling them PTSD rather than expressing individual emotions specifically (Polce-Lynch et al., 1998). Perhaps males tend to be more comfortable with the term PTSD because it is used to describe emotional problems that male veterans experience.

In the U.S., suicide is the 10th leading cause of death in adults and the second most common cause of death in adolescents (CDC, 2020). Notable risk factors include the presence of a medical illness (Steele et al., 2018). Although persons with cancer are more likely to commit suicide than the general population (Vivek Kumar et al., 2017), literatures have focused mostly on older cancer survivors (Anguiano et al., 2012). In a study on suicide and suicide attempts in AYAs with cancer aged 15–30, the relative risk of suicidal behavior was found to be 1.6 after cancer diagnosis, in comparison with age-matched non-cancer controls (Lu et al., 2013). The relative risk (2.5) was greatest immediately after cancer diagnosis, and during the first year after diagnosis it was 1.5 (Lu et al., 2013). The rate of suicidal ideation in the present study is lower than what has been reported in previous studies. These AYAs with cancer may have been reluctant to express suicide ideation, because suicide is one of the few remaining taboo topics among the general public (Former, 2015). Also, many of the bloggers were beyond active treatment, when suicide ideation may decrease. Suicide ideation and suicide attempts may be the most severe consequence of emotional or physical distress among AYAs with cancer. Safe environments to express suicide ideation with mental health surveillance for AYAs with cancer are needed.

Physical needs

Although there were no statistically significant age and gender differences in the themes under the physical needs domain, male YAs with cancer reported somewhat more pain than did female EAs with cancer. This may be due to differences in prevalence of cancer types between age and gender. Hair loss and weight changes could extend beyond physical needs to sexual and social function, and self- esteem among female AYAs. As one female blogger described it, hair was not just hair, it was her identity. In general, for cancer patients, fatigue is one of the most prevalent concerns (Fitch et al., 2019). Previous studies reported that 48% of AYAs with cancer reported severe fatigue (Poort et al., 2017). Although not seen in the current study, female gender and greater age have been identified as a predictor for higher fatigue (Geue et al., 2014). Also, a previous study reported that 49% of people with acute lymphoblastic leukemia aged between 18 and 41 reported sleep disturbances (Rytting et al., 2017). Bloggers in the current study discussed these symptoms less frequently than had been reported in previous literature.

Social needs

Society's lack of awareness about men's health, including testicular cancer was expressed by some bloggers. Even though testicular cancer is the most prevalent cancer in AYA males, and testicular cancer is about as common in young men as breast cancer is in young women, few people talk about it. Males are uncomfortable discussing testicular cancer and its prevention (Ugboma, 2020). Yet such discussion must be shared.

Some AYAs with cancer in the present study expressed unmet needs for friends and peers. Younger adults with cancer have reported higher levels of social isolation from their peer and social groups than older adults with cancer do, because they perceive themselves to be "different" from others (Campbell-Enns & Woodgate, 2015; D'Agostino & Edelstein, 2013). For friends who do not have cancer, a cancer diagnosis can be a source of emotional discomfort and distress, and so they may respond to their sick friends by avoiding them (Zebrack & Isaacson, 2012). Alienation and isolation are thus frequently reported among AYAs with cancer, as AYAs miss out on sharing life experiences with non-cancer peers (Husson et al., 2018). As a result, these young people often make new friends, perhaps as a function of their own increased maturity and need to let go of existing friends (Zebrack & Isaacson, 2012). In previous studies, AYAs with cancer have identified other cancer peers as important sources of support, because cancer peers can understand and acknowledge them in ways that people who have not experienced cancer cannot (Kent et al., 2013).

Intimate sexual and emotional relationships, a greatly meaningful part of human life, are initiated during adolescence and young adulthood (Zebrack & Isaacson, 2012). As they form relationships, individuals inevitably reveal and disclose themselves. These disclosures are complicated by the effects of cancer, and the issues of disclosing one's cancer history with others is particularly significant for AYAs (Barnett et al., 2014). Disclosing a cancer history can mean risking rejection and alienation, further complicating negative perceptions of one's sexuality and body (Barnett et al., 2014). Cancer-related infertility also challenges intimate relationships, due to the inability to have biological children (Cherven et al., 2021). Thus the process of dating and disclosure of a cancer history is a new, unpredictable topic for AYAs with cancer. As a result, AYAs may experience low self-esteem and ultimately feel alone.

Practical needs

Education and work are important factors in forming a sense of identity and in achieving independence (Parsons et al., 2012). Althoug most AYAs with cancer are able to return to school or work after trea ment, they often report a need to adapt and to reduce job tasks an work hours because of treatment's side effects (Ketterl et al., 2019 Parsons et al., 2012). Given that much of one's salary growth occurs i the first decade of one's career, breaks or delays in school and caree may influence long-term career paths, lifetime earnings, and, ultimately, financial status (Zebrack & Isaacson, 2012). A prior study, for example, found that AYAs with cancer who had received chemotherapy experienced problems with cognitive function two to four times mor at work than did those who did not undergo chemotherapy, translating into an annual productivity loss of USD $2250 per AYA survivor (Guy et al., 2014). Return to school and work programs as well as online resources such as Cancer and Careers that address work after a cancer diagnosis can be beneficial to help with reentry and with negotiating appropriate accommodations, which can facilitate successful reintegration (Kosola et al., 2018). Programs for AYAs with cancer that suppor their achievement at school or work and that encourage their relationships with their classmates and coworkers can also be beneficial.

