

Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis

Brad J. Zebrack^{1*}, Virginia Corbett², Leanne Embry³, Christine Aguilar³, Kathleen A. Meeske⁴, Brandon Hayes-Lattin⁵, Rebecca Block⁵, David T. Zeman⁶ and Steven Cole⁷

¹School of Social Work, University of Michigan, Ann Arbor, MI, USA

²Michigan State University, Lansing, MI, USA

³University of Texas Health Science Center at San Antonio, San Antonio, TX, USA

⁴Children's Hospital Los Angeles, University of Southern California, Los Angeles, CA, USA

⁵Oregon Health and Sciences University, Portland, OR, USA

⁶University of Michigan, Ann Arbor, MI, USA

⁷HopeLab Foundation, Redwood City, CA, USA

*Correspondence to:

School of Social Work, University of Michigan, Ann Arbor, MI 48109-1106, USA. E-mail: zebrack@umich.edu

Abstract

Purpose: Identifying at-risk adolescent and young adult (AYA) cancer patients and referring them to age-appropriate psychosocial support services may be instrumental in reducing psychological distress and promoting psychosocial adaptation. The purpose of this study is to identify trajectories of clinically significant levels of distress throughout the first year following diagnosis and to distinguish factors, including supportive care service use, that predict the extent to which AYAs report distress.

Methods: In this prospective multisite study, 215 AYAs aged 15–39 years were assessed for psychological distress and psychosocial support service use within the first 4 months of diagnosis and again 6 and 12 months later. On the basis of distress scores, respondents were assigned to one of four distress trajectory groups (Resilient, Recovery, Delayed, and Chronic). Multiple logistic regression analyses examined whether demographics, clinical variables, and reports of unsatisfied need for psychosocial support were associated with distress trajectories over 1 year.

Results: Twelve percent of AYAs reported clinically significant chronic distress throughout the first 12 months following diagnosis. An additional 15% reported delayed distress. Substantial proportions of AYAs reported that needs for information (57%), counseling (41%), and practical support (39%) remained unsatisfied at 12 months following diagnosis. Not getting counseling needs met, particularly with regard to professional mental health services, was observed to be significantly associated with distress over time.

Conclusions: Substantial proportions of AYAs are not utilizing psychosocial support services. Findings suggest the importance of identifying psychologically distressed AYAs and addressing their needs for mental health counseling throughout a continuum of care.

Copyright © 2014 John Wiley & Sons, Ltd.

Received: 2 July 2013

Revised: 26 February 2014

Accepted: 4 March 2014

A diagnosis of cancer can be physically, financially, and emotionally devastating to adolescent and young adult (AYA) patients. AYAs experience significant disruptions in their education and work lives, isolation from friends and social groups, and challenges understanding medical information [1–3]. They have unique disease management and coping needs related to identity exploration and formation, completion of education, career development, friendship, dating and marriage, and parenthood [1,2,4,5]. Yet, recent reports suggest that AYAs' needs for psychosocial support to manage these life disruptions are substantially unmet [6–8]. Also, studies routinely indicate that 30–40% of cancer patients of all ages report clinically significant levels of emotional distress at diagnosis and throughout a continuum of care [9,10].

However, reports of the prevalence of clinically significant distress among AYAs are inconsistent, ranging from 6% to 41% in independent cross-sectional studies with varying sample sizes, age ranges, timing of data collection, and instrumentation [7,9,11,12].

The stress and coping models that have been applied to the study of cancer suggest that cancer and its treatment disrupt life and that patients' quality of life is predicated on their ability to respond to – or cope with – these challenges [13,14]. Benjamin's popular notion of the 'active patient' [15] was prescient of subsequent research suggesting that quality of life is enhanced in cancer patients who are cognitively and behaviorally engaged in a process of healing and rehabilitation [16]. AYAs' attainment and use of information, emotional support,

and practical support, when needed, is suggestive of an active behavioral coping style – of being an active patient involved in one's own recovery process – and may be associated with positive psychosocial adjustment [17]. Conversely, experiencing unmet need for information, emotional support, or practical support, or not utilizing available supportive care services for whatever reasons, may debilitate young people's efforts to cope with their disease and thus complicate psychosocial adjustment [7]. For some AYAs, not using psychosocial support services may be attributable to personal choice or other intrapersonal factors including personality trait, fear or inability to accept what is happening to them, or an avoidant coping style. However, recent reports suggest that cancer patients' reports of unmet need for psychosocial support are more likely a result of services not being available, accessible, affordable, or age appropriate, or else perceived as such [18–20].

