

Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review

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Abstract: Adolescents and young adults (AYAs) with cancer must simultaneously navigate the challenges associated with their cancer experience, whilst striving to achieve a number of important developmental milestones at the cusp of adulthood. The disruption caused by their cancer experience at this critical life-stage is assumed to be responsible for significant distress among AYAs living with cancer. The quality and severity of psychological outcomes among AYAs remain poorly documented, however. This review examined the existing literature on psychological outcomes among AYAs living with cancer. All psychological outcomes (both distress and positive adjustment) were included, and AYAs were included across the cancer trajectory, ranging from newly-diagnosed patients, to long-term cancer survivors. Four key research questions were addressed. Section 1 answered the question, “*What is the nature and prevalence of distress (and other psychological outcomes) among AYAs living with cancer?*” and documented rates of clinical distress, as well as evidence for the trajectory of this distress over time. Section 2 examined the individual, cancer/treatment-related and socio-demographic factors that have been identified as predictors of these outcomes in this existing literature. Section 3 examined current theoretical models relevant to explaining psychological outcomes among AYAs, including developmental models, socio-cognitive and family-systems models, stress-coping frameworks, and cognitive appraisal models (including trauma and meaning making models). The mechanisms implicated in each model were discussed, as was the existing evidence for each model. Converging evidence implicating the potential role of autobiographical memory and future thinking systems in how AYAs process and integrate their cancer experience into their current sense of self and future goals are highlighted. Finally, Section 4 addressed the future of psycho-oncology in understanding and conceptualizing psychological outcomes among AYAs living with cancer, by discussing recent empirical advancements in adjacent, non-oncology fields that might improve our understanding of psychological outcomes in AYAs living with cancer. Included in these were models of memory and future thinking drawn from the broader psychology literature that identify important mechanisms involved in adjustment, as well as experimental paradigms for the study of these mechanisms within analogue, non-cancer AYA samples.

Keywords: Adaptation; psychological; adolescents; young adults; neoplasms; experimental studies

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The adolescent and young adult (AYA) years are a time of complex developmental change. During this period, young people strive towards gaining autonomy and independence, whilst forming important adult social, emotional, and

adaptive coping skills (1,2). A diagnosis of cancer at this stage can challenge and interrupt these aspects of development. Young people's underdeveloped coping skills can also interfere with their capacity to successfully

navigate the demands of the cancer experience. Combined, these factors may contribute to young people's suboptimal treatment-related outcomes, as well as the documented challenges of long-term cancer survivorship (3,4). Given the many years of life that lie ahead for young people following successful cancer treatment, the manner in which AYAs adjust to the experience, and the subsequent quality of their survival, is important to understand.

In order to improve the psychological outcomes of this group, research must move beyond merely documenting the prevalence and nature of poor outcomes, to identifying factors that may underpin the emergence of these psychological outcomes (5). This review aimed to address several significant gaps in the current literature on the psychological outcomes in AYAs with cancer. In particular, the following research questions were posed:

- I. What is the nature and prevalence of distress (and other psychological outcomes) among AYAs living with cancer?
- II. What individual, cancer/treatment-related and socio-demographic factors have been identified as predictors of these outcomes?
- III. What mechanisms of action have been suggested by relevant theoretical models of AYA psychological adaptation to cancer, and what available evidence is there for these?
- IV. What empirical advancements in adjacent, non-oncology fields have been made that might improve our understanding of psychological outcomes in AYAs living with cancer?

Research question 1: what is the nature and prevalence of distress (and other psychological outcomes) among AYAs living with cancer?

The wide range of reported distress seen in AYAs with cancer has been frequently noted in the literature (6,7), although to date there has been no comprehensive review of psychological outcomes in this group. Empirical and clinical definitions of "AYA" also vary widely, ranging from 10-44 years across reports depending upon whether they are based on age, or developmental stage (8). For the purposes of this review, the broadest age range of AYAs living with cancer was used (i.e., AYAs could be current patients, recent, or long-term survivors of cancer) in order to capture data across the cancer trajectory within this developmental stage. Studies were included if participants were either (I) diagnosed with cancer during the AYA years; or (II) an AYA

survivor of a pediatric cancer. All forms of psychological outcomes were examined in this review. Across studies, sample sizes have ranged from N=16 (9) to 9,126 (10), and in order to include all relevant studies, have included samples of young people from eight years old (11,12) and long-term survivors of cancer as old as 54 (13), from 4-8 weeks post-diagnosis (14) up to 41 years post-diagnosis (15). *Table 1* presents the data extracted on prevalence of psychological outcomes, and echoes the wide range of findings.

Clinical distress

Across the studies examined, 'clinical' levels of distress was variously defined as meeting criteria for the diagnosis of a mental disorder (e.g., post-traumatic stress disorder; PTSD) to scoring highly enough or beyond a clinical 'cut-off' score on a particular measure (e.g., anxiety or depression symptoms). Rates of clinical distress ranged from 5.4% (50) to 56.5% (27). A large proportion of studies reviewed (23/54) focused on post-traumatic stress symptoms (PTSS) to capture the occurrence of post-cancer distress. Of these studies, the prevalence of clinically elevated PTSS ranged from 4.8% partial PTSS combined with associated functional impairment or distress (47) to 78% with partial PTSS (30), and for diagnoses of PTSD to range from 0% (for PTSD specific to a cancer trauma) (31) to 29% PTSS indicative of possible PTSD among AYAs within 16 months of diagnosis (56). Several studies reported clinical PTSD in approximately one-fifth of their sample, however (23,25,37,42,56).

Estimated rates of clinical depression range from 5% moderate-severe depression symptoms (62) to 24% mild/major depression diagnoses (59). Reported rates of clinical anxiety range from 12% (14) to 23% among recently diagnosed AYAs (17). A growing number of studies (32,33,43,49,51,52,55,57) used the Brief Symptom Inventory-Short Form to measure distress (BSI-18) (63) which provides a composite distress score of depression, anxiety and somatic distress, and has a good factor structure in AYA survivors of childhood cancer (43). These studies found clinical distress ranged from 11% (51), to 22.2% (52) among long-term AYA cancer survivors, and up to 28% in AYAs within four months of diagnosis (57).

Trajectory of distress

Only a few studies compared AYAs' psychological outcomes across different stages of treatment, or examined the

Table 1 Prevalence and nature of psychological outcomes documented among AYAs with cancer

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
On treatment/recently diagnosed						
Allen, 1997 (16)	N=42	12-20 (M =15.4)	All cancers (57% bone sarcomas)	Newly diagnosed ≤ 9 weeks ago	33% of AYAs with cancer had mild-moderate depression vs. 16% controls. Moderate-severe depression seen in 5% of AYAs vs. 13% controls. No differences in anxiety between AYAs and controls	–
Dyson, 2012 (17)	N=53 (Female 43%)	16-30	All cancers (57% sarcomas)	Newly diagnosed ≤ 4 months ago	25% of participants experienced elevated levels of distress ≤ 4 months post-diagnosis diagnosis. 17% scored ≥ clinical cut-off for depression, and 23% scored 1 SD > mean on anxiety symptoms	–
Hedström, 2005 (14)	N=56 (Female 42.8%)	13-19	All cancers (35.7% lymphoma)	Newly diagnosed (4-8 weeks prior)	Clinical anxiety symptoms were seen in 12% of patients, and depression symptoms in 21%. Ratings of mental health and vitality QoL were also lower than norm values	–
Mattsson, 2009 (18)	N=61 (Female 39%)	13-19 (M =16±1.6)	All cancers, primary or recurrent dx (26% ALL)	Diagnosed ≤ 18 months ago	Soon after diagnosis, more AYAs than expected by chance showed psychosocial dysfunction, and 'incomplete' psychosocial functioning, with fewer showing good/excellent psychosocial functioning. At 18 months, more AYAs showed excellent psychosocial functioning (38%), and fewer showed incomplete psychosocial functioning	–
Wilder Smith, 2013 (19)	N=523 (Female 36.7%)	15-41 (50.5% ≤ 29 years at study)	All cancers (39.0% germ cell tumors)	Diagnosed 6-14 months ago at study entry	AYAs reported significantly worse HRQoL (physical and mental health scales) than general and healthy populations. AYAs aged 15-17 reported worse physical and work/ school functioning than AYAs aged 18-25. AYAs aged 18-24 years reported significantly worse general health, physical functioning, physical role limitations, and emotional role limitations compared with population norms	–