Few AYAs with cancer in this study described financial issues, whic is puzzling because previous studies have found that financial concerns are a problem for many AYA survivors. Not surprisingly, EAs in the present study tended to discuss their parents' cancer-related financial difficulties, whereas YAs tended to discuss their own financial concerns. A systematic review of the financial burden found that a significant number of AYAs with cancer reported material (reduction in income and medical debt), psychosocial (distress about medical costs), and behavioral (forgoing medical care) financial issues (Salsman et al., 2021). Financial challenges associated with cancer management are more adverse for AYAs than for older adult patients, because older adults are more likely to have financial resources (Kent et al., 2013) and insurance prior to diagnosis (Kent et al., 2012) and less likely to have childcare costs.

All of the bloggers who identified parenting issues were YAs, and females were more likely to blog about parenting needs. This is a very difficult time for parents, who must then face coping with a cancer diagnosis and its treatment while also continuing to take care of their children (Matuszczak-Świgoń & Bakiera, 2021). In line with the findings of the present study, a prior study found that people with cancer who had young children had issues about being a good parent, explaining their cancer to their children, and maintaining routine at home (Matuszczak-Świgoń & Bakiera, 2021). In the present study, especially single parents reported more responsibilities and work in providing childcare and doing chores while taking care of themselves.

Sexual needs

Sexual needs identified by the AYAs in this study were described more often by the female YAs with cancer. Discussions of unmet sexual needs in these previous studies are higher than those in the present study, perhaps because of differences in time since active treatment and the percentage of females. Negative influences of treatment on physical appearance such as scarring, hair loss, and weight change can cause body dissatisfaction and feelings of shame (Brierley et al., 2019) and affect sexual health and identity (Geue et al., 2015). This comes at a time when AYAs with cancer may be more aware of their body and when they are forming their adult identities and new intimate relationships (Geue et al., 2015; Graugaard et al., 2018), which can affect dating, romantic relationships, and the formation of self-identity. A previous study found that embarrassment about topics related to body image change and sexuality is a common barrier that may prevent AYAs from openly discussing their needs and concerns (Martins et al., 2018). A practical guide for addressing sexuality could be given soon after diagnosis in order to normalize discussions throughout treatment and survivorship. A member of the treatment team with sexual health expertise could assess patient needs and provide tailored services ([illegible] et al., 2018).

Some of the bloggers described fear of losing their ability to have biological children. This could cause grief and existential suffering, change future plans, lower self-esteem, and negatively impact dating and romantic relationships. Fertility and premature menopause issues were identified significantly more often among the female AYAs. A previous study found that 50% of AYAs with cancer who had completed active treatment 1–3 years previously reported menopause or fertility concerns (Jones et al., 2020). Some females have felt that their future made no sense if they could not conceive biological children, resulting in depression and anxiety (Agustus et al., 2017). In light of its impact on their persona and future life, AYAs have described the prospect of possible infertility as worse than the cancer diagnosis itself (Alander et al., 2021). Findings from this and other studies suggest AYAs need detailed information about fertility preservation.

Informational needs

In line with the present study's findings for sexual and emotional/psychological needs, the female AYAs' informational needs mainly involved cancer-related symptom management for emotional distress and altered sexual function, communication about sexual function with healthcare professionals, and survivorship care. A systematic review of needs among AYAs with cancer found that AYAs described a need for honest, timely, age-appropriate information in various areas, especially fertility, treatment, and survivorship; higher informational needs were associated with greater emotional distress and lower satisfaction with cancer care (Bibby et al., 2017). Especially consistent with the present study, information about fertility was a key concern, with AYAs needing detailed information about fertility preservation options.

Spiritual needs

Although discussed infrequently in this study, another study found that AYAs who received a diagnosis of cancer and thus faced the possibility of untimely death often increased a focus on spirituality that continued throughout their disease trajectory (Taylor et al., 2015). Studies of older adults with cancer have suggested significant relationships between spiritual well-being and various indicators of psychological well-being (Bai & Lazenby, 2015; Chaar et al., 2018). Future research could also address spiritual distress among AYAs with cancer and increase our understanding of the role of spirituality.

