

# Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review

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## Abstract

**Purpose** A cancer diagnosis during adolescence or young adulthood (AYA; defined as ages 15–39) generates unique medical and psychosocial needs as developmental milestones are simultaneously impacted. Past research highlights that AYAs' experiences and psychosocial outcomes are different, and more research and attention is needed. We aimed to identify and synthesize literature regarding psychosocial outcomes, unique needs, and existing psychosocial interventions pertaining to individuals diagnosed with cancer exclusively during AYA, and to highlight areas for future research.

**Methods** A systematic literature search was conducted using MEDLINE (via PubMed), EMBASE, Cochrane, Web of Science, and PsycINFO (via OVID). Grey literature was

searched using key term variations and combinations. Overall, 15,301 records were assessed by two independent reviewers, with 38 studies meeting inclusion criteria.

**Results** Data synthesis of the 38 articles was organized by four main themes based on quality of life and survivorship: physical well-being (7 studies), psychological well-being (8 studies), social well-being (9 studies), and survivorship care (14 studies). The paucity of studies for such broad inclusion criteria highlights that this population is often combined or subsumed under other age groups, missing needs unique to these AYAs.

**Conclusions** AYA cancer survivors' experiences are nuanced, with interacting variables contributing to post-treatment outcomes. AYAs require age-appropriate and flexible care, informational needs and treatment-related education that foster

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autonomy for long-term survivorship, as well as improved follow-up care and psychological outcomes.

*Implications for Cancer Survivors* By incorporating these findings into practice, the informational and unmet needs of AYAs can be addressed effectively. Education and programming is lacking specific and general subject matter specific to AYAs, incorporating ranging needs at different treatment stages.

**Keywords** Adolescent · Cancer survivorship · Literature review · Neoplasms · Young adult

## Introduction

A diagnosis of cancer during adolescence and young adulthood (i.e., “AYAs”) can generate medical and psychosocial needs and consequences unique to this age group [1, 2]. While the majority of past research has focused on survivors of childhood cancers, more people between the ages of 15–39 years of age are diagnosed with cancer than those in the first 15 years of life, and these rates are increasing [3].

Survivors of cancer diagnosed in adolescence or young adulthood will likely engender different experiences than those diagnosed as children or older adults. For example, a key feature within the adolescent population (i.e., individuals ages 15–18) is the intersection of the cancer experience with a period of rapid biological and psychosocial development. Specific developmental constructs which may be challenged for this group include autonomy and independence, peer pressure, social and sexual maturation, fertility, and finances [4]. Moreover, adverse and late effects of treatment can physically impact survivors, as well as cause short- and long-term effects on their self-image and well-being [5, 6]. Furthermore, young adults (i.e., individuals ages 19–39) also present with unique challenges regarding the interaction between the cancer experience and psychosocial development. Cancer diagnosis and treatment may present unexpected challenges and choices in the context of a new marriage/partnership, educational or occupational pursuits, finances, or child rearing. Consequently, whereas prior reviews of the literature have highlighted the need for further exploration and clarification of outcomes within the AYA population, given that this specific age group has been typically assessed in combination with younger and/or older ages [7], this systematic review aimed to identify relevant psychosocial outcomes, specific needs, and existing psychosocial interventions pertaining to those diagnosed with cancer exclusively during AYA.

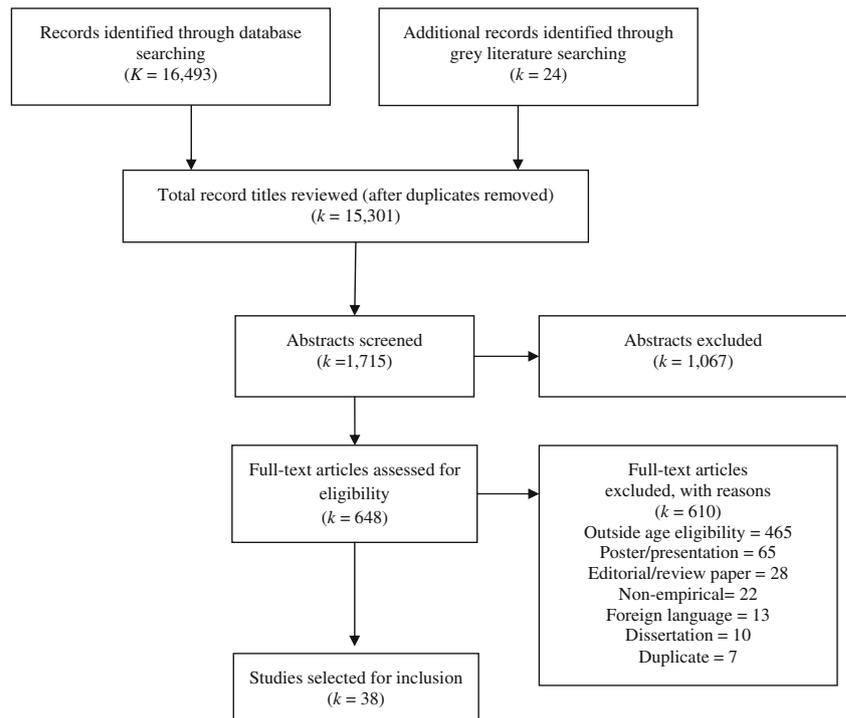
## Method

### Literature search

A systematic search for articles was conducted using MEDLINE (via PubMed), Embase, Cochrane, Web of Science, and PsycINFO (via OVID). There were no date, language, or publication type restrictions; each database was search in its entirety, through March 2014. With the exception of Web of Science, which does not employ a controlled vocabulary, both controlled vocabulary and text words were used in the development of the database search strategy.

The search strategy had three components, with all concepts linked together via the AND operator: (1) cancer survivors, survivorship; (2) psychosocial, behavior therapy, alternative therapy, interventions; and (3) outcomes, unique needs, adjustment. After combining the concepts in all five databases, the following keyword and controlled vocabulary terms (where applicable) were added to the search using the AND operator in an effort to be as comprehensive as possible: adolescent, young adult, AYA (Table 2 Appendix). Using the filter option to limit results by age group was more limiting than adding a separate concept with these terms to the overall search. The decision was made to retrieve a greater number of results rather than possibly eliminating relevant records.

Grey literature sources were also searched using variations and combinations of the following terms: cancer survivor\*, psychosocial, intervention\*, treatment\*, adolescent\*, young adult\*, AYA, outcome\*, result\*, needs, and adjustment. The resources searched were: National Cancer Institute’s (NCI) Report of the Adolescent and Young Adult Oncology Progress Review Group (<http://www.cancer.gov/cancertopics/aya/reports>), National Coalition for Cancer Survivorship (<http://www.canceradvocacy.org>), American Psychosocial Oncology Society (APOS) conference proceedings (<http://www.apos-society.org>), International Psycho-Oncology Society (IPOS) conference proceedings (<http://www.ipos-society.org>), New York Academy of Medicine (NYAM) Grey Literature Report (<http://www.greylit.org>), and Online Computer Library Center (OCLC) WorldCat (for theses/dissertations) (<http://www.worldcat.org>). An *advanced search* (or equivalent) feature was used wherever possible (OCLC WorldCat, NYAM Grey Literature Report) to ensure that the most targeted results were retrieved. All grey literature search results were compiled in a separate document and are included in the PRISMA Flow Diagram (Fig. 1) in the number of “additional records identified” box under the “Identification” phase of the overall review process.