Bonanno's stress-coping model may be particularly useful for understanding the relationship between psychosocial support service use and AYAs' emotional responses to cancer and its treatment [21]. By distinguishing resilience as an important protective psychological factor and coping response to trauma (including life-threatening illness), Bonanno's model counterbalances older stress-coping models that assumed the existence of only psychopathological responses to aversive events. The model depicts four prototypical patterns, or trajectories, of disruption in normal functioning across time following interpersonal loss or traumatic events. Each trajectory represents a theoretically derived coping response to trauma exposure. The first trajectory suggests that some individuals will experience an immediate and subsequently chronic distress response over time, often indicated by clinically significant symptoms of depression or anxiety (Chronic group). A second trajectory is characterized by a delay in reporting clinically significant distress symptoms (Delayed group). A third group is characterized as recovering, in that initial reports of clinically significant distress diminish over time and that patients eventually return to pre-event levels (Recovery group). Finally, a fourth group is resilient, demonstrating only mild to moderate levels of distress over time, never reaching clinical significance (Resilient group). Citing evidence that resilience is common among people exposed to various traumas, Bonanno distinguishes resilience from recovery, as well as from the other two trajectories, in that resilience reflects an ability to maintain relatively stable and healthy levels of psychological and physical functioning even when exposed to a highly disruptive event or life-threatening situation [21]. Bonanno's model offers an opportunity to study a broad range of psychological outcomes among AYA cancer patients over time and their correlates.

The purpose of this study is to (1) substantiate AYAs' use of and unmet need for psychosocial support services

over 1 year following diagnosis, (2) identify longitudinal trajectories of psychological response among AYA cancer patients throughout the first 12–16 months following diagnosis, and (3) examine the relationship between unmet needs and distress trajectories. We suggest that trajectories may be, at least in part, a function of AYA use and engagement of psychosocial support services and that behavioral engagement may be a mechanism or determinant of resilience. We consider unmet need to be an indicator of non-active engagement regardless of whether lack of service use is due to personal choice or motivation, or the inaccessibility of services. We hypothesized that reporting unsatisfied needs for psychosocial support services at baseline would be associated with a decreased likelihood of demonstrating resilience over time, after controlling for age at diagnosis, gender, race, change in employment status or school attendance following diagnosis, and cancer type/severity. The findings will assist clinicians in identifying at-risk patients in need of referral for psychosocial support services.

Methods

Patients and methods

A prospective, longitudinal, multisite study assessed psychological distress and psychosocial service needs in AYAs at three time points: within 4 months of diagnosis (baseline) and then 6 and 12 months after the first

Table 1. Psychosocial services

Information and informational resources
Information about my illness, treatment, and risks for recurrence or second cancers
Internet sites that offer cancer education or support appropriate for adolescents and young adults
Information about infertility or options for having children
Information or counseling about exercise and physical fitness
Information or counseling about diet and nutrition
Emotional support services
Community centers, camps, retreats, or adventure programs that offer cancer education or support appropriate for adolescents and young adults
Counseling by mental health professionals (such as psychiatrists, social workers, and psychologists) to help with anxiety, depression, or emotional stress
Counseling or guidance related to sexuality or intimacy
Religious or spiritual support or counseling
Family counseling
Practical support services
Help with understanding health insurance, disability, or social security
Child care
Infertility treatment (including artificial insemination, <i>in vitro</i> fertilization, and surrogacy)
Transportation assistance (such as taxi vouchers, American Cancer Society van rides, and Para-transit)
Complementary and alternative health care (i.e., herbal treatment, acupuncture, biofeedback, meditation, and visualization or guided imagery)

assessment. Eligibility criteria included patients aged 15–39 years (and patients 14 years old anticipated to turn 15 years during treatment), diagnosed with any form of invasive cancer for the first time, and able to read and understand English or Spanish. Over a 2-year period (March 2008 to April 2010), research staff at three

participating institutions monitored clinic rosters and subsequently identified 286 eligible patients for study recruitment. Fifty-eight patients did not provide consent, either because they refused participation or because physicians denied access to patients who they believed were too sick to participate. An additional 12 AYAs did not return a

Table 2. Sample descriptive and comparison of respondents/non-respondents ($n = 215$)