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Zabora, 2001 (20)	N=4,496 (Female 58%)	19-95 (15.7% aged 19-39)	All cancers (breast cancer 27.8% of total sample)	Range up to \geq 4 years post-diagnosis (58% newly-diagnosed)	Clinical distress levels (measured by the BSI-18) were detected in 42% of <20 years old, 40.1% of 20-29 years old, and 37.5% of 30-39 years old, compared to an overall sample mean of 35.1%	–
Recently off-treatment/early survivorship						
Arpawong, 2013 (21)	N=94 (Female 48%)	11-21	All cancers (38% leukemia)	Recently off-treatment (\leq 6 months)	Survivors with higher PTSS & depressive symptoms had lower PTG	Survivors more likely to report a positive change in PTG than negative/no change
Barakat, 2006 (22)	N=150 (Female 52%)	11-19	All cancers (35.1% solid tumors)	Post-treatment \geq 1 year	–	84.7% reported \geq 1 positive changes post-cancer; 32% had \geq 4
Hobbie, 2000 (23)	N=78 (Female 50%)	18-40 (M =25 \pm 4.4)	All cancers (37.2% ALL)	Post-treatment \geq 18 months (M =11.0 \pm 5.5 years)	20.5% of survivors met PTSD criteria since treatment completion. Clinically significant avoidant (16.7%) and intrusive (9%) symptoms also reported by a minority. AYAs with PTSD also had elevated scores on depression and other facets of anxiety (e.g., obsessive-compulsive or phobic anxiety) relative to survivors without PTSD	–
Lebel, 2013 (24)	N=3,239 (Female 100%)	18-34 (subset n=100)	Breast cancer	Post-treatment (M =2.87 \pm 3.94)	Women aged 18-34 and 35-49 expressed the highest levels of FCR, with 18-34 years old reporting the greatest total FCR than women in all older age categories. AYAs aged 18-34 reported more worries about health, womanhood, role, and death, than older women	–

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Schwartz, 2006 (25)	N=57	18-28 (M = 21.7±2.65)	All cancers (26.3% ALL)	Off-treatment ≥ 1 year (in remission)	AYAs ~5 times more likely to have PTSD (rate of 17.5%) vs. controls (3.6%). Survivors reported worse physical HRQoL and less positive affect than controls	–
Servitzoglou, 2008 (26)	N=103 (Female 57%)	15-29 (M =19.8)	All cancers (49.5% leukemia)	Off-treatment ≥ 2 years	AYAs had significantly higher anxiety vs. controls. AYAs scored lower on some aspects of self-esteem, social functioning, reported more frequent health-related worries, and used ‘distancing’ coping strategies more often than controls. Almost half of AYAs (48.6%) did not feel comfortable discussing their illness experience with friends. Fewer AYAs reported having “high professional expectations and ambitions” (49.5% vs. 65.2% of controls)	AYAs more optimistic (65% vs. 55.2%) and less uncertain (31.1% vs. 35.5%) about their future; rated family/friends as more supportive
Stuber, 1997 (12)	N=186 (Females 50%)	8-20	All cancers (32% leukemia)	Off-treatment ≥ 1 year	Mean total PTSS score in mild range. Top four endorsed symptoms: changed world view 22.0%, changed activities 21.9%, increased arousal 18.4%; and changed interpersonal relationships 15.3%	–
Yanez, 2013 (27)	N=322 (Female 68.4 %)	18-39 (M =31.8)	All cancers (23.9% breast)	Off-treatment 0-60 months (M =21.2±16.7 months)	Mean PTSS score on the IES > the cut point of 20, suggesting clinically elevated distress. 56.5% of the sample indicated clinically elevated PTSS	–
Long-term survivorship						
Alderfer, 2009 (28)	N=144 (Female 52%)	11-19 (M = 14.7±2.4)	All cancers (31% leukemia)	1-12 years post-treatment (M =5.3±2.9 years)	8.3% of survivors in this sample qualified for a diagnosis of PTSD at some time since their cancer diagnosis	–
Chan, 2013 (29)	N=614 (Female 41.4%)	16-39 (M = 21.9±5.6)	All cancers (45.4% leukemia)	≥5 years post-diagnosis	19% survivors and 22% sibling controls had clinically significant distress. Survivors had lower scores in physical role and functioning, but similar mental, social, and psychological well-being to siblings	–

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Erickson, 2001 (30)	N=40 (Female 65%)	12-35 (M =20.3)	All cancers (55% ALL)	≥5 years post-diagnosis	10% of all participants met full current PTSD criteria, with a further 78% meeting partial PTSD criteria (having ≥1 re-experiencing, avoidance, or increased arousal symptom criteria at a functionally significant level, defined as a moderate severity score ≥2)	–
Gerhardt, 2007 (31)	N=56 (Female 44%)	≥18 (M = 18.6±0.75)	Non-CNS cancers (39% lymphoma)	Long-term survivors (M =7.29±2.17 post-diagnosis)	29% AYAs reported a trauma, and 9% AYAs reported a cancer-related trauma. No AYAs with cancer traumas met PTSD criteria, and only 3 reported ≥1 PTSS (60%). Fewer AYAs with cancer traumas (vs. non-cancer traumas) had PTSD or significant PTSS	–
Gianinazzi, 2013a (32)	N=407 (Female: 45%)	16-19	All cancers (33% leukemia)	≥5 years post-diagnosis	13% AYAs met clinical distress cut-off vs. 11% siblings. More women than men met distress cut-off. Distress worse among survivors relative to distressed siblings, German adolescents, and community psychotherapy patients (anxiety/somatization). Male survivors > siblings in somatization, depression, and in the GSI	–
Gianinazzi, 2013b (33)	N=1,602 (Female 47%)	≥16 (M = 25.1±8.1)	All cancers (36% leukemia)	≥5 years post-diagnosis (M =20.5±7.4 years)	14% of AYAs were clinically distressed (BSI-18) and overall, 10% utilized mental health-care services. 14% of siblings were also clinically distressed, and overall 8% of siblings had utilized mental health-care services	–
Kamibeppu, 2010 (34)	N=185 (Female 58.3%)	16-40 (M =23)	All cancers (57% leukemia)	≥5 years post-diagnosis	No differences between AYAs vs. controls on depression and anxiety. Females > males on depression and anxiety across survivors & controls. Female AYAs > controls on total PTSS and hyperarousal scores, while male AYAs > controls on total PTSS and subscales	Survivors > controls on PTG, both for total score and all subscales (females and male)

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Kazak, 1989 (35)	N=35 (Female 37%)	10-15 (M =12.2)	ALL, AML, NHL	≥5 years post-diagnosis	No differences between AYAs & controls on parent-rated internalizing, externalizing, behavior problems, or social competence	–
Kazak, 1997 (11)	N=130 (Female 49%)	8-19 (M = 13.5±3.36)	Leukemias (83.9% ALL)	Post-treatment ≥ 1 year	AYAs did not show significantly greater PTSS compared to healthy controls: 12.6% and 1.6% of survivors had PTSS scores in moderate/severe ranges respectively, vs. 14%/1.4% in controls. Survivors had lower PTSS scores vs. stressed/traumatized controls	–
Kazak, 2001 (36)	N=130 (Female 50.2%)	18-36 (M = 25±4.04)	All cancers (25.2% ALL)	≥5 years post-diagnosis	6.2% AYAs met criteria for full, current PTSD diagnosis. 63.3% AYAs fulfilled Criterion B (re-experiencing symptoms) while 31% fulfilled Criterion D (Arousal symptoms). Avoidance (Criterion C) symptoms were less commonly reported (14.7%)	–
Kazak, 2004 (37)	N=150 (Female 52%)	11.1-19.3 (M = 14.7±2.4)	All cancers (30.5% leukemia)	Long-term CCS: M =5.3±2.9 post-treatment	17.6% of AYAs had moderate-severe PTSS. 4.7% AYAs met criteria for current PTSD and 8.0% for PTSD since diagnosis. Most AYAs met criteria for PTSD cluster B symptoms (re-experiencing), and 41.3% met criteria for PTSD cluster D	–
Kazak, 2010 (38)	N=167 (Female 53%)	16-30 (M = 20.5±3.2)	All cancers (44.9% leukemia)	Long-term survivors: ≥ 5 years post-diagnosis	No differences between AYAs and controls in psychological distress (general distress or post-traumatic stress) or HRQoL. Cancer survivors had less positive (lower healthy competency) health beliefs	Survivors scored higher than controls in satisfaction with health care
Langeveld, 2004 (39)	N=500 (Female 47%)	16-49 (median =24)	All cancers (43% solid tumors)	Long-term survivors: ≥ 5 years post treatment	12% of AYAs showed severe PTSS scores. Female AYAs had severe scores at a rate of 20% compared to 6% among male survivors	