**Fig. 1** PRISMA flow chart

### Study inclusion criteria

Studies were deemed eligible for inclusion if they included an original characterization of psychosocial outcomes and/or interventions in patients who are survivors of cancer initially diagnosed between ages 15–39.

### Study selection and characteristics

All titles were independently reviewed for eligibility by two co-authors (from a pool of seven possible reviewers). Next, each potentially eligible article was randomly assigned to a pair of co-authors for full abstract screening. For the full-text review phase, the randomly assigned author teams consisted of a primary reviewer and a secondary reviewer for the purposes of verification and quality assurance. Both reviewers independently completed standardized coding forms to extract the pre-determined information from each potentially eligible article. All reviewers then met as a group and compared full-text article reviews to resolve any potential discrepancies and make final decisions regarding article inclusion. Each author independently searched references from the included full-text articles to determine whether they should be also considered for inclusion.

Study quality and risk-of-bias was assessed using a modified version of the Downs and Black Study Quality checklist [46]. All included articles were reviewed and rated for the following nine quality indicators: (1) Is the hypothesis/aim/objective of the study clearly described?; (2) Are the main

outcomes to be measured clearly described in the Introduction or Methods section?; (3) Are the characteristics of the patients included in the study clearly described?; (4) Are the main findings of the study clearly described?; (5) Have actual probability values been reported from the main outcomes except where the probability value is less than 0.001?; (6) Were the subjects asked to participate in the study representative of the entire population from which they were recruited?; (7) Were those subjects who were prepared to participate representative of the entire population from which they were recruited?; (8) If any of the results of the study were based on “data dredging”, was this made clear?; and (9) Were the main outcome measures used accurate (valid and reliable)? Studies were categorized as “high quality” if they satisfied at least 7 of the 9 quality indicators.

### Results

Database searches initially identified 16,493 articles, with an additional 24 identified via grey literature searching. After duplicates were removed, 15,301 article titles were each reviewed by two independent reviewers for eligibility. Following title review, it was determined that 1,715 unique article abstracts would be reviewed. A total of 648 articles were retained for the full text-review. A total of 610 (94 %) full-text articles were excluded for the following reasons: outside age eligibility ( $k=465$ ), poster/presentation ( $k=65$ ), editorial/review paper ( $k=28$ ), non-empirical ( $k=22$ ), foreign

language without translation ( $k=13$ ), dissertation ( $k=10$ ), duplicate ( $k=7$ ), or unable to confirm eligibility from study authors ( $k=1$ ). Two studies made use of identical datasets; we retained the study that best characterized this dataset to avoid double counting [47]. Poster/presentation abstracts and dissertations, while included in the initial database and grey literature search, were excluded from this review due to lack of specificity of diagnosis age. A total of 38 articles met inclusion criteria (Fig. 1).

### Study characteristics

Table 1 includes a summary of participant demographics and study characteristics for the 38 included articles. Thirty-three studies utilized a cross-sectional design, five utilized prospective methods, and two were randomized intervention or feasibility studies. Studies spanned a range of methodologies, including nine using large population or registry-based survey databases (e.g., SEER cancer registries, Behavioral Risk Factor Surveillance System), multi-center studies, and 17 qualitative analyses. Cancer diagnoses were mixed in 30 studies, with the remaining eight single diagnosis studies. Five studies were exclusively female, with one exclusively male. Six international studies were included (Canada [ $k=4$ ], Australia [ $k=1$ ], Germany [ $k=1$ ]). Results were synthesized into four sections based on a quality of life (QOL) model and survivorship care recommendations as outlined in the Institute of Medicine's (IOM) report [48]: (1) physical well-being and symptoms, (2) psychological well-being, (3) social well-being, and (4) survivorship care. While sufficient quantitative data was not included in studies to permit completion of a meta-analysis, studies often described results overlapping with these sections. As such, we report how many studies were primarily and secondarily included within each section.

### Physical well-being and symptoms

Physical well-being is defined by an individual's functional/physical activities, health behaviors, and knowledge of health and/or disease [48]. Symptoms also include strength/fatigue, sleep/rest, overall physical health, diet, fertility, and pain. These symptoms are known to impact overall well-being, and for cancer survivors can be significantly impacted by treatment side effects or late-effects [5]. Physical well-being was reflected primarily in seven (18 %) studies and two secondarily.

A large-scale health-based registry comparing AYAs with and without a cancer history found that AYA survivors have poorer health behaviors and compared with same-age controls [39]. Current smoking was significantly greater among AYA survivors (26 %) compared to controls (18 %), although no difference in binge drinking rates (14 vs. 15 %). More AYA survivors reported no leisure-time physical activity in the past

month (31 vs. 24 %). Another national health survey found that compared to female healthy controls, female survivors reported poorer physical health, and were more likely to meet criteria for lifetime and current medical conditions, greater health-related disabilities, and greater functional limitations [25].

Psychosexual, fertility, and body image sequelae were found among male and female AYAs [9, 17, 22, 24]. Keim-Malpass and colleagues [22] reported relevance and gender-specific effects of sexual sequelae of diagnosis/treatment (e.g., functioning, fertility, gender norms). AYAs reported significantly lower health-related quality of life compared to those diagnosed at younger ages, leukemia or sarcoma survivors, or healthy controls [49].

Several studies reported specialized structured programming needs for AYA survivors, including the need for supportive care, information concerning health promotion, the cancer treatment they had undergone, nutrition, dealing with insurance, and other survivorship concerns (sexuality, fertility) [10, 36, 41]. This information was utilized to develop and test an information-based workshop series addressing the unmet needs among young breast cancer survivors [10]. After 6 months, intervention did not increase participants' cancer-related knowledge or self-reported physical activity [10]. Rabin [37], Valle [41] and respective colleagues reported on the development and pilot testing of internet-based interventions targeting physical activity among young adult survivors. Both found that interventions utilizing social media and online components were both feasible and acceptable to this group of survivors. Compared to childhood survivors' preferences, AYAs do not prefer camp-based intervention delivery to improve diet and exercise behaviors [8].

Access to and use of alternative or integrative services has been established as effective with cancer patients and survivors [50, 51]; however, little research has focused on these benefits among this age-specific cohort. Park and colleagues [34] found that 37 % AYAs used complementary medicine approaches since their diagnosis, including yoga to promote flexibility and relaxation.

### Psychological well-being

Psychological well-being was reflected primarily in eight (21 %) studies and eight secondarily. The IOM defines this QOL section as areas of psychological and mental health, including: control, anxiety, depression, enjoyment/leisure, cognition/attention, or psychopharmacological use [48]. Psychological well-being additionally includes AYA's fear of recurrence or being different, feeling different, cancer-related disclosure, distress of diagnosis, and control of treatment.