Characteristics	Total sample $n = 215$	Respondents $n = 152$	Non-respondents $n = 63$	χ^2 (p -value) ^a
	n (%)	n (%)	n (%)	
Gender				
Female	101 (47.0)	69 (45.4)	32 (50.8)	0.52
Male	114 (53.0)	83 (54.6)	31 (49.2)	(.47)
Race				
Non-Hispanic White/Caucasian	95 (44.2)	67 (44.7)	28 (44.4)	5.75
Hispanic/Latino	91 (42.3)	69 (46.0)	22 (34.9)	(.057)
Others		14 (9.3)	13 (20.6)	
African American	11 (5.1)			
Asian/Pacific Islander	13 (6.0)			
American Indian/Alaskan Native	3 (1.4)			
Change in work/school				
Remained in work/school	84 (40.6)	59 (39.9)	25 (42.4)	0.11
Stopped or remained out of work/school	123 (59.4)	89 (60.1)	34 (57.6)	(.74)
Type of cancer/severity				
80–100% survival rate	65 (30.2)	41 (27.0)	24 (38.1)	3.36
Thyroid carcinoma	1 (0.5)			(.19)
Testicular carcinoma	14 (6.5)			
Malignant melanoma	1 (0.5)			
Hodgkin lymphoma	23 (10.7)			
Breast carcinoma	19 (8.8)			
Carcinoma of cervix	7 (3.3)			
50–80% survival rate	87 (40.5)	62 (40.8)	25 (39.7)	
Head/neck carcinoma	9 (4.2)			
Ovarian carcinoma	2 (0.9)			
Non-Hodgkin lymphoma	17 (7.9)			
Soft tissue sarcoma	11 (5.1)			
Colorectal carcinoma	5 (2.3)			
Osteosarcoma	17 (7.9)			
Central nervous system/brain tumor	14 (6.5)			
Kaposi sarcoma	1 (0.5)			
Ewing sarcoma	9 (4.2)			
Other sarcoma	2 (0.9)			
<50% survival rate	63 (29.3)	49 (32.2)	14 (22.2)	
Acute myeloid leukemia	16 (7.4)			
Acute lymphoid leukemia	34 (15.8)			
Rhabdomyosarcoma	8 (3.7)			
Lung carcinoma	1 (0.5)			
Adrenocortical carcinoma	2 (0.9)			
Hepatic carcinoma	2 (0.9)			
	Mean (SD)	Mean (SD)	Mean (SD)	t -test (p -value) ^a
Age at diagnosis	23.6 (8.9)	22.7 (8.97)	25.6 (8.36)	2.20 (.03)
Global Symptom Index (BSI-18)	56.9 (10.0)	56.9 (10.1)	56.7 (9.81)	−0.21 (.84)
No. of unmet information needs	1.62 (1.39)	1.47 (1.30)	1.98 (1.53)	2.52 (.01)
No. of unmet counseling needs	1.13 (1.34)	1.13 (1.33)	1.14 (1.37)	0.89 (.93)
No. of unmet practical needs	1.28 (1.31)	1.23 (1.28)	1.41 (1.36)	0.93 (.35)

Bold indicates total for the category.

Percentages do not always total 100% because of missing data.

BSI-18, Brief Symptom Inventory-18.

^aTest statistics for comparing respondents to non-respondents.

completed baseline survey after providing consent, and one died. Thus, the sample consisted of 215 eligible patients who completed baseline surveys, for a response rate of 75%. Informed consent or assent was obtained from all participating patients and parents. Institutional Review Board approval was obtained from each participating site and the coordinating center. Additional methodological details are reported elsewhere [8,12].

Measures

Distress

The Brief Symptom Inventory-18 (BSI-18) is a standardized 18-item self-report scale using a 5-point Likert scale (from 0 'not at all' to 4 'extreme') to indicate how much respondents have been bothered by distress symptoms over the past 7 days [22]. Results generate age-adjusted and gender-adjusted *T*-scores for comparison with population norms for three subscales of depressive symptoms, somatic distress, and anxiety symptoms, and an overall Global Symptom Index (GSI). A mean GSI score of 50 and standard deviation of 10 represent norms for a community-based non-oncology population. Higher scores indicate greater levels of distress. An overall GSI score ≥ 63 , or a score ≥ 63 on two of three subscales, suggests clinically significant distress or 'caseness'. The BSI-18 is a shortened version of the 53-item BSI, which has demonstrated reliability and validity in more than 400 research studies, including samples of healthy adolescents (13 years and older) [23]. The use of the BSI for distress screening in various cancer populations is widespread [24–26]. Internal reliability (Cronbach's alpha) of the BSI-18 in a large cohort study of childhood cancer survivors ranged from 0.75 to 0.90 [27] and was 0.90 for the current sample.

Service use and unsatisfied need

This instrument was developed specifically to assess AYAs' expressed needs for (1) information or informational resources, (2) counseling services, and (3) practical support services. Content was derived from prior qualitative research and theories of stress and coping as applied to AYA cancer survivors (see Table 1 for list of items) [28]. The instrument has been utilized in prior investigations of AYA cancer patients and survivors [8,29–31]. Respondents indicate which of 15 services they have used and which they would like to use in the future. Response categories include the following: 'Have used and would like to use more', 'Have used and have no further need', 'Have NOT used but would like to', and 'Have NOT used and have no need'. Unsatisfied need is operationalized as a desire to use a service, regardless of whether the service had been used in the past. For purposes of multivariate analyses to test the hypothesis that unmet need around the time of diagnosis (baseline) was associated with distress trajectories, three

unsatisfied need subscale scores were tabulated by counting the number of unsatisfied informational, counseling, and practical support items at baseline. Each subscale score ranged from 0 to 5, with higher scores indicating greater unsatisfied need.