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Lee, 2007 (40)	N=45 (Female 62%)	22-47 (M = 27.4±5.54)	All cancers (37.8% leukemia)	Post-treatment 4-31 years (M = 14.2±6.1 years)	13.3% of AYAs had scores indicative of possible PTSD. Almost two-thirds (62%) had clinically significant symptoms in one of the three symptom clusters. High levels of re-experiencing (40%), arousal (55.5%) and avoidance (24.4%) also found	–
Maunsell, 2006 (41)	N=1,334 (Female 52%)	15-37 (M = 23.0±5.2)	All cancers (25% leukemia)	≥5 years post treatment	Fewer AYAs (62.1%) than controls (71.1%) reported very good/excellent general health. However, QoL differences between AYAs and controls were small, possibly not clinically important	–
Meeske, 2001 (42)	N=51 (Female 43%)	18-37 (M = 24±4.3)	All cancers (39.0% leukemia)	CCS: 2.8-26.7 years post-treatment	20% of AYAs met full PTSD criteria. AYAs with PTSD reported clinically significant levels of psychological distress and significantly lower QoL on all domains, compared to the non-PTSD group	–
Phillips-Salimi, 2012 (4)	N=651 (Female 81.3%)	M = 33.49±8.36	All cancers (41.9% cervical cancer)	CCS: 0-30 years post-diagnosis (M = 17.1±8.1 years)	Controlling for age, sex, and minority status, AYAs reported poorer socioeconomic outcomes, life satisfaction, social and emotional support, general health, and reported more comorbid conditions, days/month of poor physical and mental health than controls	–
Phillips-Salimi, 2013 (15)	N=100 (Female 100%)	18-59 (M = 39.5±10.79), diagnosed 15-29	All breast/gynaecological cancers (69% cervical)	CCS ≥1 year post-diagnosis (M = 16.7±10.0 years, range 1-41 years)	AYAs reported significantly poorer physical and mental health scores (on 7/8 indices) relative to controls without cancer. Survivors were four times more likely to meet criteria for significant psychological distress than controls. No differences between groups on level of functional impairment associated with this distress	–

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Recklitis, 2006 (43)	N=8,945	18-48 (median = 26; 50.8% aged 18-26)	All cancers (29.4% leukemias)	CCS: 6-29 years since diagnosis (median = 17 years)	AYAs reported significantly lower distress scores than gender-matched community norms. The prevalence of significant psychological distress was also lower (7.4% of men, 9% of women) than community rates (10%). AYAs' psychological symptoms (18.9% with clinical distress) were also significantly lower than scores reported in adult cancer patients (22.3%)	–
Recklitis, 2010 (10)	N=9,126 (Female 47.3%)	18-48 (66.5% aged 18-29)	All cancers (29.4% leukemias)	CCS: 6-29 years since diagnosis	A significantly higher proportion of CCS reported suicidal ideation (7.8%) relative to sibling controls (4.5%)	–
Rourke, 2007 (44)	N=182 (Female 53.8%)	18-37 (M = 24.8±4.5)	All cancers (25.8% leukemias)	≥5 years post-diagnosis and ≥2 years post-treatment	15.9% of survivors met full PTSD criteria since finishing cancer treatment, and of these 90% met criteria for current PTSD (14.3% total sample). Most AYAs (75.3%) met criteria for re-experiencing symptoms (Criterion B), almost half (47.3%) met criteria for arousal symptoms (Criterion D), while 25.8% met criteria for avoidance symptoms (Criterion C)	–
Seitz, 2010 (45)	N=820 (Female 52%)	M = 30.4±6.0 years	All cancers (30.5% lymphomas)	≥5 years post-treatment (M = 13.7±6.0 years)	Survivors were ~twice as likely as controls to report clinically significant distress: 22.4% survivors had clinically relevant PTS, anxiety and/or depression symptoms vs. 14.0% controls. Both male and female AYAs >3 times more likely to show significant PTSS vs. controls. Female survivors also ~twice as likely to report depression/anxiety symptoms vs. controls. 24.3% survivors met DSM-IV criteria for ≥1 mental disorder vs. 15.3% controls. Both anxiety disorders and depression detected more often in survivors (16.5% and 14.9% respectively) than controls (11.0% and 9.3%)	–

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Stuber, 2010 (46)	N=6,542 (Female 52.3%)	18-53 (M = 31.85±7.55)	All cancers (33.4% leukemia)	Long-term survivors: 15-24 years since dx	N=589 (9%) of the survivors reported a pattern of symptoms, clinical distress and/or functional impairment consistent with a PTSD diagnosis, a rate four times greater than in siblings (2%)	
Stuber, 2011 (47)	N=6,542	As above	As above	Long-term survivors	Rates of survivors meeting criteria for clinical distress depended on criteria used: 9% of survivors met full criteria for PTSD + functional impairment; 7.5% met full PTSD criteria without impairment; 4.8% showed partial symptoms + impairment/distress; and 11.4% met partial symptoms without impairment/distress	
Teall, 2013 (48)	N=28 (Female 50%)	18-32 (M = 25.1±4.5)	Bone tumors	Long-term survivors ≥ 5 years post-diagnosis	Survivors reported significantly less depressive symptoms compared to community adult norms	Survivors reported significantly higher social support and self-evaluations of intellectual capabilities vs. norms
Wenninger, 2013 (49)	N=164 (Female 50.6%)	18-46 (M = 28.9±7.0)	All cancers (leukemia 41.4%)	CCS: 0-23 years post-treatment (M = 2.6±4.0)	14% of AYAs had scores indicative of clinically significant PTSD. The risk of developing PTSD was highest in solid tumor survivors (26%) compared with other diagnoses (11%). More survivors identified with clinical distress in symptoms of depression, anxiety and somatization (17%) vs. population norms (10%)	

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Zebrack, 2002 (50)	N=5,736 (Female 44.6%)	18-48 (M = 26.9±6.2, median =26)	Leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma	CCS: 5-29 years post-diagnosis (M =16.3±4.8 years)	AYAs ~1.6-1.7 times more likely to report clinical depressive symptoms and somatic distress vs. comparison siblings. 5.4% of leukemia/lymphoma survivors showed symptomatic levels of depression, compared to 3.4% of siblings. More AYAs (12.7%) had clinically significant somatic distress than siblings (8.0%). Hodgkin's disease survivors (15.0%) had the highest rates of somatic distress followed by leukemia (11.6%) and NHL survivors (11.4%)	
Zebrack, 2004 (51)	N=1,101 (Female 46%)	18-44 (M = 26.5±5.5)	Brain cancer	CCS: ≥5 years post-diagnosis	11% of AYAs reported clinically significant distress vs. 5% siblings and rates were similar to general population norms. However, brain cancer survivors appear more likely to report symptoms of distress, particularly depression, compared to healthy siblings	
Zebrack, 2011 (52)	N=621 (Female 52.8%)	18-39 (diagnosed ≤ 21 years)	All cancers (61% hematological disease)	Off-treatment and disease-free: 2-37 years post-diagnosis (median =16)	BSI-18 scores indicated that 22.2% of survivors exceeded the threshold for "caseness for distress" (i.e., clinical distress)	
Zeltzer, 2008 (13)	N=7,147 (Female 51.3%)	18-54 (median =32)	All cancers (29.2% ALL)	CCS: 15-34 years post-diagnosis (median =23)	Survivors reported significantly greater symptoms of global distress vs. comparison siblings; however scores for both groups were still below population norms. Survivors showed poorer overall physical HRQoL, but not emotional aspects of HRQoL	Most survivors reported present, and envisioned having future, life satisfaction

Table 1 (continued)

Table 1 (*continued*)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Longitudinal/cross-sectional studies						
Decker, 2007 (53)	N=193 (Female 45%)	11-22	All non-CNS cancers	Recent (1-4 years post-diagnosis) and long-term survivors (≥5 years post-diagnosis)	Focus but not overall level of uncertainty differed according to time since diagnosis. Newly diagnosed: higher uncertainty for future pain, the unpredictable illness course, staff responsibilities, and self-care concerns. Survivors ≥5 years: higher uncertainty related to knowing what was wrong, and more unanswered questions and about the probability of successful treatment	
Jörngården, 2007 (54)	N=42 (Female 45.2%)	13-19 at diagnosis (M =15.7)	All cancers (47.6% lymphoma)	Newly diagnosed AYAs followed up at 6, 12 and 18 months	At diagnosis: AYAs with cancer reported significantly higher depression and lower vitality and mental health HRQoL vs. controls; no differences on anxiety. At 6-month: AYAs had worse Vitality and Mental Health HRQoL; no differences on anxiety or depression. At 12-month: AYAs did not differ from controls. At 18-month: AYAs with cancer reported lower levels of anxiety and depression, and higher Vitality HRQoL vs. controls	
Kim, 2013 (55)	N=223 (Female 41.4%)	15-39 (M = 21.92±4.69)	All cancers (71.7% hematological cancers)	Recent to long-term survivors (post-diagnosis ≥ 2 years)	Both male and female AYAs > norms on total distress scores. 20.6% had significant distress on the BSI-18. More psychologically distressed AYAs (18.5% of male and 23.9% of female) than US population norms. Distress prevalence ranged from 50% among survivors diagnosed > 20 years ago, to 8.1% of those diagnosed 10-14 years ago. Reported distress highest in solid/ soft tissue tumors (31.2%) and lowest for CNS/brain cancer (6.7%)	–