Unmet emotional and psychological needs were reported as major concerns for AYAs after post-treatment [29, 38]. Overall, AYA survivors reported  $\geq 14$  days of poor mental

**Table 1** Demographics, design characteristics, quality assessment, and major findings for included studies ( $K=38$ )

Study	Aims	<i>N</i>	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
Badr et al. 2013 [8] <sup>a</sup>	(1) Examine diet and exercise behaviors (HRQOL) of survivors; (2) Examine HRQOL, lifestyle behaviors, and intervention preferences among childhood compared with AYA survivors	170	17.7 (5.6); N/R	Post-treatment	48 %	31 %	Mixed	Cross-sectional; qualitative	<ul style="list-style-type: none"> <li>- AYAs reported significantly lower HRQOL (physical appearance) compared to those diagnosed at an earlier age, survivors of leukemia or sarcoma, and healthy populations.</li> <li>- Significant portion of sample did not meet national recommendations for dietary intake or physical activity.</li> <li>- Childhood survivors preferred a camp-based intervention delivery compared to AYAs.</li> </ul>
Bellizzi et al. 2012 [9] <sup>a</sup>	Describe psychosocial impact of cancer diagnosis during AYA	523	29 (6.7); N/R	Various stages: during treatment, post-treatment	63 %	41 %	Mixed	Cross-sectional; SEER Cancer Registries	<ul style="list-style-type: none"> <li>- Diagnosis worsened finances, body image, feelings of control over life, work plans, relationship/ family planning.</li> <li>- Diagnosis improved relationships, future plans/goals, and health competence.</li> </ul>
Bloom et al. 2008 [10] <sup>a</sup>	Intervention for breast cancer survivors 5 years post-treatment, aimed to improve: (1) knowledge of breast cancer, the treatment, and long-term health concerns; (2) lifestyle habits; (3) communication with family and physicians	404	N/R	Post-treatment	100 %	24 %	Breast	Intervention study; Prospective; RCT (wait list control), 3 1-day workshops assessed at baseline and 6 months	<ul style="list-style-type: none"> <li>- Participants diagnosed as AYA did not show a difference in disease knowledge or physical activity as a function of intervention.</li> </ul>
Carpenter et al. 1989 [11] <sup>a</sup>	Impact of time since treatment on psychosocial well-being	43	28.9 (6.1); 18-45	Post-treatment	54 %	N/R	Hodgkin's lymphoma	Cross-sectional; Combined self-report, expert report (structured)	<ul style="list-style-type: none"> <li>- AYAs &gt;2 years post-treatment (<math>n=28</math>) report significantly better adjustment in vocational environment compared to AYAs on active treatment (<math>n=15</math>).</li> <li>- AYAs &gt;2 years post-treatment reported worsened psychosocial well-being and functioning; including worsened positive attitude toward care.</li> <li>- Time since treatment a potential moderator.</li> </ul>
Carpentier et al. 2011 [12] <sup>a</sup>	Perceptions of masculinity and self-image in testicular cancer survivors	21	27.1	Post-treatment	0 %	N/R	Testicular	Cross-sectional; Qualitative	<ul style="list-style-type: none"> <li>- Four major themes: (1) embarrassment and treatment delay, (2) feeling different, (3) being different, (4) difficulties with disclosure.</li> </ul>
D'Agostino et al. 2013 [13] <sup>a</sup>	Identify psychosocial challenges and resource needs of childhood and AYA survivors	22	N/R; 18-35	Post-treatment	45 %	N/R	Mixed	Cross-sectional; Qualitative	<ul style="list-style-type: none"> <li>- Concerns specific to AYAs: (1) financial independence; (2) protecting parents.</li> <li>- Both childhood and AYA survivors described similar resource needs: (1) peer support; (2) age-specific information; (3) proactive health care providers raising salient issues.</li> <li>- AYAs have similar psychosocial and information needs that differ from pediatric or adult survivors.</li> </ul>
Deyell et al. 2013 [14] <sup>a</sup>	Antidepressant use among AYA survivors	2389	28.8 (10/9); N/R	Various stages: at diagnosis, post-treatment	49 %	N/R	Mixed	Cross-sectional; Registry-based	<ul style="list-style-type: none"> <li>- Survivors ages 15–20 at diagnosis had nearly twice likelihood of antidepressant prescription use</li> </ul>

**Table 1** (continued)

Study	Aims	N	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
Dieluweit, et al. 2011 [15] <sup>a</sup>	Describe utilization of oncological and psychosocial care among AYA survivors	820	30.4 (6.0); N/R	Post-treatment	51 %	N/R	Mixed	surveys; in Canada Cross-sectional; Retrospective survey; Registry-based survey (GCCR); in Germany	compared to those <5 years at diagnosis. - 26.2 % no longer regularly attended oncological follow-ups. - 44.4 % had received psychosocial care mainly focused during treatment or immediately post-treatment. - Among 184 survivors reporting symptoms of posttraumatic stress, anxiety or depression, 12 % received psychosocial care and 13.6 % took psychotropic medication.
Dyson et al. 2012 [16] <sup>a</sup>	(1) Relationship between unmet needs and distress among young people with cancer; (2) Identify predictors of distress	53	21.0 (0.5); 16-30	Various stages: pre-treatment; during treatment	53 %	N/R	Mixed	Cross-sectional; Descriptive	- Major unmet needs identified: physical and daily living, psychological, health system and information and patient care and support. - Pre-treatment predicted increased depression and state anxiety; treatment post-surgery predicted reduced anxiety. - Main predictors of depression and anxiety were physical, daily living needs, health system and information needs (controlling for treatment status).
Gorman et al. 2011 [17] <sup>a</sup>	Breast cancer survivors perspective on treatment decisions and fertility concerns	20	N/R; 26-38	Post-treatment	100 %	0 %	Breast	Cross-sectional; Qualitative	- Four major themes: (1) do whatever necessary to eliminate cancer and move on with life; (2) fertility concerns differ for every woman; (3) oncologists are a big part of survivorship; (4) fertility discussed too late. - Overall themes: treatment decisions motivated by survival; fertility concerns varied by life circumstance and age at diagnosis; improvements in providing fertility information pre and post-treatment are needed.
Harlan, et al. 2011 [18] <sup>a</sup>	(1) Feasibility of using cancer registry to examine issues of treatment or health outcomes among AYA survivors; (2) Establish AYA HOPE Study	524	N/R; 15-39	Various stages: during treatment, post-treatment	37 %	18 %	Mixed	Feasibility study; Prospective; SEER Cancer Registries	- Cancer registries are a valuable foundation for observational, longitudinal, population-based research, but require extensive resources. - Age, cancer site, education and time since diagnosis were not associated with participation, although males, Hispanics and non-Hispanic blacks were less likely to participate.
Hauken et al. 2013 [19] <sup>a</sup>	Experience re-entering life post-treatment; Perceptions of problem-solving	20	31.1 (N/R); 24-35	Post-treatment	75 %	N/R	Mixed	Cross-sectional; Qualitative	- Four major themes: (1) lack of preparation (by healthcare providers post-treatment period); (2) late effects pervade entire life; (3) lack of social understanding (discrepancy between negative influence of late effects while social networks expected them to

Table 1 (continued)