Sociodemographic data reported by patients included age at diagnosis, gender, race, school or employment status before diagnosis, and school or employment status at time of baseline survey. Changes in employment status or school attendance pre-diagnosis and post-diagnosis were examined, with data recoded into the following two categories: (1) remained in work/school and (2) stopped or remained out of work/school. Clinical data included type of cancer. Surveillance, Epidemiology, and End Results codes were used to categorize cancer type by severity of disease [32]. Three categories of severity were generated for this study on the basis of epidemiological evidence specific to AYAs: (1) diseases with expected 5-year survival rates greater than 80% (e.g., Hodgkin lymphoma); (2) diseases with expected 5-year survival rates of 50–80% (e.g., osteosarcoma); and (3) all other invasive malignancies with expected 5-year survival rates less than 50% (e.g., leukemia) [33] (Table 2).

Data analysis

Each respondent was assigned to a distress trajectory group on the basis of BSI-18 scores at each of three time points (baseline, 6-month follow-up, and 12-month follow-up). AYAs whose distress scores exceeded the threshold for caseness at all three time points were assigned to the Chronic group. Those whose scores exceeded the threshold for caseness only at 12-month follow-up, or at 6- and 12-month follow-up, were assigned to the Delayed group. Those whose scores indicated caseness only at baseline, or at baseline and 6-month follow-up, were assigned to the Recovery group. AYAs whose scores never reached the threshold for caseness were assigned to the Resilient group. Cross-tabulations

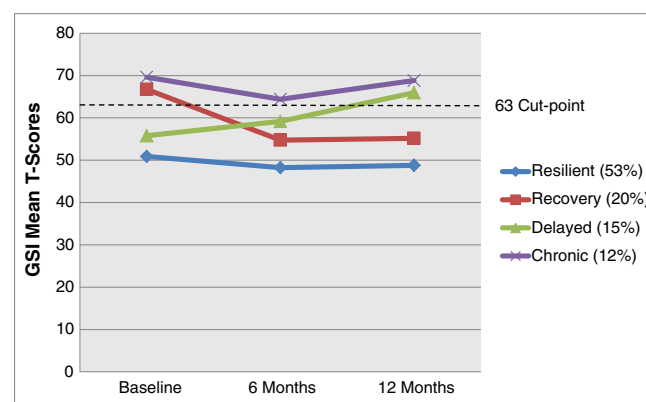


Figure 1. Mean Global Symptom Index (GSI) scores at three time points for adolescents and young adults in each distress trajectory

and Chi-square tests were utilized to examine associations between the four distress trajectories and gender, race, change in work/school after diagnosis, and cancer type/severity. Descriptive statistics summarized the proportions of AYAs reporting unmet needs for informational, counseling, and practical support at each cross-sectional time point. Cross-tabulations and Chi-square were also utilized to examine prevalence of unmet needs at 12-month follow-up for resilient AYAs as compared with all others (Chronic, Delayed, and Recovery groups combined). Multiple logistic regression analysis examined the numbers of unsatisfied information, counseling, and

practical support needs at baseline and their relationship to a dichotomized outcome (Combined groups=0; Resilient group=1), after controlling for demographics and cancer severity.

Results

Of the 215 patients who completed the baseline survey, 179 (83% of baseline respondents) completed the 6-month survey, and 165 (77%) completed the 12-month survey. One hundred fifty-two AYAs (71%) completed surveys at all three time points. Of the 50 patients lost to follow-