Table 1 (*continued*)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Kwak, 2012 (56)	N=151 (Female 45%)	15-39	All cancers (23.4% leukemia)	≤1 year post-dx	At 6 and 12 months, 39% and 44% of participants reported moderate-severe levels of PTSS; 29% had PTSS levels suggestive of PTSD. No differences in PTSS severity between 6-12 months	–
Kwak, 2013 (57)	N=215 (Female 47%)	14-39 (M =22.7)	All cancers (23.4% leukemia)	On treatment: assessed ≤ 4 months post-diagnosis and 6 and 12 months later	Within the first 4 months of diagnosis, 28% had BSI-18 scores indicative of clinical distress. Distress symptoms were greater than population norms at diagnosis, reduced at the 6-month follow-up, but increased to a level exceeding population norms at the 12-month follow-up. A statistically but not clinically significant decline in distress over one year was observed	–
Larsson, 2010 (58) (NB: follow-up from Jörngården, 2007)	N=39 (Female 46.2%)	13-19 at diagnosis (M = 19.8±1.7)	All cancers (46.2% lymphoma)	Newly diagnosed, followed up at 6, 12, 18, 24, 36 and 48-month post-diagnosis	See above for data up to 18 months (Jörngården, 2007). At 18-month: AYAs with cancer reported lower levels of anxiety and depression, and higher Vitality HRQoL compared with healthy controls. At 24-month: AYAs had lower anxiety and depression symptoms vs. controls. At 36-month: AYAs report lower depression symptoms vs. controls. At 48-month: AYAs report lower depression & anxiety, and better vitality HRQoL vs. controls	
Oren, 2012 (9)	N=16 (Female 66%)	10-18 (M = 15.0±1.9)	Differentiated thyroid cancers (DTC)	Time since dx: < 12 mo., 25%; 12-24 mo., 12.5%; >24 mo., 62.5%	Adolescent DTC patients did not have significantly different QoL or anxiety compared with autoimmune hypothyroidism (comparison) patients and with healthy population norms. QoL and anxiety level parameters were not influenced by age, time since diagnosis, or medical factors measured at the time of assessment	

Table 1 (continued)

Table 1 (continued)

First author, year (Reference)	Sample	Age range (years)	Cancer type(s)	Treatment status	Prevalence of distress	Positive adaptation
Tebbi, 1988 (59)	N=30 (Female 47%)	13-21 (M = 17.5±2.7)	Not specified	Range of time since diagnosis 1-228 months, (M =62±59.6 months)	Questionnaire responses indicated 13% AYAs reported moderate depression, and no AYAs had severe depression. Females had significantly higher distress than males. Interview-based data indicated that 14% AYAs had mild (minor) depression, and 10% had major depression	
von Essen, 2000 (60)	N=51 (Female 43%)	8-18 years; subgroup 10-18 years	Mix (27% ALL)	On and off-treatment; ranged from 1-106 months post-diagnosis	No differences in distress between on and off treatment groups. On treatment: neither self-esteem, depression, nor anxiety scores for 10-18 y differed from norms. Off-treatment: self-esteem scores lower than norms, in particular for subscales "Physical components" and "Psychological well-being". Off-treatment AYAs also reported higher depression and anxiety symptoms vs. norms. Of the 14% who met the cut-off for mild depression 86% of these were off treatment	
Walker, 2010 (61)	N=51 (Female 43%)	10-19 (M = 14.2±2.7)	All cancers (41% ALL)	Assessed pre (T1) and 1 week post (T2) chemotherapy administration	No differences were found in symptom distress between T1 and T2. The top three most frequent symptoms causing distress at both time-points were physical (at T1: tiredness, pain, and appetite changes, all >50% frequency; T2: tiredness, nausea, and pain/appetite changes, 47.8-67.4% frequency). About one-third reported distress associated with sadness at both time-points (32.6%) and a similar proportion reported significant worry (T1: 30.6%, T2: 26.1%)	

Abbreviations: ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; AYA, adolescent and young adult; BSI-18, Brief Symptom Inventory-Short Form; CCS, childhood cancer survivor(s); CNS, central nervous system; GSI, Global Severity Index (of the BSI-18); HRQoL, health-related quality of life; M, mean; NHL, non-Hodgkins lymphoma; PTSD, post-traumatic stress disorder; PTSS, post-traumatic stress symptoms; QoL, quality of life.

trajectories of their distress over time (see *Table 1*). One group has reported heightened distress at diagnosis that reduced over the subsequent 18-month period to the point where AYAs showed better wellbeing than healthy controls (54,58) and was sustained at a 48-month post-diagnosis follow-up (58). However, in other studies, high rates of distress did not substantively decrease between a 6- and 12-month follow-up among newly diagnosed AYAs (56,57) or from pre- to post-chemotherapy administration (61). Additionally, studies examining distress across survivors differing lengths from treatment has found no differences in a range of distress levels according to time since diagnosis (9,53) or between on- versus off-treatment groups (60). Additionally, one study of long-term AYA survivors of childhood cancer found the highest rates of clinical distress among survivors diagnosed more than 20 years previously (55).

Distress in comparison to the norm, and to siblings

Adequately conceptualizing the impact of cancer on AYAs' psychological outcomes also necessitates a comprehensive understanding of how these outcomes differ to what we might otherwise expect to see among AYAs without cancer. Several of the studies in this review compared AYAs' outcomes either to sibling controls (13,29,32,46,50,51), general population/community norms or healthy matched peers (4,9,11,13,15,19,25,26,34,35,38,41,43,45,48,49,55,57,60,62,64-67), older cancer patients (24,43,68), comparison medical or mental health patient groups (9) or some combination of these (13,43). The majority of these studies report that AYAs demonstrated significantly higher rates and/or levels of distress relative to their comparison group (4,15,19,25,26,32,34,41,45,46,49-51,55,57,60,69).

Some studies documented levels of distress that were either not significantly different to, or were in fact lower than, their comparison group however (9,11,29,35,38,39,43,48,62,64-66). One study found that although long-term AYA survivors had significantly higher distress than their comparison siblings, both groups were less distressed relative to population norms (13). The studies finding similar or better adjustment among AYAs with cancer appeared to range widely in regards to their sample sizes, cancer types, age ranges, length of time since diagnosis, and outcome measures.

Positive outcomes

Despite growing interest in concepts of positive outcomes

such as post-traumatic growth (PTG) and benefit-finding (70-72), as seen in *Table 1*, few studies documented the prevalence of these outcomes alongside distress. These studies found that most AYAs experience some degree of PTG (22), AYAs are more likely to report a positive than negative or no change in PTG (21), and that the level of PTG among long-term survivors significantly exceeds healthy controls (34). The emergence of adaptive outcomes alongside clinical-level distress echoes qualitative explorations of AYAs' cancer experiences (73-75). However, to date there has been little consensus regarding factors that underpin the level of distress or positive adaptation experienced by AYAs.

In the next stage of this review, the literature was examined for factors that had been linked with psychological outcomes among AYAs. Evidence related to individual factors, cancer- or treatment-related factors, and socio-demographic factors was examined in turn, and a summary of each follows.

Research question 2: what individual, cancer/ treatment-related and socio-demographic factors have been identified as predictors of these outcomes?

Individual factors

Age

The impact of age at diagnosis on later psychological outcomes has been repeatedly examined. To date, the results have been mixed. One study highlighted that younger age at diagnosis predicted suicidal ideation in long-term survivorship, possibly due to later functional impairment (10). Several studies have found that age at diagnosis did not predict PTSS/PTSD (11,30,49), depression symptoms (50), general psychological distress (49-52) or QoL (68) in longer-term survivorship. The pattern of significant results supports the notion that a cancer diagnosis during the adolescent/emerging adult years is critical, however. That is, pediatric studies have tended to find that an older age at diagnosis (i.e., into adolescence) is predictive of adaptation, including both PTG and PTSS (22), and PTSD diagnoses (25), greater psychological distress, fewer positive health beliefs and a lower sense of cognitive competence (38), greater depression symptoms (52,60), anxiety (60), and worse QoL both on- and off-treatment (18,67) and into survivorship (76). By contrast, reports from the adult oncology sector have been mixed. Some have found that relative to older adults, younger adults experience greater distress, including higher fear of cancer

recurrence (24), anxiety, depression, and somatization symptoms (20), while another demonstrated lower rates of distress among AYA long-term cancer survivors than in adult oncology (43).

The data on the impact of AYAs' current age on psychological outcomes has shown that an older AYA age at follow-up is associated with poorer physical and mental adaptation (29), greater levels of PTSD (46) and cancer- and future-related worries (66) in longer-term survivorship. However, in many cases, an AYAs' current age has not been found to predict psychological outcomes, including QoL or anxiety, regardless of time since diagnosis (9), distress (27), PTSS/PTSD (11,30,37), suicidal ideation (10), PTG (77), or benefit finding in long-term survivors (48). One study examining cross-sections of AYAs in different age brackets found that both 'emerging adults' (19-25 years old) and 'young adults' (26-39 years) had significantly higher general psychological distress and depression symptoms relative to adolescents aged 15-19, and the emerging adults also showed significantly greater anxiety than the adolescent group (55).