Study	Aims	N	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
Keegan, et al. 2012 [20] <sup>a</sup>	Identify unmet information needs and associated sociodemographic and health-related factors	523	N/R; 15-39	Various stages: during treatment, post-treatment	37 %	19 %	Mixed	Cross-sectional; Survey; SEER Cancer Registries; AYA HOPE Study	<p>be cured); (4) being neither sick nor healthy (not identifying as patients, but feeling neither healthy nor recovered because of late effects).</p> <ul style="list-style-type: none"> <li>-&gt; half of AYAs had unmet information and service needs relating to their cancer. Unmet services ranged from 29 % (in-home nursing) to 75 % (support group).</li> <li>- Majority who needed specific medical professionals (e.g., pain management expert, physical/occupational therapist, mental health worker, medical financial advice) did not receive help.</li> <li>- Unmet information needs significantly greater among: older AYAs, men, non-white race/ethnicity, poor general health or fair/poor quality of care.</li> <li>- Factors associated with both unmet service and information needs: physical health or emotional problems interfering with social activities, or having 3+ physical treatment-related symptoms.</li> </ul>
Keim-Malpass & Steeves 2012 [21] <sup>a</sup>	Explore women's experience with cancer with online illness blogs	16	N/R; 20-39	Various stages: during treatment, post-treatment	100 %	N/R	Mixed	Cross-sectional; Qualitative	<ul style="list-style-type: none"> <li>- Personal narratives revealed transitions from initial cancer diagnosis, through treatment, into long-term survivorship.</li> <li>- Four major themes: (1) living in the middle; (2) new normal; (3) urgency; (4) transition into the abyss.</li> </ul>
Keim-Malpass, et al. 2013 [22] <sup>a</sup>	To explore: (1) life disruptions due to cancer; (2) facilitators and barriers in accessing healthcare services during and post-treatment	16	N/R; 20-39	Various stages: during treatment, post-treatment	100 %	N/R	Mixed	Cross-sectional; Qualitative	<ul style="list-style-type: none"> <li>- Four major themes: (1) pain and fatigue; (2) insurance and financial barriers; (3) concerns related to fertility; (4) symptoms of posttraumatic stress and anxiety.</li> </ul>
Kirchoff et al. 2012 [23] <sup>a</sup>	Limitation in health care access and utilization among AYA survivors compared to general U.S. population	979	N/R; 20-39	Post-treatment	87 %	25 %	Mixed	Cross-sectional; Descriptive; Health-based Registry (BRFSS)	<ul style="list-style-type: none"> <li>- Proportions of uninsured survivors and controls did not differ. AYAs reported forgoing care due to a higher level of cost than controls. Cost barriers particularly high for survivors ages 20–29 and female survivors. Survivors reporting poorer health had more cost barriers. Uninsured survivors reported lower use of health care than controls.</li> </ul>
Lee et al. 2011 [24] <sup>a</sup>	Explore fertility-related health services and reproductive choices in breast cancer survivors	24	N/R; 23-39	Post-treatment	100 %	0 %	Breast	Cross-sectional; Qualitative	<ul style="list-style-type: none"> <li>- Five major themes: (1) survivorship and risk-taking (e.g., priorities and perceived risks of survival); (2) denial of choice (due to cancer, treatment, and services); (3) grief associated with loss of choice; (4) advice from health professionals; (5) role of services</li> </ul>

**Table 1** (continued)

Study	Aims	N	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
Love & Sabiston 2011 [25] <sup>a</sup>	(1) Explore social support and enduring distress as predictors of psychosocial growth; (2) Examine moderating role of physical activity	64	28.8 (5.5); 20-39	Post-treatment	73 %	5 %	Mixed	Cross-sectional, Descriptive	<ul style="list-style-type: none"> <li>in facilitating choice (e.g., written information, timing of discussions, offering of fertility services appointments).</li> <li>- Stress and social support significant predictors of psychosocial growth.</li> <li>- Strong positive correlation between social support and psychological growth in inactive individuals and weaker correlation for active individuals.</li> </ul>
Mattson et al. 2013 [26] <sup>a</sup>	(1) Examine QOL among young adults survivors in relation to middle-aged and older adults; (2) identify common areas of concern; (3) explore association of individual characteristics with QOL	48	30.2 (4.6); N/R	Post-treatment	46 %	27 %	Leukemia (40 %), Lymphoma (60 %)	Cross-sectional; Descriptive	<ul style="list-style-type: none"> <li>- No significant correlations between QOL and current age, age at treatment completion, or time since treatment.</li> <li>- Social well-being was related to age, and spiritual well-being to race.</li> <li>- Participant themes included: need for additional education and peer group support, worry about disease recurrence, long-term late effects, and physical symptoms and return to normalcy.</li> </ul>
Miedema et al. 2007 [27] <sup>a</sup>	Develop a model illustrating bidirectional nature of coping strategies throughout cancer experience	15	N/R; 21-43	Various stages	60 %	N/R	Mixed	Cross-sectional; Qualitative; in Canada	<ul style="list-style-type: none"> <li>- Major themes distinguished coping at different stages: (1) pre-cancer life; (2) diagnosis phase (information, relational interactions, perceptions); (3) treatment phase (taking action, control, adaptation, situation self); (4) post-treatment/ remission/ palliative phase (normalcy).</li> </ul>
Miedema et al. 2013 [28] <sup>a</sup>	Identify and compare characteristics of rural and urban AYA cancer survivors' access to healthcare resources	30	32.1; N/R	Post-treatment	70 %	7 %	Mixed	Cross-sectional: Qualitative; in Canada	<ul style="list-style-type: none"> <li>- AYA profiles differed by three characteristics: (1) difference of proportion of cancer types between rural and urban groups; (2) rural participants had lower educational achievements, less full-time employment and therefore lower average incomes; (3) rural AYAs experienced greater delay in diagnosis.</li> <li>- Rural AYAs reported less access to services, but reported considerably higher levels of satisfaction with care received than urban participants.</li> </ul>
Millar et al. 2010 [29] <sup>a</sup>	(1) Identify most common unmet needs for AYAs at various stages post-treatment; (2) Identify correlates with psychological functioning	63	20.4 (N/R); 18-24	Various stages	64 %	N/R	N/R	Cross-sectional, Descriptive	<ul style="list-style-type: none"> <li>- Unmet needs ≤1 year post-treatment: structure of care, emotional/ psychological, school/ occupational, informational, and relationships.</li> <li>- Unmet needs 1–5 years post-treatment: structure of care, emotional/ psychological, informational, relationships, and process of care.</li> <li>- Unmet needs &gt;5 years post-treatment: emotional/</li> </ul>

Table 1 (continued)

Study	Aims	N	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
Mumma et al. 1992 [30] <sup>a</sup>	(1) Psychosexual functioning following successful treatment for acute leukemia >1 year post-treatment; (2) impact of bone marrow transplant (BMT) vs. conventional chemotherapy only (CO)	70	26 (5.0); N/R	Post-treatment	51 %	10 %	Leukemia	Cross-sectional, Descriptive	<ul style="list-style-type: none"> <li>psychological and school/occupational.</li> <li>- More years post-treatment correlated with greater unmet emotional/ psychological needs.</li> <li>- 90 % BMT women reported absent menses, 19 % women treated with chemotherapy.</li> <li>- 36 % BMT men and 13 % CO men were offered sperm banking.</li> <li>- No significant psychosexual dysfunction differences between BMT and CO groups (sexual drive, satisfaction, body image, gender role definition, sexual relations).</li> <li>- BMT women had lower average frequency of sexual behaviors vs. CO women, and BMT and CO men.</li> <li>- Women and men reported poorer body image compared to physically healthy individuals.</li> <li>- Women reported decreased sexual drive and less satisfaction than the physically healthy.</li> </ul>
O'Callaghan, Barry, & Thompson 2012 [31] <sup>a</sup>	Explore AYA survivors' perspectives on the role of music in their lives during cancer journey	12	21 (2.7); 15-25	Various stages: during treatment; post-treatment	N/R	N/R	Mixed	Cross-sectional, Qualitative; in Australia	<ul style="list-style-type: none"> <li>- Three major themes: (1) music was positive/helpful throughout cancer journey, promoted understanding, provided helpful physical, emotional, and imagery states; (2) All reported listening to music everyday post-diagnosis, some wrote own music; (3) Interactions with music and attitudes about music often changed after cancer diagnosis and throughout the cancer journey.</li> </ul>
Park et al. 2013 [32] <sup>a</sup>	Describe yoga use and impact among AYA survivors since diagnosis	286	33.3 (7.1); 18-47	Various stages: during treatment; post-treatment	N/R	N/R	Mixed	Cross-sectional, Descriptive	<ul style="list-style-type: none"> <li>- 37 % used complementary medicine approaches. 32 % participated in yoga for health reasons since diagnosis, 22 % of whom took specialized yoga for survivors.</li> <li>- Yoga reportedly used to promote flexibility and relaxation.</li> <li>- Predictor of higher yoga use was female gender. Overall yoga was used more commonly by survivors with greater resources.</li> <li>- Higher education with increased yoga use was related to enhanced feelings of well-being.</li> </ul>
Parsons et al. 2008 [33] <sup>a</sup>	Explore following themes among people with osteosarcoma: (1) illness experience; (2) experiences resuming vocational pursuits, (3) relationship between these experiences	14	N/R	Various stages: During treatment; post-treatment	43 %	N/R	Osteosarcoma	Cross-sectional, Qualitative; in Canada	<ul style="list-style-type: none"> <li>- Respondents depicted osteosarcoma as a crisis that entailed "illness work" as well as "identity work."</li> <li>- "Illness work:" defined as efforts involved in processing treatment and cancer care from time of diagnosis.</li> </ul>