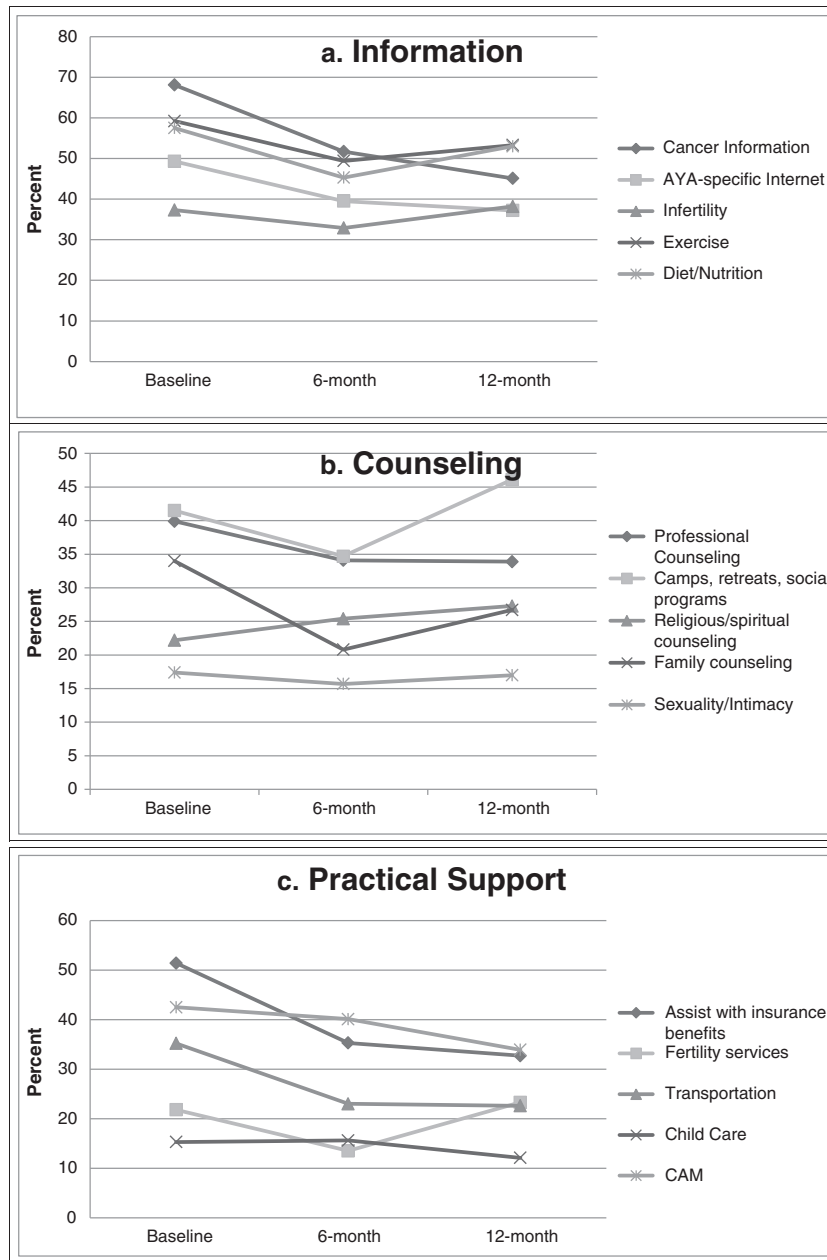


Figure 2. Percent of adolescent and young adults (AYAs) reporting unsatisfied (a) information, (b) counseling, and (c) practical support needs at baseline, 6-month, and 12-month follow-up

up between baseline and 12 months, mortality accounted for 28% of total attrition ($n=14$). The 152 patients who responded to all three data collection time points were significantly younger (age 22.7 years) than the 63 who did not (age 25.6 years). They also reported significantly fewer unmet informational needs at baseline (Table 2). Otherwise, no other significant differences in demographics, cancer severity, reports of unmet need, or baseline distress scores (BSI) were observed (Table 2).

Distress groups and correlates

Of the 152 AYAs who completed surveys at all three time points, 18 (12%) obtained scores suggestive of a Chronic distress group, 23 (15%) were assigned to the Delayed group, 30 (20%) to the Recovery group, and 81 (53%) to the Resilient group. Figure 1 depicts the mean GSI distress score for each of the trajectory groups at each of the three data collection time points. Thirty-five percent of AYAs reported clinically significant distress at least once during the observation period. At the bivariate level, assignment to one of the four distress groups was not significantly associated with gender, race, age, work/school status at baseline, or cancer severity (at $p < .05$).

Unsatisfied needs

Figure 2 summarizes the proportions of AYAs at each time point who reported unsatisfied need for each of 15 support services assessed (i.e., informational, counseling, and practical). Fifty-seven percent (57%) of participants reported that their need for at least one of the five information items (i.e., cancer information, Internet sites offering education or support, infertility information, exercise information, and diet/nutrition information) was unsatisfied at 12-month follow-up. Forty-one percent (41%) of AYAs indicated that at least one counseling need (i.e., professional mental health counseling, camps/retreats offering AYA-specific education/support, religious/spiritual counseling, family counseling, and counseling to address issues related to sexuality or intimacy) was unmet at 12-month follow-up. At 12-month follow-up, 39% of AYAs reported unsatisfied need for at least one practical support service (i.e., help with health insurance, disability, or social security; infertility services; transportation assistance; child care; and complementary and alternative medicine, including herbal treatment, acupuncture, biofeedback, meditation, and visualization or guided imagery).

Unsatisfied needs and resilience

In comparing resilient AYAs with all others, significant differences were observed in reporting unsatisfied needs for counseling from a mental health professional, family counseling, and infertility services, with Resilient AYAs being less likely than others to report these unsatisfied

Table 3. Multivariate analysis of variables predicting likelihood for assignment to the combined delayed, recovery, and chronic trajectory group ($n=71$) versus resilience trajectory ($n=81$)

	OR (95% CI)
Age at diagnosis	1.06 (1.01–1.11)
Gender (1 = male)	1.17 (.56–2.46)
Race (1 = non-White)	0.65 (.32–1.35)
Cancer severity (1 = 50–80% survival)	0.95 (.41–2.19)
Cancer severity (1 = 80–100% survival)	1.38 (.53–3.58)
School/employment status change (1 = stopped/remained out of school/work)	0.45 (.21–.94)
No. of unmet information needs at baseline	1.29 (.91–1.82)
No. of unmet counseling needs at baseline	0.63 (.44–.90)
No. of unmet practical support needs at baseline	0.74 (.51–1.06)
Cox and Snell R^2	0.15

Bold is statistically significant odds ratio at $p < .05$.