Gender

Studies that have examined the role of gender on psychological outcomes have fairly conclusively documented that, similar to general population findings (78,79), females report greater distress. As with general population data, researchers have suggested that this could reflect both a differential vulnerability to psychological distress, differences in the expression of this distress (e.g., PTS symptoms versus risk behaviors such as alcohol/substance abuse) or simply differences in the social acceptability of reporting this distress (39). In particular, studies to date have found that female gender is predictive of greater psychological distress (13,32,34,51,55,64), in particular persistent PTSS (12,39,47), poorer physical and mental health-related quality of life (HRQoL) (13,18,29,66,67), lower perceived social support (48), greater symptoms of depression and somatic distress (18,50,62), and anxiety/somatization (18,55,62) across the cancer trajectory.

However, some exceptions to this pattern have emerged. Some studies have documented that females and males showed similar levels of benefit finding in long-term survivorship (48), and not significantly different internalization or externalization symptoms (65), suicidal ideation (10), or PTG experiences (77). One recent study also found that male AYA survivors within five years post-treatment reported greater distress than did their female counterparts (27).

Cancer and treatment related factors

Much of the existing literature-in particular, survivorship research-has endeavored to identify risk and protective factors for psychological outcomes based on cancer and treatment-related factors. The rationale for much of this work has been to isolate easily identifiable, clinical or medical patient factors that may contribute to 'profiling' AYAs' psychosocial risk, and thus facilitating more targeted intervention (13). In addition, the clear variability in the functional impact associated with different diagnoses and treatment regimens makes understanding their association with later adjustment an important aim.

Type of disease

A number of studies examining the impact of a young person's specific cancer diagnosis on subsequent distress have found this to have no measurable impact on the incidence of PTSS/PTSD (25,31), depression symptoms (50), or psychological distress among either recently-diagnosed AYAs (57) or in long-term survivors (50-52). However, significant findings in this literature have tended to converge around a few cancer types. Sarcomas (bone and soft tissue tumors) have been associated with patients experiencing a poorer HRQoL (19,29,41), and a lower likelihood of endorsing PTG (21). This may be due in part to the impact of amputation on psychosocial functioning/QoL (64,69).

Brain and central nervous system (CNS) malignancies have also been identified as being associated with poorer physical and mental health HRQoL in longer-term survivorship (29,41,52) as well as a greater risk of suicidal ideation in long-term survivorship (10). Given the known higher incidence of late effects and impaired functioning among young survivors with bone and CNS malignancies in particular (80,81), these findings are perhaps not surprising. One study also identified higher rates of PTSD-specific distress, but not more general psychological distress, among solid tumor survivors relative to long-term leukemia/lymphoma survivors (49), while another study documented that survivors of leukemia/non-Hodgkins lymphoma who were not treated with cranial radiotherapy were more likely to experience PTSS, although there was no apparent reason for this result (39).

Disease severity

In line with findings related to several specific cancer types, objectively-rated cancer/disease severity *per se* has been repeatedly shown not to predict psychological outcomes

among AYAs. In particular, studies have found that disease severity is not predictive of PTG or PTSS (22), fear of cancer recurrence among female cancer survivors (24), PTG in AYAs survivors (77), or general psychological distress among recently diagnosed AYAs (57). Furthermore, some studies have documented that having a cancer relapse, or a secondary malignant cancer is also not predictive of PTSD outcomes (25,46) or suicidal ideation in long-term survivorship (10).

Medical/physical burden

Consistent with an interpretation that specific cancer types might influence levels of distress via their impact on general functioning, a number of studies have found that experiencing a greater burden of medical side-effects during treatment, or late effects following treatment completion, is associated with greater psychological distress among AYAs. Experiencing ongoing physical symptoms could act as ongoing reminders of past traumatic experiences, and/or contribute to an ongoing sense of life threat (39).

Although there are some exceptions to this finding (25,51), many studies have found poorer physical health status/late effects (including cognitive/neurological late effects) to be associated with PTSS (31,39), clinically significant distress (13,27,32,38,49,51,52), poorer HRQoL (13,19,38,41,52,66,69,76), symptoms of anxiety and somatization (52), and beliefs about health-related competence (38) in long-term survivorship. One recent study also found that long-term survivors with poor self-reported physical health were almost three times more likely to report experiencing suicidal ideation (10). Of note, the association between poor physical health and suicidal ideation remained significant even after depression symptoms were controlled for (10). Longitudinal studies examining AYAs diagnosed within the past year found that greater reported treatment side-effects were associated with greater PTSS at a 6- and 12-month follow-up (56).

Treatment-related variables

The type, duration, and intensity of cancer treatment experienced by AYAs have repeatedly been examined as a potential modifier of later psychosocial outcomes. The combined results of these studies are mixed. A number of studies have documented that treatment-related factors are not predictive of depression, anxiety, or self-esteem either on- or off-treatment (60), PTSS/PTSD (25,31), higher psychological distress (51), suicidal ideation (10), or either parent- or teen-rated psychosocial QoL (82). By contrast,

some studies have found treatment intensity to be associated with a significantly greater risk of PTSD (46,47), less positive health beliefs, and greater anxiety (38) and poorer general health and role functioning aspects of QoL (41) in long-term survivorship.

Studies exploring the impact of specific treatment modalities appear similarly inconclusive, with one apparent positive association for each null finding. For example, while surgical intervention was not related to levels of benefit finding in long-term survivorship in one study (48), in another, it predicted higher levels of PTSS at a 12-month follow-up, among AYAs diagnosed in the past year (56). Another study of young women with breast cancer also found that having radical surgery was associated with more body image concerns, which in turn was associated with greater symptoms of anxiety, depression, and fatigue (83). Similarly, intensive chemotherapy exposure predicted greater depressive symptoms in long-term survivorship in one study (50) but not psychological distress in another (51).

The associations appear clearest for cranial radiotherapy however, which appears predictive of a greater risk for PTSD (46), greater psychological distress and poorer HRQoL/wellbeing (13,64) in long-term survivorship, in particular when it occurred at <4 years of age (46). Again, like the findings for CNS malignancies, this is likely reflective of subsequent cognitive/neurological difficulties. Interestingly, one study found that not having a history of bone marrow transplantation was correlated with greater PTSS in longer-term survivorship (40). The authors speculated that this may be due to patients' appraisals of a BMT being a near-miraculous 'life saving'—rather than traumatic—procedure at the time.

Treatment status

Finally, treatment status (i.e., on versus off-treatment) and time since treatment completion have been examined across numerous studies. While in one study, being pre-treatment predicted depression and anxiety (17), being currently on-treatment has been found to be predictive of a poorer HRQoL (19,67), higher levels of PTSS (56) and significantly higher distress at any given point during a 12-month follow-up, while off-treatment status predicted lower distress (57) and HRQoL comparable to healthy controls (67).

A number of studies have also highlighted the occurrence of off-treatment distress among AYAs, however. One study comparing on- versus off-treatment adolescents found that the majority (86%) of the adolescents in their cohort who

demonstrated clinical depression symptoms in their sample were off-treatment (60). Other studies have documented that in the off-treatment phase, being closer to the treatment-completion point (or fewer years post-diagnosis) predicted greater PTSS (12) and a greater likelihood of reporting depression symptoms and distress (52). A recent study examining AYAs cross-sectionally according to time since treatment found that the highest levels of distress were endorsed by AYAs who were 1-2 years post-treatment relative to AYAs who completed treatment either <1 year or 2-5 years ago, suggesting that the most vulnerable post-treatment period may be between 1-2 years since completing therapy (27).

Studies examining outcomes into longer-term survivorship have illustrated the potential longevity of AYAs' distress, however. One study found that survivors within nine years of finishing treatment had significantly better mental health than did either survivors 9-18 years into survivorship, or those more than 18 years from diagnosis (29), while in another study, survivors reported greater cancer- and future-related worries the further in years they were from diagnosis (66). Symptoms of psychological distress, depression, and somatization, were significantly higher among one sample of survivors diagnosed >20 years previously, relative to AYAs diagnosed earlier than this (55). By contrast, several other studies have not found time since diagnosis or treatment to be predictive of later QoL or anxiety (9,52), PTSS/PTSD (11,25,30,31), depression symptoms or general psychological distress (50,52), however.

Socio-demographic factors

Increasingly, studies have turned their efforts towards identifying factors related to AYAs' social standing (e.g., ethnicity, income, education, work status), that might influence their adaptation to cancer. These data suggest that AYAs who are socially disadvantaged in some way are likely to experience greater distress.

Educational status

Having a lower educational attainment has typically been found to be predictive of poorer physical HRQoL (13,19,52) and greater symptoms of PTSS/PTSD (39,46), depression and somatic distress (50,51), psychological distress (13,52) and suicidal ideation (10), in long-term survivorship. Relatedly, two North American studies documented Hispanic ethnicity to be predictive of poorer outcomes; in one, Hispanic ethnicity predicted poorer physical HRQoL (19),

while another found that being English-speaking Hispanic was associated with lower PTG outcomes relative to either white non-Hispanics, or primarily Spanish-speaking Hispanics (21).