**Table 1** (continued)

Study	Aims	N	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
Parsons et al. 2012 [34] <sup>a</sup>	Impact of cancer on returning to work and education 15 to 35 months post-diagnosis	388	N/R	Various stages: At diagnosis, during treatment	36 %	27 %	Mixed	Prospective, Descriptive; AYA HOPE Study	<ul style="list-style-type: none"> <li>- “Identity work:” defined as a transformative process occurring after diagnosis and throughout treatment.</li> <li>- “Vocational work:” defined as the work occurring in workplace or educational setting.</li> <li>- 34.5 % working/school full-time pre-diagnosis reported cancer had negative impact on plans.</li> <li>- &gt;50 % patients in school or working full-time pre-diagnosis reported some type of problem at work or school both at time of initial survey and follow-up.</li> <li>- Survivors diagnosed with acute lymphocytic leukemia and non-Hodgkin’s lymphoma less likely than other cancers to be working or in school at follow-up.</li> </ul>
Phillips-Salimi & Andrykowski 2013 [35] <sup>a</sup>	Describe physical and mental health status of female cancer survivors (FCS) compared to female non-cancer controls (NCC)	400	39.5 (10.8); 18-59	Post-treatment	100 %	36 %	Mixed	Cross-sectional; Descriptive; National health survey (NHIS)	<ul style="list-style-type: none"> <li>- FCS group reported significantly poorer physical and mental health than controls.</li> <li>- FCS group had significantly poorer scores on 7 of 8 mental health outcomes, were more likely to meet criteria for serious psychological distress, and reported greater lifetime and current prevalence of various medical conditions, more health-related disabilities, and greater functional limitations than NCCs.</li> </ul>
Rabin et al. 2011 [36] <sup>a</sup>	Explore behavioral and psychosocial program needs of AYA survivors	20	33.5 (3.8); 18-39	Post-treatment	75 %	10 %	Mixed	Cross-sectional, Qualitative	<ul style="list-style-type: none"> <li>- Described programs of interest included: those targeting physical activity, relaxation, emotional support, provision of cancer-related and other info, nutrition/weight loss, and programs targeting their similarities (e.g., age, diagnosis, time since diagnosis, gender).</li> <li>- Major themes: choice, flexibility, convenience, similarity to other programs.</li> <li>- Barriers: practical/concrete barriers (e.g., limited time), lack of awareness of programs/health issues (e.g., fatigue), psychosocial barriers (e.g., low motivation).</li> </ul>
Rabin et al. 2013 [37] <sup>a</sup>	Explore intervention format and delivery preference among AYA survivors	20	33.5 (3.8); 18-39	Post-treatment	75 %	10 %	Mixed	Cross-sectional, Qualitative	<ul style="list-style-type: none"> <li>- Major theme: considering competing needs/obligations (e.g., work, family).</li> <li>- Three subthemes: (1) importance of convenient interventions; (2) need for social support interventions; (3) participants comfortable with computer-based and online programs.</li> </ul>
Sammallahti et al. 1995 [38] <sup>a</sup>	Identify psychological defenses of osteosarcoma survivors	16	26 (3.0); N/R	Post-treatment	50 %	N/R	Osteosarcoma	Cross-sectional; Descriptive	

Table 1 (continued)

Study	Aims	N	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
	compared to healthy controls								- Survivors were well-adjusted, with no evidence of the self-report biased by defensiveness. - Significant difference between groups suggests survivors have problems in trusting that they can obtain support and understanding from other people when needed.
Tai et al. 2012 [39] <sup>a</sup>	Evaluate self-reported health status of AYA survivors compared to healthy controls	4054	N/R	Post-treatment	81 %	21 %	Mixed	Prospective; Health-based registry (BRFSS)	- Current smoking significantly greater among survivors (26 % compared to controls (18 %)). - Compared to controls, more survivors reported no leisure-time physical activity (31 % vs. 24 %) and ≥14 days of poor mental health in the past month (20 % vs. 10 %). - No difference in binge drinking (14 % vs. 15 %).
Thompson et al. 2009 [40] <sup>a</sup>	Explore medical, psychological, and social needs of AYAs during transition from active treatment to survivorship	8	N/R	End of treatment	63 %	N/R	Mixed	Cross-sectional; Qualitative	- Three major themes, ten subthemes: (1) information provision/communication (diagnosis and decision-making, fertility, treatment information); (2) treatment process (sexuality and body image, psychosocial support, healthcare professionals skills, hospital environment); (3) post-treatment care/survivorship (finishing treatment, ongoing health concerns, future directions).
Valle et al. 2013 [41] <sup>a</sup>	Feasibility and preliminary efficacy of a Facebook-based intervention (FITNET) aimed at increasing moderate-to-vigorous intensity physical activity (PA) compared with a Facebook-based self-help (SC) condition	86	FITNET arm: 30.8 (5.7); N/R. SC arm: 32.7 (4.2); N/R	Post-treatment	91 %	7 %	Mixed	Prospective; RCT with baseline assessment and 12-week follow-up	- 77 % completed post-intervention assessments; both groups would recommend the program to other survivors. - Over 12 weeks, both groups increased self-reported weekly minutes of moderate-to-vigorous PA, no significant difference between groups. - Increases in light PA were 135 min/week greater in FITNET group relative to SC group. - FITNET group reported significant weight loss over time (-2.1 kg, $p = 0.004$ ; $p = 0.083$ between groups).
Yanez et al. 2013 [42] <sup>a</sup>	Describe prevalence and factors associated with distress among AYA survivors	322	31.8 (5.4); N/R	Post-treatment	N/R	N/R	Mixed	Cross-sectional	- Overall clinically elevated distress was reported post-treatment; significant main effects with length of time post-treatment, global impact, and cancer-related education/work interruption. - Interaction between time since treatment and cancer-related education/work interruption on distress: AYAs 13–60 months post-treatment and who reported education/work interruption were significantly more distressed.