OR, odds ratio; CI, confidence interval.

needs at 12-month follow-up. Twenty-six percent (26%) of AYAs in the Resilient trajectory ($n=21$) reported that their need for counseling from a mental health professional was unsatisfied at 12-month follow-up, as compared with 48% of all other AYAs ($X^2=7.90$; $p=.005$). Twenty-two percent (22%) of Resilient AYAs ($n=18$) indicated that need for family counseling was unsatisfied at 12-month follow-up, as compared with 37% ($n=26$) of all others ($X^2=3.81$; $p=.05$). Eighteen percent (18%) of Resilient AYAs ($n=14$) reported that need for infertility services remained unmet at 12-month follow-up, compared with 33% ($n=23$) of all others ($X^2=4.74$; $p=.03$).

Multivariate analysis determined the extent to which demographic characteristics, cancer severity, and number of unsatisfied needs at baseline was associated with distress trajectories (Chronic, Recovery, and Delayed groups combined=0; Resilience group=1). Results suggested that the 81 AYAs in the Resilience trajectory group were of significantly older age at diagnosis, less likely to have experienced disruption in school or work at diagnosis, and significantly less likely to report unmet counseling needs at baseline (Table 3).

Conclusion

The present study assessed psychological distress among 215 AYA oncology patients at three points in time within 16 months following their initial cancer diagnosis. Results revealed that 12% of participants maintained clinically significant levels of distress at all three time points and an additional 15% evidenced a delay in eventually reporting clinically significant distress at 12-month follow-up. Thus, the prevalence of clinically significant distress at 12-month follow-up was 27% for this sample. The proportion of AYAs reporting clinically significant distress in this study may be an underestimate of the true prevalence when compared with prevalence rates of

30–40% reported for older adult patients throughout a continuum of care [9,10] and with studies suggesting that the prevalence of distress is significantly higher in AYAs when compared with older adult cancer patients [34–38].

For purposes of a healthy population comparison, the Centers for Disease Prevention and Control reported a 3.1–4.0% prevalence of serious psychological distress and a 8.3–10.2% prevalence of depression among young people aged 18–44 years in the USA in 2008 and 2009 [39]. Thus, exposure to cancer and its treatment obviously increases the risk of psychological distress for AYAs during the first year following diagnosis, regardless of the type of cancer and associated prognosis. It is important to note that pre-cancer mental health history may be a predictor of psychological distress and subsequent coping capability for AYAs; thus, assessment of pre-cancer mental health history seems important for identifying patients at risk for clinically significant distress throughout a continuum of care. Unfortunately, we were unable to determine which participants experienced depression or other mental health disorders prior to their cancer diagnosis, as doing so exceeded the scope of the study as well as the availability of resources to collect this information accurately and reliably.

Since the National Cancer Institute's Adolescent and Young Adult Oncology Progress Review Group in 2006 [40], we have witnessed increased attention to the oncology care needs of AYAs [5,41,42]. Given recent growth in the creation and availability of new clinical care programs, psychosocial support services, and adventure therapy programs for AYAs, why do we witness a substantial prevalence of unmet need in this study? It is possible that AYAs may not utilize existing psychosocial services because of fear or stigma related to use of mental health services or from not wanting to be seen as different from their friends and peers [4]. However, population-based data from the 2010 National Health Interview Survey, inclusive of 1777 survivors of adult-onset cancer, suggested that lack of knowledge or perceived unavailability of services accounted for 90% of the reasons why cancer patients do not utilize psychosocial support services with demonstrated benefit [20]. The delivery of quality care to AYAs requires psychosocial screening and assessment throughout a continuum of care in order for AYAs to benefit from services provided by mental health professionals and patient support organizations offering psychosocial and peer support. We find it notable that one-fourth of AYAs in the Resilient trajectory group, while assumedly maintaining relatively stable levels of psychological functioning, still indicated that their need for emotional support and counseling from a professional mental health provider was unsatisfied at 12-month follow-up. This subset represents resilient AYAs engaged in active coping but unable to locate accessible or appropriate services. Further research is needed

to better understand AYA experiences of distress, adaptation, and service utilization throughout a continuum of care.