Economic factors

Indices of potential economic hardship and burden echo this pattern. Having a lower income has been associated with greater symptoms of PTSD (46), depression and somatic distress (50), and psychological distress (13,51,52,55), suicidal ideation (10), as well as poorer HRQoL (13,52) in long-term survivorship [*cf.* (27)]. North American studies that have documented health insurance status have also found that not having health insurance was associated with PTSS (40), and greater psychological distress and poorer HRQoL (13) in longer-term survivorship.

Occupational status

Data pertaining to AYAs' study/work status appears to reflect the combined impact of pre-existing psychosocial vulnerabilities, together with the cumulative negative impact of significant study/career disruption. One early study documented that higher vocational satisfaction was associated with greater psychological wellbeing, while increased sick-leave from work was significantly related to lower wellbeing and a greater stress reaction among young survivors (64). Since then, numerous studies have linked current unemployment to more severe symptoms of depression and somatic distress (50), PTSS/PTSD (39,47), general psychological distress (13,51,52), suicidal ideation (10), poorer HRQoL (13,52,66), and a greater degree of cancer- and future-related worries (66) in longer-term survivorship, though one recent study did not replicate this finding among Korean survivors (55).

Two recent longitudinal studies have further highlighted the potentially protective aspects of being engaged in study/work: one study of recently diagnosed AYAs found that those who remained engaged with work/study post-diagnosis reported slight decreases in PTSS over time, those who stopped work due to cancer/treatment (but had been recently studying/working prior to diagnosis) showed no increases in distress, but that unemployment/not studying prior to diagnosis was a risk factor for increasing PTSS between a 6- and 12-month follow-up, regardless of changes in their employment/study status (56). Another longitudinal study of recently diagnosed AYAs followed up 6- and 12-month later found that being in school/employed at any given point was associated with lower distress (57). Finally, a study

examining AYA outcomes across stages of post-treatment survivorship found that although there were no significant associations between cancer-related work/study interruption and distress in the first 12 months post-treatment, survivors who had finished treatment 1-5 years, and who reported educational/work interruption, reported significantly more psychological distress (27).

Research question 3: what mechanisms of action have been suggested by relevant theoretical models of AYA psychological adaptation to cancer, and what available evidence is there for these?

The preceding review documented several individual, cancer/treatment-related, and socio-demographic factors that tended to lead to a pattern of poorer functioning. These included female gender, a diagnosis during the adolescent/young adult years, a diagnosis of a more highly impairing cancer (e.g., CNS malignancy, Sarcoma), more substantial medical/late effects, as well as lower educational attainment, and significant, ongoing interruptions to study/work functioning. Beyond simply identifying these factors as a 'profile' of AYAs more vulnerable to distress, research efforts need to highlight potential pathways to intervention. Theoretical models may be useful in identifying putative causal mechanisms that can then be examined [e.g., see (5,46,84,85)]. Unfortunately, two recent reviews of psychological interventions for AYAs with cancer found few studies are anchored in a theoretical framework (86,87). A failure to identify the psychological mechanisms critical to cancer-related adjustment among AYAs in a theoretically-driven, evidence-based, manner is likely to hamper both screening efforts (i.e., the identification of distress) as well as the effectiveness of intervention (5,87).

A brief review of theoretical models relevant to AYAs follows, including the basic tenets and available evidence for each.

Developmental models

The theory

Developmental accounts of distress and psychological adaptation of AYAs highlight that the challenges involved in the cancer experience occur against a developmental trajectory—that of the movement towards independent functioning as an adult member of society (88). Consequently, as seen through the lens of developmental

models, the emergence of distress or resilience is a function of the extent to which the illness interrupts key developmental tasks, and/or the extent to which the young person is able to negotiate these hurdles to normal, age-appropriate development.

Arnett's [2000] model of emerging adulthood (89) is a particularly relevant example. 'Emerging adulthood' (the years from 18-25) is proposed to be a distinct period in which young people must focus on four key developmental tasks, including accepting responsibility for oneself, making independent decisions, establishing a relationship with one's parent(s) as an equal adult, and being financially independent from one's parent(s). During this period, young adults try on 'possible selves' as they move towards making commitments particularly in the areas of love, study and work (89). Consequently, the extent to which a cancer experience interferes with young people's achievement of these goals—and their related activities—is likely to determine distress/adjustment thereafter.

The evidence

Much of the evidence for a developmental account of AYAs' adjustment to illness is qualitative or descriptive in nature. The challenges involved with negotiating autonomy versus parental dependence, the distress related to the impact of cancer on sexuality/romantic relationships, and the importance of peer-related concerns all highlight the developmental impact of cancer (75,88,90). One recent study found that a number of the unmet needs reported by emerging adult cancer survivors related to these key developmental tasks (e.g., loss of independence) and in turn, having more unmet needs was associated with greater levels of anxiety and stress (91). Unlike younger cancer patients, AYAs also tend to grapple with the meaning of their cancer experience in the context of 'who they are', and this factor uniquely relates to their distress (36). Further, consistent with the functional goals of this period, the reviewed evidence linking study/work disruptions with distress seems compelling evidence to support the importance of being engaged with developmentally-appropriate tasks.

While this account of distress in AYAs is consistent with the unique issues that face AYAs, used in isolation, the developmental framework appears to lack some degree of explanatory power in accounting for psychological outcomes. That is, while cancer presumably disrupts the developmental goals of all AYAs to at least some degree, only a minority develop clinically relevant distress (92). Whether, and how, the disruption of identity development during

the AYA years by cancer impacts long-term adjustment also remains poorly understood. Further, difficulty achieving a developmental task (e.g., being able to work/study) could both drive ongoing distress (as an underlying mechanism), or simply be a symptom of this maladaptation (an outcome). Consequently, although developmental models provide a useful backdrop to understanding the key issues facing AYAs living with cancer, they may not be able to fully account for individual differences in the development of distress due to their lack of identifiable, testable mechanisms.

Socio-ecological and family systems models

The theory

Not unlike developmental models, both socio-ecological and family systems models suggest that the quality of functioning within a family will be associated with, or even predictive of, the extent to which the young person is themselves able to adjust (93-95). Family-level factors such as communication (including appraisal of stressors and coping capacity), cohesiveness (emotional connection, support), flexibility/adaptation (responsiveness to change) and reciprocity within relationships, as well as effective coping skills, distress (and its expression), and resources are implicated as important determinants of how a family negotiates stressful events, and how the young person adapts. In a similar way, models accounting for the impact and importance of peer systems on AYA outcomes highlight the impact of both the structure (e.g., size, availability, frequency of contact) and function (e.g., subjective perceptions of supportiveness) of peer networks as predictors of AYA adjustment (86). The Adolescent Resilience Model (96) incorporates both social and family support as protective factors that assist young people in negotiating illness-related risks (illness uncertainty, disease and symptom-related distress).

The evidence

Of the reviewed studies, some found concordance between reports of parent and child distress, QoL and family functioning (82,97). Further, poorer family functioning/support (including single parent status) was associated with greater distress and worse psychological outcomes in AYAs (32,60,82). In fact, one study showed that adolescents with PTSD were over five times more likely to come from a poorly functioning family (28). Poorer communication, cohesion, and role-delineation factors in adolescent-parent relationships were also implicated

in some studies, and were associated with worse mental health, self-esteem, and global competence (88), and worse psychosocial QoL for the adolescent (82). However, some studies have found that greater perceived family/social support actually predicted higher persistent PTSS (11,12), and worse depression symptoms among female AYAs (98) in survivorship, indicating that the link between family processes and psychological outcomes of AYAs may not be straightforward or completely understood. It is possible that these latter findings reflect distress associated with greater parental dependence, given that this is at odds with the developmental goal of the period (98).

Other forms of support also emerged as important in this review. Among older AYAs, being unmarried/not in a relationship predicted poorer physical aspects and mental health HRQoL (13,19,52), PTSD (46,47), greater psychological distress (13,49,51,52), and suicidal ideation (10), while living alone has been associated with PTSS in long-term survivorship (40). In support of functional models of social support, greater perceived social support was also associated with better perceived HRQoL (99), lower depression and anxiety symptoms (98), improved sexual functioning, self-worth, benefit finding, and depression symptoms in survivorship (48) and with better psychological and existential QoL, and less severe grief symptoms among AYAs with advanced cancer (100). Consequently, the pattern of evidence highlights the importance of social support in adjustment. The directionality of some of these findings may be difficult to determine, however, as just as a lack of social support may fuel symptoms of depression, so might distress (e.g., depression or PTSD) interfere with the behaviors needed to make friends, get married, and so forth.

Stress-coping models

The theory

Models of stress and coping have particularly dominated the psycho-oncology literature [e.g., (101-106)]. Typically, these are variants of Lazarus and Folkman's (107) Transactional Model of Stress and Coping, which proposes that adjustment to a stressor such as cancer is mediated both by primary appraisals (evaluation of the implications of the threat), and secondary appraisals (evaluation of available coping resources). A person's coping is thus determined by the interaction between their appraisal of the stressor being manageable (or not) given their available resources (e.g., family/friends, coping strategies, practical resources). Self-efficacy models extend these stress-coping formulations

by specifying that in order to enact coping behaviors, an individual must appraise themselves as having coping skills or mastery within the specific problem situation (108).