**Table 1** (continued)

Study	Aims	N	Age mean (SD); range	Participant treatment phase	% Female	% Non-White	Disease	Study design	Key findings
Zebrack et al. 2006 [43]	Identify health and supportive care needs for AYA patients and survivors utilizing feedback from patients, survivors, and health care providers. Iterative surveys used in 3 rounds	37	31.1 (N/R); 19-44	Various stages: during treatment; post-treatment	N/R	N/R	Mixed	Cross-sectional; Mixed qualitative-quantitative method	<ul style="list-style-type: none"> <li>- Overall providers and survivors were in general agreement, some notable exceptions.</li> <li>- Providers and survivors agreed on relative importance of adequate health insurance and oncology care addressing unique AYA developmental characteristics.</li> <li>- AYAs ranked importance of opportunities to meet other AYA survivors relatively higher, and ranked those opportunities higher than the importance of family/friend support.</li> </ul>
Zebrack et al. 2007 [44] <sup>a</sup>	Priority health and supportive care needs for AYA patients and post-treatment survivors	1088	30.8 (5.6); 18-39	Various stages: during treatment; post-treatment	76 %	11 %	Mixed	Cross-sectional; Survey	<ul style="list-style-type: none"> <li>- Highest ranked health care needs: availability of state-of-the-art treatment specific to age-group and adequate health insurance.</li> <li>- Highest ranked supportive care needs: support from family and friends.</li> <li>- Younger AYAs reported need for fertility information and services; older AYAs placed greater emphasis on need for psychological counseling and age-appropriate information.</li> </ul>
Zebrack et al. 2010 [45] <sup>a</sup>	Explore behavior that may promote or inhibit healthy psychosocial adjustment for AYAs with cancer	17	N/R; 18-35	Various stages: during treatment; post-treatment	N/R	N/R	N/R	Cross-sectional, Qualitative	<ul style="list-style-type: none"> <li>- Four major themes: (1) informational support; (2) practical support; (3) interpersonal/social support; (4) emotional support.</li> <li>- Identified 11 “helpful” and 9 “harmful/hurtful” sub-categories.</li> <li>- Most common categories were interpersonal comments and actions. More helpful than hurtful comments were reported, except in the informational category, where the “bad news” about cancer and the style of information sharing increased “hurt.”</li> </ul>

N/R not reported, AYA adolescent and young adulthood, CNS central nervous system, HRQOL health-related quality of life, RCT randomized control trial, BMT bone marrow transplant, SEER surveillance, epidemiology, and end-results cancer registries, BRFSS Behavioral Risk Factor Surveillance System, NHIS National Health Interview Study, GCCR, German Childhood Cancer Registry, AYA HOPE Adolescent and Young Adult Health Outcomes and Patient Experience Study

<sup>a</sup> Indicates a “high quality” study

health in the past 30 days (20 vs. 10 %) compared to healthy controls (20 vs. 10 %) [39]. Another study found survivors to be well-adjusted, with stress and social support as significant predictors of posttraumatic growth [38]. The relationship between stress (negative relationship) social support (positive relationship) and post-traumatic growth was moderated by level of physical activity; the relationship with social support and psychological growth was stronger for individuals with lower levels of physical activity [25].

Individuals diagnosed between the ages of 15 and 20 were nearly twice as likely to use antidepressant medication as individuals diagnosed before age 5, and AYA survivors reported symptoms of post-traumatic stress, anxiety, and depression, as well as fears of recurrence [14, 15, 22, 26]. Female AYAs scored significantly more poorly than healthy peers on seven out of eight mental health outcomes and were more likely than peers to meet criteria for serious psychological distress [35], and in another study reported experiencing persistent struggles, such as post-traumatic stress symptoms, anxiety, pain, and fatigue [22]. In a large survey study, more than half of AYAs who needed mental health services did not receive them, and emotional problems interfering with social activities were associated with unmet service and information needs [20]. From an international perspective, almost half of survivors in a German study reported receiving psychosocial care during or immediately post-treatment; and among those reporting clinical symptoms, only 12 % received psychological help and 14 % psychotropic medication [15]. Additionally, 75 % of AYA survivors reported the desire for a support group [20, 26]. Overall, higher psychosocial stress increased the likelihood of obtaining psychosocial treatment and psychotropic medication, and AYAs diagnosed with a second malignancy were more likely to receive psychosocial treatment. Older AYAs were more likely to follow-up with oncological care on the recommended schedule. Controlling for treatment status, predictors of depression include physical or daily living needs, and health system and information needs [16].

Disease and treatment features also affected psychosocial outcomes and treatment-seeking [41, 52]. Cancer diagnosis is a potential moderator of being in school or employment at follow-up, with ALL and non-Hodgkin's Lymphoma diagnoses less likely to be in one of these groups compared with other diagnoses [9, 34]. AYAs experiencing cancer-related education or work interruption were significantly more distressed [42]. Individuals who required intensive care or stem cell transplant were more likely to receive psychosocial treatment. AYAs greater than 2 years post-treatment reported worsened psychosocial well-being and functioning, and decreased positive attitude towards care [11].

Coping at each phase presents new challenges: diagnosis phase (i.e., information, relational interactions, and perceptions), treatment phase (i.e., taking action, control, adaptation, situation self), and post-treatment/remission/palliative phase

(i.e., normalcy) [27]. AYAs report a lack of survivorship preparation (especially from healthcare providers), late effects that pervade their entire life, a lack of post-treatment understanding from social networks, and difficulty coming to terms being “neither sick nor healthy” [19]. A qualitative analysis of young women's online narratives found four themes describing the transition into long-term survivorship: living in the middle (after treatment but before “remission”), new normal, urgency, and transition into the abyss [21]. Specifically, osteosarcoma survivors reported that cancer treatment caused them to redefine their personal and professional work into different categories (i.e., illness work, identity work, vocational work), ultimately altering their pre-treatment goals [33].

Among breast cancer survivors, treatment decisions were greatly motivated and determined by survival chances; however as noted above, fertility options, services, and empowerment were either inadequate or provided too late during and post-treatment [17, 24]. Women reported persistent struggle regarding fertility concerns [22]. Both women and men who received bone marrow transplant or chemotherapy reported poorer body image, and women reported lower frequency of sexual behaviors, decreased sexual drive, and less satisfaction post-treatment than physically healthy controls [30].

Using a constructivist grounded theory methodology, O'Callaghan and colleagues [31] found that interactions with music were helpful during and post-treatment for 12 AYAs to facilitate positive emotions and states, as well as transition off treatment.

### Social well-being

Social well-being was reflected primarily in nine (24 %) studies and two secondarily. This section is defined by outcomes related to family distress, roles and relationships, affection/sexual function, appearance, enjoyment, isolation, finances, education and employment.

AYA survivors reported that cancer worsened feelings of control over life, finances, work plans, social relationships, and relationship or family planning, and increased concern in these areas [9, 11, 13]. Trusting that they could find support when they needed it was reported as difficult [9, 29, 38]. AYAs described the need for greater peer and family support throughout their cancer journey [13, 44], more opportunities to meet other AYA survivors [43], and the perception of interpersonal social support as promoting healthy psychosocial adjustment at various treatment stages [40, 45]. Social support was found to be a significant predictor of psychosocial growth [25]. AYAs also endorsed a positive impact of cancer in the following areas: improved relationships, future planning/goals, and health competence [9].

Masculinity and self-image were impacted among testicular cancer survivors, who perceived the following social challenges: feeling different, viewing their differences as

“damaged goods,” struggles with cancer-related disclosures, and feelings of embarrassment that directly lead to treatment and medical care delays [12].