The finding that more than half of this AYA sample fit a trajectory of resilience is consistent with studies indicating that resilience is common for individuals exposed to traumatic events, including a cancer diagnosis [21,43,44]. In examining responses to acute life events, Bonnano suggested that little is known regarding the mechanisms that activate resilience and that no one factor has emerged as being directly tied to a resilient trajectory [45]. It is likely that resilience is a function of both internal and external factors and resources, such as cognitive appraisal, personality, and social support [46]. A primary goal of this study was to determine how AYAs' trajectories of distress over time were related to their reporting of unsatisfied needs in the areas of information, counseling, and practical support. We observed that resilient AYAs tended to be older, to have remained employed or in school, and to report fewer unmet needs for counseling services. Thus, feeling that their emotional needs are satisfied and remaining engaged in their social world to the extent possible appear related to resilience and perhaps increases in salience as they get older. A specific focus on mechanisms or determinants of resilience were beyond the scope of this study but certainly are warranted.

Still the question remains: Does engagement and use of services satisfy AYAs' needs for information, emotional support, and practical support, and thus promote resilience? Or does resilience encourage or promote AYA engagement and subsequent benefit from psychosocial support services? The linear regression analyses reported here prohibited a determination of the direction of causation. Unsatisfied counseling needs may contribute to distress just as one's experience of distress may prohibit an individual from seeking mental health care. Regardless of the direction of causation, however, this observed relationship indicates a need for clinical attention. Clinically significant levels of emotional distress place AYA patients at risk for poor adherence to therapy and thus lowered potential for survival [47]; yet independent studies and systematic reviews purport that psychologically distressing problems created or exacerbated by cancer can be effectively addressed by psychosocial and peer support interventions geared specifically for AYAs [48,49]. Substantial proportions of AYAs in this study reported that their needs for psychosocial support services were not being met, and particularly at the cessation of treatment, a critical transitional phase of cancer care when many cancer patients experience spikes in anxiety and emotional distress, an increased need for information related to post-treatment follow-up care, and uncertainties about life after cancer [12,50]. Models of oncology care that address the unique medical, psychosocial, and developmental needs of AYAs throughout a continuum of care are needed.

This study's strengths include a large and ethnically diverse sample derived from multiple tertiary care institutions and assessed longitudinally, with a minimal and acceptable rate of attrition. However, the findings are somewhat limited in that 25% of the potentially eligible sample pool was inaccessible, presumably because many of these patients were too ill to participate. Their absence from the study may, in fact, contribute to an underestimation of distress in this sample. Use of the BSI-18 may have further contributed to an underestimation of the true prevalence of distress in the AYA population. In a study of comparably aged young adult survivors of childhood cancer, Recklitis and Rodriguez suggested that the BSI-18 demonstrated low sensitivity (41.78%) in determining clinically significant cases of distress when using published algorithms for determining caseness [51]. Other limitations of the study include a reliance on self-report questionnaire data alone and lack of available data relating to cognitive, psychological, or appraisal factors known to be associated with individuals' responses to trauma. Another limitation of this study involves the service use questionnaire. Although used previously in research and results reported in the literature, there are no reports of its validation or psychometric properties.

Finally, a limitation of Bonanno's trauma model as it applies to cancer is that it does not allow for assessing

positive adaptation or growth attributable to cancer. Empirical evidence exists to support the assertion that some young people are not only resilient but actually experience and report a better or more fulfilling life after cancer [44,52,53]. Thus, age-appropriate and developmentally appropriate psychosocial support interventions for AYAs are needed to not only alleviate distress but also promote growth and facilitate successful achievement of the developmental life tasks associated with adolescence and young adulthood. Findings reflect the importance of identifying factors associated with distress, psychosocial adaptation, and growth, and the extent to which informational, counseling, and practical support influence these outcomes throughout a continuum of care that initiates at diagnosis, continues through treatment, and transitions to survivorship or else the terminal phases of treatment and the end of life.

Acknowledgement

This work was supported by HopeLab Foundation, Redwood City, CA.

Conflict of interest

The authors have declared no conflicts of interest.