Whilst these types of appraisals are taking place in a continuous manner, people are assumed to behaviorally respond either using problem-focused coping strategies (e.g., trying to directly solve/change the problem causing their distress) or by using emotion-focused coping (trying to regulate their distress surrounding a situation), and many people might use both approaches. These behavioral responses have also been conceptualized as approach/avoidance (109,110) or 'primary' and 'secondary' control (111) in other models. The adaptability of these coping styles may depend on the stage of the cancer trajectory. For example, more avoidant strategies (e.g., wishful thinking or denial) may be adaptive during the early stages of cancer treatment as an emotion regulation strategy, while persistent avoidance is likely to perpetuate distress due to 'traumatic' or distressing material not being processed and integrated into autobiographical memory (30,49,112).

The evidence

Studies that have examined coping styles among AYAs have found that having a greater cancer-related burden or 'intrusion' on functioning (e.g., longer treatment duration, experiencing radiotherapy/chemotherapy, being older at diagnosis) predicted AYAs' using more passive/avoidant and less active coping strategies (113). In another study, coping factors explained significant portions of variance in anxiety, depression and somatization symptoms on the BSI-18 (38%), and rendered the relative contribution of medical late-effects non-significant, suggesting that cognitive variables may be more critical in determining how young people adjust than the impact of medical factors (49).

Across these studies, findings suggest that avoidant coping and emotion-focused coping strategies (e.g., optimism, perceived consequences, and perceived treatment control) and having a negative emotional representation of the illness, were related to distress (49), and worse HRQoL (113). Low optimism about the future course of the disease (49,113), and having a tendency to suppress negative thoughts (49) were also strongly predictive of poorer adaptation. This pattern of results portrays a profile of survivors vulnerable to ongoing distress about past experiences (via thought suppression strategies) and future-related hopelessness (via pessimism). These findings echo previous studies which found that more avoidant/repressive coping styles were associated with greater PTSD/

distress (30), as lower wellbeing and higher stress (64), and greater self-reported fatigue (114), while enacting goal re-engagement and approach coping strategies (e.g., by using positive reappraisal) is associated with reporting positive changes since cancer (115,116). The importance of AYAs' perceived self-efficacy to engage in such goal re-engagement and problem-solving behaviors is perhaps supported by one study which found that lower self-esteem was linked with greater cancer- and future-related worries (66).

Given that several studies suggest that using more proactive, problem-focused coping strategies are adaptive, stress and coping frameworks are intuitively appealing. However, although these studies highlight coping 'profiles' or styles associated with adaptation, they do not account for how AYAs might 'arrive' at the maladaptive coping appraisals, or why they might engage in an avoidant coping style that seems critical to their distress. Other authors have also noted that the tendency in the coping literature to align cognitive and behavioral 'coping strategies' as different options along a single continuum across a diversity of situations may not be particularly useful, and obscures the fact that cognitive factors (e.g., levels of emotional avoidance, active problem-solving) may in fact mediate behavioral outcomes (e.g., engagement in pleasant activities, information seeking) (117,118).

Cognitive appraisal models

The theory

Cognitive models extend stress-coping type formulations by focusing on how adaptive an individual's appraisal of the illness event is. Such models argue that cognitive mechanisms which allow the cancer survivor to actively reconcile their 'new knowledge' of the world with their pre-existing assumptive structures may ultimately lead to a reduction in distress after the trauma, and more adaptive outcomes long-term. Across cognitive appraisal models, a common assumption is that a health crisis prompts patients to develop illness representations influenced by pre-existing belief structures. For example, Mishel's (119) Uncertainty in Illness model predicts that the extent of people's distress and/or adaptive coping in response to a serious illness is dependent upon their interpretations (or appraisals) of the inherent uncertainty involved in this illness as either (I) a threat or danger; or (II) a positive opportunity.

A set of cognitive models have also conceptualized cancer as a 'trauma' (12,120,121). In these models, distress (post-traumatic stress; PTS) and adaptation (PTG) is a function

of the appraisals a person has about the trauma, and about the world/self in its aftermath. Meaning making theory proposes that confrontation with a severe stressor often leads to a shattering of global life assumptions, initiating cognitive processing to rebuild their meaning systems (122). According to Tedeschi and colleagues (123-125), the destruction of core schemas leads to a loss of coherence, perceived control and self-esteem regarding identity. The subsequent inability to reconcile the thoughts, images, and memories related to the trauma (e.g., cancer) with core beliefs, results in post-traumatic processes of intrusion and avoidance (122). By contrast, the process of making meaning is assumed to lead to better adjustment, although whether this occurs via a process of effortful, positive reappraisal (and suffering) (125), or simply via positive reinterpretations of the cancer experience (126) is a topic of contention in the literature (71).

The evidence

Given the potential relevance of cognitive models to explain psychological outcomes in AYAs, the number of studies exploring the relationship between such variables and psychological outcomes is small. Several studies have linked the experience of prior/concurrent life stressors (e.g., school difficulties; parental separation/divorce) to PTSS (12) and distress in survivorship (32). However, most studies have focused on the relationship between illness-related cognitions and distress. Optimism about prognosis predicted improved HRQoL among AYA cancer survivors in one study, independent of actual health status (69). Additionally, survivors who have had PTSD since completing treatment have shown perceptions of greater current life threat, and of cancer treatment intensity (23,44), as well as perceiving a greater, more negative impact of stressful/traumatic life events, cancer-related late effects, and impact on life goals, relative to survivors without PTSD (44). Appraisals regarding the extent to which treatment was difficult, 'scary', or life-threatening, have been shown to predict PTSS (12), PTG (22) and distress in survivorship (49), while perceptions of cancer having had a generally more negative impact have been linked to distress (27), poorer psychosocial functioning (52), worse anxiety and self-esteem (127), and QoL (52) as have perceptions of having more unmet needs (17), even years into survivorship. These associations may reflect broader alterations to AYAs' beliefs about the world, their life, or their future; however this were not measured in these studies.

The impact of illness-related appraisals on adjustment may be particularly marked among AYAs because of their

age. That is, AYAs may be prone to experiencing cancer as more life-threatening, inexplicable, and burdensome than their younger counterparts, who may lack the cognitive capacity for this level of existential/abstract thought (2,89), or older adults, who are likely to have more life experience with illness (and for whom illness is a more expected event) (24). Consistent with this, recent research has found that the intrusiveness of illness-related thoughts was predictive of fear of cancer recurrence symptoms among younger women with breast cancer, and consistently explained the relationship found in this study between younger age and distress (24). The authors hypothesized that the developmental incongruity of the cancer diagnosis in the young adult years may make this reality seem more unexpected, which could lead to difficulty integrating this reality into new beliefs about the world.

Relatedly, recent studies have highlighted that AYAs who identify more strongly with a 'survivor' identity show better psychological well-being and PTG, than those who describe themselves as a cancer 'victim' (128). This finding suggests that AYAs may need to first integrate and process their cancer experience (and put it in their past, as a 'survivor') before growth can take place. The cognitive processes involved in AYAs reaching this 'identity' remain a little unclear, however. One study found that engaging in thought suppression strategies for negative thoughts was associated with significantly higher psychological distress in long-term survivorship (49), while another found that individuals' propensity to engage in either positive or negative cancer-related attentional biases and rumination was associated with subsequent psychological outcomes (where negative rumination partially mediated PTSD outcomes, and 'positive rumination' partially mediated PTG outcomes) (129). Such cognitive processes may account for the impact of medical factors (e.g., illness severity), individual characteristics (e.g., previous experience) and the generation of adaptive cognitive appraisals and integration of the cancer experience (130,131).

In sum, cognitive models of adaptation indicate that several types of cognitive appraisals are linked with maladaptation, such as greater perceptions of burden, life threat, and illness severity. However, much of this literature has been descriptive or cross-sectional. Given the lack of longitudinal or experimental data, it is unclear (I) to what extent these types of appraisals may reflect actual, objective burdens; and (II) to what extent such appraisal processes might be causal mechanisms, or simply a symptomatic facet of a post-cancer distress syndrome. Evidence for

the relationship between ‘positive’ and ‘negative’ facets of adjustment also remains mixed.

In the midst of a developmental period where AYAs are forming a sense of self and future life goals, the present review highlights that how they appraise their cancer experience, how they view themselves as cancer patients/survivors, and how well they are able to problem-solve and re-engage with goals, is associated with their subsequent adaptation. These converging lines of evidence point to the potential importance of understanding how autobiographical memory and future thinking mechanisms might shape the psychological outcomes of AYAs living with cancer. The potential role of such mechanisms remains understudied and poorly understood within the current literature, however. The next section of this review examines empirical advancements in non-oncology fields that may be relevant in identifying and testing mechanisms of adaptation among AYAs.