Overall, AYA’s experiences transitioning off treatment are challenging, complex, and long-term [21, 27, 29]. A registry-based study found that 35 % of survivors working or in school full-time pre-diagnosis believed that cancer had a negative impact on their plans, and greater than 50 % reported problems with work or school post-diagnosis [34]. Acute Lymphocytic Leukemia (ALL) and Non-Hodgkin’s Lymphoma survivors were less likely than other cancers to be working or in school 15 to 35 months post-diagnosis [34]. When examining time since treatment, AYAs greater than 2 years post-treatment were found to have greater adjustment in vocational environments compared to AYAs on active treatment [11].

After one or more years post-treatment for acute leukemia, no significant difference in psychosexual dysfunction was found between those treated with a bone marrow transplant (BMT) and chemotherapy only [30]. By gender, however, females overall reported decreased sexual drive, and female BMT survivors had lower frequency of sexual behaviors than all other groups.

### Survivorship care

Survivorship care is comprised of essential components of care that facilitates access to comprehensive and coordinated care. The IOM has collaboratively defined this to include: prevention of relapse, new cancers or late effects, surveillance/follow-up care of cancer and assessment of medical and psychosocial late effects. This also includes intervention for consequences of cancer treatment, coordination between providers, health insurance access, and treatment-related informational needs. This section was primarily reflected in 14 (37 %) studies and 3 secondarily.

Survivorship, as defined by the National Cancer Institute, includes multifaceted aspects of the physical, psychosocial, and economic issues of cancer, beyond diagnosis and treatment [49]. Issues/concerns and specific needs for AYA survivorship emerged in 10 (26 %) of studies. Qualitative survivorship themes included: feelings about cancer survivorship, work/education participation or outcomes, “being sick nor healthy,” attitudes towards healthcare and intervention modalities, pain/fatigue, sexual functioning and fertility, risk behaviors (e.g., smoking, physical activity), and physical status and health [19, 24, 37, 40].

AYA information needs include information regarding aspects of survivorship that AYAs describe as important, helpful, or particularly lacking in the current healthcare system or survivorship culture. This includes needs at diagnosis, during treatment, and post-treatment. The content of these three areas of need include disease/treatment information and education

regarding issues such as follow-up care, psychosocial resources, or fertility preservation. The primary theme noted in within this domain was the need for care and resources to be targeted to the age-specific and unique needs of the AYA population [45]. Numerous studies emphasized that age-appropriate information and affordable care are critical to providing long-term support to AYAs diagnosed with cancer [22, 42, 43, 53]. The need for flexibility in treatment scheduling to allow for work and family demands was frequently endorsed [35, 54]. A consistent theme was a desire to gain support from peer survivors or peer support groups, who were familiar with the unique challenges of managing cancer at a young age [19, 29, 40]. Informational needs regarding fertility were emphasized [29]. Results noted that many women felt they were insufficiently informed regarding health promotion, fertility concerns and fertility-related treatment effects; although they acknowledged the complexity of addressing this topic in the midst of survival and treatment-related concerns [17, 24, 29]. Older AYAs also described the need for care to foster greater autonomy in care decisions as they aged.

The importance of providing AYAs with relevant information as they transition to survivorship is consistent with the broader literature in cancer survivorship. AYAs desired information concerning possible late and long-term side-effects of treatment, their capacity to pursue family and work-related goals in the future, the transition to survivorship and what to expect, guidance on which health professionals to seek out for various issues, as well as access to supportive care to manage challenges in reintegrating to school and work roles [19, 26, 34]. A multi-center examination of this issue with a survey of 523 AYAs approximately 1 year from treatment for a variety of cancer diagnoses found that more than 50 % reported unmet information needs, primarily around the potential for recurrence and secondary cancers, as well as long-term side effects [20]. Another study found that AYA survivors desired better educational and occupational support services after completing treatment [29]. Further analysis revealed that those who were male, older, non-white, of poorer overall health, with more treatment-related side effects (i.e., >3), and who perceived that their quality of medical care had been poorer were more likely to report unmet needs. Additionally, AYAs reporting poorer physical or mental health also reported greater unmet service and information needs. AYAs with more years elapsed since treatment also tended to report a worse attitude toward their ongoing medical care.

Health services and access to health services are defined generally as availability and access to interventions, medical and survivorship resources, medical appointments, screening, and/or follow-ups, as well as health-care utilization and psychosocial care needs for survivors and families. This additionally can include the delivery of medical information or services, and method interventions are conducted. Among AYAs, common health services and access themes included fertility

preservation and information, cost and location barriers, insurance delays, lack of existing services, and communication with healthcare providers.

Overall, AYAs desire better communication regarding, and access to, fertility preservation options [23, 52, 53]. As noted above, some survivors perceived that such options were provided too late during their treatment, while others reported being provided inadequate information (or time) to make a sound decision, forcing them to make rushed treatment decisions, such as choosing between delayed treatment and infertility risks [17, 24]. A minority noted that providers did not discuss fertility options at all and felt they were not included in a decision that should have been their own [24]. AYAs that were provided with only written fertility information described it as not useful, or useful only to prompt dialogue with providers. Speaking with a fertility specialist was desirable, and women expressed desire to have open and honest discussions with providers regarding fertility [24].

Providers and patients agreed on the importance of having adequate health insurance and follow-up plans [43]. Availability of state-of-the-art, age-specific treatment and adequate health insurance were the most highly ranked healthcare needs among emerging adult survivors [52]. In a population-based study, survivors reported poorer overall health reported greater cost barriers. AYA survivors reported going without care as a result of higher costs than non-cancer controls, and cost barriers were particularly high for 20–29 year-old survivors, and for female survivors [23]. After completion of cancer treatment, survivors are often persistently faced with delayed treatment bills, high health insurance premiums, and long waits for qualify for life insurance due to having a “pre-existing condition” [21].

Post-treatment financial concerns can greatly affect AYA survivors’ independence. As many AYAs must take time off from work or school for cancer care, they may lose insurance benefits and can experience a difficult time re-entering the workforce or re-enrolling in school. Because of treatment bills and continuing follow-up and healthcare costs, AYAs may become entirely financially dependent on their parents during the post-treatment phase [27, 53]. AYAs in their 20s or younger and/or less physically active AYAs were more likely to encounter cost barriers compared with older and/or more physically active AYAs.

Generally, studies reported that older AYAs were more likely to follow-up with oncological care on the recommended schedule. Similarly, females were generally more likely to comply with recommended oncological follow-up (but also experience greater cost barriers) compared to men. However, males were more likely to experience unmet service needs. Hispanic and non-Hispanic black survivors were less likely to participate in studies compared with other racial/ethnic groups, and non-white AYA survivors were more likely to experience unmet service needs. Additionally, geographic

location also creates barriers for this population. For example, patients living in rural communities, compared to urban areas, have limited access to the specialized cancer care resources and services, often resulting in delayed diagnoses [28].

With respect to study quality, 6 of the 38 articles (16 %) satisfied all 9 indicators from the modified Downs and Black study quality checklist [46]. Eighteen of the included articles (47 %) were only missing 1 of the 9 quality indicators, with the vast majority of these studies not specifying whether the subjects who were prepared to participate were representative of the entire population from which they were recruited. A total of 13 articles (34 %) were missing 2 of the 9 quality indicators, with one remaining article missing 5 quality indicators [43].