Implications for practice and research

The findings of this study provide insights into AYAs' cancer experiences and suggest implications for nurses. AYAs with cancer receive care in both adult and pediatric oncology setting. However, nurses in both settings often lack knowledge and experience in working with this age group and may not be accustomed to the specific developmental issues of AYAs with cancer and how to best assist them with those issues ([illegible] et al., 2015). Regardless of clinical experience, having additional education and information in order to provide suggestions to AYAs with cancer is beneficial to nurses. The findings of this study suggest key points regarding psychosocial screening with AYAs with cancer. Nurse can provide integrated systematic screening across the entire cancer journey to proactively identify needs and respond with developmentally appropriate support, resources, and referrals. A prior study found that more than half of AYAs did not seek help for their needs (Jones et al., 2020). The most common reasons why AYAs did not report their issues were that they did not think anything could be done about them, that someone had told them it was something normal to experience, that they did not want to ask anyone due to embarrassment, that they think that some issues such as financial, school, childcare, and work issues are not relevant to medical concerns, that they did not know that services were available, or where to go to access services. Given that AYAs may not initiate discussions about their needs, nurses should provide a safe, non-judgmental environment in which to encourage them to express their needs and should offer care-related information before AYAs ask.

Despite the effort to include the blog posts written by AYAs aged 15 to 17 years, there were only few blog posts written by this age AYAs with cancer. One possible reason is that teenagers might use different social media platforms. According to the Pew Research Center (2019), the dominant social media platforms among teenagers are Snapchat, Instagram, YouTube, and TikTok. These platforms are more likely to utilize video and images rather than written blog posts. Thus, when including online data generated by AYAs aged 15–17 years, future research should consider the social media platforms AYAs predominantly use. Future studies also can investigate if support from different sources might correlate with different types of needs and explore possible interactions between age and gender among AYAs with cancer in needs and support. Given that offline support groups and comprehensive oncology centers tend to be located in big cities, social media and mobile application-based psychosocial interventions may be beneficial for AYAs with cancer, even those living in rural areas, because AYAs with cancer can access psychosocial support through the Internet without physical restrictions. In addition, in research design and the enrollment of AYA participants, racial and ethnic diversity should be considered. According to one previous study, racial disparities exist within AYA enrollment for cancer clinical trials, and Black AYAs aged 20–29 and Black male AYAs are least likely to enroll (Siembida et al., 2020). Moreover, future research is needed to explore the most effective ways to communicate with AYAs about effective sources of support and resources that are available to them.

Limitations

There are several limitations to the present study. First, this study does not reflect other possible perspectives, such as those of families, friends, or healthcare professionals, about the experiences of AYAs with cancer. Participant information such as race/ethnicity, marital status, or other sociodemographic and cancer-related clinical variables could not be obtained because user profiles in this online cancer community provide limited information, even though the unmet needs of AYAs with cancer may differ by these variables. It is difficult to verify the authenticity of participants' written information online. Because the blog writers in this study were limited to an English-speakers with Internet access and the capability and willingness to use the website, they are not representative of all AYAs with cancer. The online cancer community website was chosen for this study because it provided at least some background information to address the research questions such as age and gender. However, it may present a skewed data set because the data were collected from only one online cancer community. Although the website provides four options: female, male, non-binary, or prefer not to specify, participants' gender responses were dichotomous, female or male. Therefore, the findings by gender may not be applicable to AYAs with cancer who have other gender identities. Lastly, the bloggers in the present study might have expressed more needs if it had been possible to ask follow-up questions about their blog posts on this website.

Conclusions

The innovative methodology of this study may provide new insights into the expressed needs among AYAs with cancer. A prior study compared how AYAs with cancer express their needs in online and face-to-face support groups by counting their word frequencies and analyzing the style of their language (Thompson et al., 2016). Their findings suggest that AYAs in online support groups describe more negative feelings, engage in more information seeking for decision-making, and more frequently discuss sensitive topics such as friendships and sex than do AYAs in face-to-face support groups. Consistent with the prior study's findings, the present study may reveal more candid thoughts about unmet needs among AYAs with cancer online in comparison with the findings of face-to-face interviews or surveys. The data collection methodology used in this study differs from previous studies in another way. A survey on which respondents select items from a list of possible needs may elicit responses different from blog posts where individuals generate what is on their minds without prompts from predetermined categories. Perhaps those who blog about their cancer experiences perceive cancer differently than those who participate in formal research studies on this topic. Even though the data collection methodology this study used is different from prior studies, many of the need that surfaced in our study had been reported previously. Thus what this study add is validation of those themes using a different methodology.

We believe that the strength of this study and the uniqueness of our analyses provide insights into AYAs' cancer experience and implications for both nurses and future research. AYAs with cancer have various unmet needs and their unmet needs were different by age and gender. When developing and implementing tailored psychosocial programs for AYAs with cancer, nurses and other healthcare providers should assess their specific developmental needs holistically throughout their cancer journey and should provide sources of support routinely rather than in responses to crisis.

Author statement

EC were responsible for all aspects of the study's conceptualization, design, execution, data analysis, and data reporting. HB contributed to the study conception and design, participated in data analysis and interpretation, and revisions of all previous versions of the manuscript. SK participated in data analysis and interpretation. EC, HB, and SK read and approved the final manuscript.

Declaration of Competing Interest

None.

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