Research question 4: what empirical advancements in adjacent, non-oncology fields have been made that might improve our understanding of psychological outcomes in AYAs living with cancer?

Researchers have recently highlighted that endeavours to identify and test mechanisms will necessarily involve a greater degree of cross-pollination between those conducting clinical-level interventions research, and those conducting experimental manipulations of putative mechanisms (5). Given the developmental relevance of how AYAs process and integrate their cancer experience into their past, draw from it in their present, and incorporate it into their future goals, it seems appropriate to draw from recent developments in the broader psychology literature pertaining to autobiographical memory, future imaginings, and the self.

Recent models of the self and its roots in autobiographical memory may be used to explain how the disruption of cancer may affect a person’s ongoing goals and sense of self. Two recent models of autobiographical memory may be particularly relevant. The Self-Memory System (132) highlights that a person’s current goals and assumptions about the world provide a stable lens for their current sense of self, goals, and predictions for the future. Consequently, according to this model, negative psychological outcomes may emerge when young people selectively draw upon memories/future imaginings consistent with current

psychological concerns (e.g., past cancer threat, fear of future cancer recurrence, sense of personal vulnerability). This model highlights the importance of the content of memory/future thinking—what young people remember and imagine (e.g., preoccupied with illness). The CaR-FA-X theory (which identifies ‘*capture and rumination, functional avoidance, and executive control*’ processes) (133) recently built upon this by emphasizing the role of memory specificity—the way people remember the past or imagine the future.

According to the CaR-FA-X theory, overgeneral, categorical memories (e.g., “*All of the times chemotherapy was hard.*”) which are summaries of events across time, rather than specific, episodic memories that occurred on a particular day (e.g., “*That afternoon last month where my friend came and chatted to me in hospital.*”). Specific memories are associated with psychological functioning outcomes as people use these situational memories as useful analogues from which to imagine their future, and draw alternative, useful solutions to problems. Consequently, overgeneral memory has been shown to impair people’s current ability to problem-solve (134,135) and their capacity to imagine the future in a clear, concrete manner (136). These effects have been shown among clinically depressed (137,138), complicated grief (139-141), and PTSD samples (142,143), as well as among healthy student AYA populations (144). Memory specificity has also been shown to be responsive to ruminative thinking processes (137,138,144), which has been hypothesized as an important factor in the maintenance of fear of cancer recurrence (145,146). Importantly, the mechanisms outlined in these models can be examined empirically using tasks such as the Autobiographical Memory Test and the Future Imaginings Task (136), while related outcomes of interest, such as social problem-solving, have been previously studied outside of oncology using the Means-Ends Problem-Solving Task (147).

In taking such a lateral, process-based approach to experimentally investigating suggested mechanisms of adjustment, a second important component is to devise non-clinical (e.g., non-cancer/illness) paradigms in which to test psychological mechanisms related to adjustment. For example, otherwise healthy young people who show significant preoccupation with, and anxiety about, their health and the potential for future illness (i.e., health anxious young people) may provide an useful analogue sample in which to study processes related to how young people with active illness-related concerns process both illness- and non-illness-related tasks, remember illness-related events, and imagine their futures.

Such an analogue sample removes the actuality of 'cancer' from the picture, and yet in both samples, young people perceive their risks of future illness to be high, are anxious about this, and exhibit cognitive and behavioral responses driven by this. Removing the impact of physical illness on outcomes is a benefit of experimental studies, as the preceding review indicates that distress long into survivorship is not solely accounted for by late effects/physical health. Understanding the maintenance of distress with the 'noise' of physical symptoms removed from the data may be an important step towards understanding distress in long-term cancer survivorship.

This approach rests on a number of important assumptions. The first is that it is possible to examine illness-concerns in the laboratory (with some degree of ecological validity). Secondly, that the way in which young people process illness-concerns in the laboratory has important implications for how they process illness-concerns in a real-life situation (generalizability). Finally, that the processes involved in managing illness concerns (e.g., thinking styles, avoidance behaviors) are likely to be common, whether or not someone actually has an illness (i.e., the way our minds work doesn't fundamentally change once we are diagnosed with cancer). These assumptions are supported by analyses indicating that health/illness concerns vary on a continuum of severity, with common mechanisms driving these concerns along this continuum (148).

Such experimental paradigms are already emerging. Among healthy AYA analogue samples, studies have shown that 'bracing' for an imminent medical test result impairs the ability to process important information both immediately before and after receiving it (149), while a self-affirmation intervention prior to giving individuals feedback about their vulnerability to a health-risk reduces both their defensiveness in receiving this information, and their subsequent self-reported health-risk behaviors (150). Recent studies using experimentally-induced 'mortality salience' (awareness of one's own eventual death) have found that individuals who are led to perceive that they are at high risk of cancer will first tend to engage in thought suppression of cancer/death-related thoughts (presumably as an emotion regulation strategy); yet, when this is prevented, they report decreased cancer-related self-examination intentions (151).

Taking such an approach has the advantage of enabling us to strengthen the science behind the interventions that we believe, for many other reasons, are likely to be useful among AYAs (e.g., cognitive-behavioral therapy, mindfulness) (87). By identifying, manipulating, and testing

cognitive and behavioral processes important to adjustment in AYAs, such interventions can be tailored to the specific mechanisms that appear important for AYAs. In turning to process-focused, empirical studies to spotlight processes potentially involved in cancer-related adaptation among AYAs, we also address clinical considerations, such as the desire not to overwhelm an already vulnerable population with research study requests. This kind of approach—studying the hypothesized process, rather than solely studying the population—may be especially important in AYAs given their scarcity as a sample to study, among other challenges (152).

Future research directions

To date, the body of evidence on the psychological outcomes of AYAs highlights a number of factors that may play a role. There is, however, a paucity of evidence relating to modifiable processes, such as cognitive or behavioral factors, that may impact the psychological adjustment of AYAs through their cancer trajectory. Understanding better how people manage to engage in processes of reappraisal, meaning making, and goal readjustment under these circumstances seems critical to explaining why some cancer survivors fare better psychologically into survivorship.

Much research has explored the way in which the cancer experience can shatter peoples' global assumptions, related to the self, others, and the world (153). These models implicate peoples' constructed identities as a focus of reconstruction in the aftermath of cancer. This biographical disruption is especially challenging for AYAs, for whom a sense of self may be still fluid and in the process of development (89). Adjusting and integrating useful appraisals regarding the threat of cancer to the self has been conceptualized as an ongoing struggle for the cancer survivor, in response not only to internal discrepancies in assumptions about the world, but also the ubiquitous reminders of this threat (131). Whilst integrating the cancer experience, the survivor must nevertheless avoid it overshadowing their sense of 'self'. Recent theoretical models have begun to incorporate such processes in their accounts of adaptation (154), however the manner in which patients arrive at this identity, or maintain this sense of self, remains largely unstudied.

Further, although numerous studies have documented the impact of cancer on AYAs' qualitative narratives, no studies have experimentally examined the impact on particular cognitive or behavioral processes on how AYAs integrate

cancer-related cognitions into autobiographical memory, on how they imagine their future lives, and how they subsequently craft life goals for themselves in the aftermath of the cancer experience. These processes are not only critical to adaptation, but are also amenable to intervention (141). Future experimental studies isolating and exploring processes of memory, future thinking, goal-setting, and the navigation of challenges through problem-solving, may be important. Studies of psychological processes that may have a maladaptive impact on these psychological efforts (e.g., cancer-related worry, rumination, or behavioral aspects such as avoidance and withdrawal) are also needed in the oncology domain.

Focusing on common psychological mechanisms that may underpin both distress and adaptation may also help to integrate the range of findings by moving away from disorder-specific to adaptation. Current models of psychological distress and adaptation have frequently centered on a trauma-model of distress, despite the fact that studies consistently find that only a minority (typically, not more than 20-30%) meet criteria for clinically-significant PTSS. There are also important conceptual distinctions that make a trauma framework an imperfect 'fit' for accounting for post-cancer psychological reactions (121,155). Consequently, while a trauma framework might account for the responses of a minority, it does not advance our understanding of how the remainder of these samples of AYAs adjust to their cancer experience. By contrast, processes such as autobiographical memory, future thinking, problem-solving, and goal-setting are universally important processes to psychological functioning among both well-functioning and various distressed populations (133,156-159). Given the universality of these psychological processes, understanding how they can be both maladaptive and adaptive will enable the shift from a body of research focused on psychopathology, to a focus on the dual outcomes of distress and resilience (160).

The recent international spotlight on AYAs with cancer is juxtaposed with the reality of increasingly resource-constrained healthcare settings worldwide (161). Given this, honing the science behind our efforts to assist AYAs to adjust to cancer is crucial. In this context, tightening approaches to effective intervention becomes even more important. Identifying theoretically-grounded mechanisms, testing these, and building a body of evidence around psychological processes using experimental settings (and possibly, analogue samples of healthy AYA populations) will facilitate the development of more effective psychosocial interventions for AYAs living with cancer.

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Footnote

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