## Discussion

This review summarized topics across 38 published studies among AYAs diagnosed with cancer exclusively as an adolescent or young adult. Using existing QOL domains and recommendations from the Institute of Medicine (IOM), we classified our review based on four key areas: physical well-being and symptoms, psychological well-being, social well-being, and survivorship care. The range of presented quality of life concerns (physical, psychological, social) emphasize the AYAs’ experience as described and reported as challenging, complex, and nuanced. Due to the unique developmental challenges of AYAs, this group is positioned to experience different outcomes from childhood or older adult survivor counterparts, and is underrepresented in the literature.

Survivorship care was represented in the largest number of studies, suggested the long-term and life-long impact on this group. These needs parallel the developmentally rich period of physical and psychological growth and autonomy that is normative for AYAs and coincides with their cancer diagnosis, treatment, and post-treatment survivorship. This growth involves both a family system (e.g., parental involvement during treatment) and may complicate or challenge the natural progression towards independence over time (e.g., financial independence, intimate relationships, autonomy over medical care).

AYAs require age-appropriate and flexible care and informational needs that garner autonomy geared towards long-term survivorship; these findings are supported by the IOM’s workshop on AYAs with cancer (of note, this summary includes survivors of pediatric cancer as well) [48]. AYAs reported need for specific medical, psychosocial, and healthcare related information early during and post-treatment (e.g., fertility options, concerns). The importance of providing this information is an underemphasized area for AYAs, and is a potentially appropriate and necessary element of AYAs’ growth and a sign of greater medical knowledge,

recognition of the importance of appropriate follow-up care, and psychological growth. Findings suggest providers and families are cautious or shy away from delivering information about short- and long-term effects of treatment. However, some results were conflicting, such as findings that cancer negatively impacts social relationships, but may also strengthen parent and sibling relationships. Women demonstrated greater internalized mental health outcomes; greater psychosocial stress was found to increase likelihood of obtaining mental health treatment and complying with follow-up care. Obtaining mental health treatment and follow-up care were also found in other studies to improve outcomes. The gender difference highlights unique moderators and areas that can impact outcomes, such as greater physical activity, treatment type (i.e., bone marrow transplant, chemotherapy), or age at diagnosis. Solidifying potential moderators provides medical providers with points of entry for greater education, screening, and intervention. This may include providing AYA's with specific post-treatment exercise recommendations appropriate for their condition, or recommending body awareness approaches (e.g., yoga, Pilates, Tai Chi) or physical activity programs (e.g., First Descents).

## Limitations

Numerous challenges exist for conducting research with this cohort, including small sample sizes, unknown selection biases (particularly for qualitative studies), self-report limitations (e.g., no ability to confirm diagnosis/treatment, lack of participants' knowledge of specific treatments received), limited generalizability, and lack of a comparison or control group. Acquiring parental consent and participants who are minors may deter institutions and IRB's away from establishing creative and innovative study recruitment and retention methods, relying on established registries or databases that often do not differentiate those diagnosed exclusively during AYA. Qualitative and large database analyses are limited by low minority representation and recruitment from rural or suburban cancer centers [18]. Overall, these limitations, along with AYAs' changing contact information (housing or employment transitions), preferred contact method (e.g., email, paper mail, landline, cell phone) and schedule for participation (accommodating school/college schedule), impact retention and participation. Results demonstrate a lack of longitudinal data with psychometrically validated measures to track outcome change; this overlooks time-sensitivity and its overlap with development during these ages [29]. Additionally, 16 % of included studies reported outcomes among international AYA populations, which can limit generalizability because health care systems and access vary greatly internationally.

## Future directions

At diagnosis and the start of treatment, healthcare providers and interventions should provide AYAs and families with greater resources about fertility (particularly for women), sexual functioning, late effects of treatment, social networks for survivors, disclosure, re-entering school/work, and attaining revised educational/career goals. These issues are developmental and not static; they should be established and adjusted over time since treatment and AYAs' age. They should be reflected in follow-up care, survivorship care planning, continuing educational interventions (e.g., consultations, education pamphlets/programs), and direct provider training. Future research should examine the effect of disruptions in educational, occupational, and family planning trajectories on QOL. Additionally, spirituality was examined in only one included study [26], and should be explored further among AYA survivors. In communities, educational or information-based workshops in high schools or college orientations may address the lack of understanding from AYAs' social networks, and ease challenges in disclosing.

Qualitative methodologies were used in 40 % of these studies, highlighting a range of AYA concerns that have not yet been addressed in traditional psychological measures, thereby making validated quantitative measurement or screening difficult. As this literature broadens, more targeted quantitative work and interventions should be applied to specific outcomes found in these studies. A dearth of work has addressed AYA-specific interventions, as only 3 papers were intervention studies. 24 % of included studies used population or registry-based surveys, highlighting feasibility for future researchers to use large databases to target specific outcomes among AYAs that can reach a larger community and diverse population.

To address AYAs' desire for more, rather than less, information, interventions and studies should explore what, when, and how much information minors and/or parents are provided, as well as the delivery and use of survivorship care plans. Findings suggest developing specific interventions targeting finances, relationships, body image issues, physical activity, and support to attain educational goals during and post-treatment. Interventions using social media or online components were found to be feasible and accessible to address these areas. Delivering care and interventions to AYAs from minority groups and living in rural areas is limited, delayed, and found to have negative impact on psychosocial outcomes. Additional barriers to utilizing interventions and study methodology should be explored. Furthermore, identifying barriers to accessing healthcare services during and post-treatment provides direction for providers and families to effectively advocate for their specific healthcare. This is a unique population that engenders multifaceted variables contributing to post-treatment outcomes. As such, they require equally multifaceted care and consideration in research and clinical practice.

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### Compliance with ethical standards

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**Conflict of interest** The authors declare that they have no conflicts of interest.

## Appendix

**Table 2** Complete list of medical subject heading (MeSH) and keyword terms

Search Query	Items found
#4 Search #1)AND#2)AND#3	16,493
#3 Search [outcome OR “Outcome and Process Assessment (Health Care)” MeSH] OR outcomes OR result OR results OR adaptation OR “Adaptation, Psychological” (MeSH) OR “Acclimatization” (MeSH) OR adjustment OR “Social Adjustment” (MeSH) OR distress OR “quality of life” OR “Quality of Life” (MeSH) OR QOL OR coping OR “unmet needs” OR “Needs Assessment” (MeSH)] Sort by: PublicationDate	6,417,999
#2 Search [psychology OR “Psychology” (MeSH) OR psychological OR psychosocial OR “Psychotherapy” (MeSH) OR psychiatry OR “Psychiatry” (MeSH) OR psychiatric OR support OR “Social Support” (MeSH) OR behavior OR “Behavior Therapy” (MeSH) OR “behavioral” OR “cognitive behavioural” OR CBT OR talk OR integrative OR “Integrative” (MeSH) OR alternative OR “Complementary Therapies” (MeSH) OR breathing OR meditation OR family OR psychopharmacology OR psychotropic OR “Psychotropic Drugs” (MeSH) AND (intervention OR “Intervention Studies” MeSH) OR treatment OR “Therapeutics” (MeSH)] Sort by: PublicationDate	3,096,896
#1 Search [adolescent OR “Adolescent” (MeSH) OR “young adult” OR “Young Adult” (MeSH) AND (neoplasm OR “neoplasms” (MeSH) OR neoplasms OR malignan* OR sarcoma OR sarcomas OR carcinoma OR carcinomas OR tumor OR tumors OR tumour OR tumours OR lesion OR lesions OR cancer OR neoplasia) AND (survivor OR “Survivors” (MeSH) OR survivors OR survivorship)] Sort by: PublicationDate	43,473

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