References

- Zebrack BJ, Chesler MA, Penn A. Psychosocial support. In *Cancer in Adolescents and Young Adults*, Bleyer WA, Barr RD, (eds.), Springer-Verlag: Berlin Heidelberg, 2007.
- Morgan S, et al. Sex, drugs, and rock 'n' roll: caring for adolescents and young adults with cancer. *J Clin Oncol* 2010;**28**(32):4825–4830.
- Palmer S, Thomas D. A practice framework for working with 15-25 year-old cancer patients treated within the adult health sector, Melbourne, Australia, onTrac@PeterMac Victorian Adolescent and Young Adult Cancer Service. 2008. (Available from: <http://www1.petermac.org/ontrac/pdf/AYA-Practice-Framework.pdf>) [March 14, 2014].
- D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*, 2011; **117**(10 Supplement):2329–2334.
- Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult (AYA) cancer patients and survivors. *J Clin Oncol* 2012; **30**(11):1221–1226.
- Keegan THM, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *J Cancer Survivorship: Res Pract* 2012;**6**:239–250.
- Dyson GJ, et al. The relationship between unmet needs and distress amongst young people with cancer. *Support Care Cancer* 2012;**20**:75–85.
- Zebrack B, et al. Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer* 2013;**119**:201–214.
- Zabora JR et al. The prevalence of psychological distress by cancer site. *Psycho-Oncology* 2001;**10**:19–28.
- Carlson LE, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer* 2004;**90**:2297–2304.
- Hedstrom M, Ljungman G, von Essen L. Perceptions of distress among adolescents recently diagnosed with cancer. *J Pediatr Hematol Oncol* 2005;**27**:15–22.
- Kwak M, et al. Trajectories of psychological distress in adolescent and young adult cancer patients: a one-year longitudinal study. *J Clin Oncol* 2013; **31**(17):2160–2166.
- Rowland JH. Developmental stage and adaptation: adult model. In *Handbook of Psycho-Oncology*, Chapter 3, Holland JC, Rowland JH, (eds.). Oxford University Press: New York, NY, 1990.
- Lazarus R, Folkman S. *Stress, Appraisal and Coping*. Springer: New York, 1984.
- Benjamin HH. *From Victim to Victor*, Dell: New York, 1989.
- Stanton AL, et al. Promoting adjustment after treatment for cancer. *Cancer* 2005; **104**(11 Suppl):2608–2613.
- Merluzzi TV, et al. Self-efficacy for coping with cancer: revision of the Cancer Behavior Inventory (Version 2.0). *Psycho-Oncology* 2001;**10**:206–217.
- Adler NE, Page A. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, National Academies Press: Washington, DC, 2008.
- Pirl WF, Jacobsen PB, DeShields TL. Opportunities for improving psychosocial care for cancer survivors. *J Clin Oncol* 2013;**31**(16):1920–1921.
- Forsythe LP, et al. Receipt of psychosocial care among cancer survivors in the United States. *J Clin Oncol* 2013;**31**(16):1961–1969.
- Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *Am Psychol* 2004;**59**(1):20–28.
- Derogatis L. BSI 18 Brief Symptom Inventory 18, Administration, Scoring, and Procedures Manual. NCS Pearson, Inc.: Minneapolis, MN, 2000.
- Derogatis LR. BSI Brief Symptom Inventory: Administration, Scoring, and Procedures Manual, National Computer Systems, Inc.: Minneapolis, MN, 1993.
- Carlson LE, Bultz BD. Cancer distress screening: needs, methods, and models. *J Psychosom Res* 2003;**55**:403–409.
- Rohan EA. Removing the stress from selecting instruments: arming social workers to take leadership in routine distress screening

- implementation. *J Psychosoc Oncol* 2012; **30**(6):667–678.
26. Jacobsen PB, *et al.* Screening for psychologic distress in ambulatory cancer patients. *Cancer* 2005; **103**:1494–1502.
 27. Recklitis CJ, *et al.* Factor structure of the Brief Symptom Inventory–18 in adult survivors of childhood cancer: results from the Childhood Cancer Survivor Study. *Psychol Assess* 2006; **18**(1):22–32.
 28. Chesler M, Barbarin O. *Childhood Cancer and the Family*, Brunner/Mazel: New York, 1987.
 29. Zebrack B. Information and service needs for young adult cancer survivors. *Support Care Cancer* 2009; **17**:349–357.
 30. Zebrack BJ. Information and service needs for young adult cancer patients. *Support Care Cancer* 2008; **16**:1353–1360.
 31. Zebrack BJ, Chesler MA. Managed care: the new context for social work in health care – implications for survivors of childhood cancer and their families. *Soc Work Health Care* 2000; **31**(2):89–104.
 32. Howlader N, *et al.* SEER cancer statistics review, 1975–2008. 2011; (Available from: http://seer.cancer.gov/csr/1975_2008/) [March 14, 2014].
 33. Bleyer A. Latest estimates of survival rates of the 24 most common cancers in adolescent and young adult Americans. *J Adolescent and Young Adult Oncol* 2011; **1**(1):37–41.
 34. Stava CJ, Lopez A, Vassilopoulou-Sellin R. Health profiles of younger and older breast cancer survivors. *Cancer* 2006; **107**(8):1752–1759.
 35. Mor V, Allen S, Malin M. The psychosocial impact of cancer on older versus younger patients and their families. *Cancer* 1994; **74**:2118–2127.
 36. Ganz PA, *et al.* The psychosocial impact of cancer on the elderly: a comparison with younger patients. *J Am Geriatr Soc* 1985; **33**:429–435.
 37. Costanzo ES, Ryff CD, Singer BH. Psychosocial adjustment among cancer survivors: findings from a national survey of health and well-being. *Health Psychol* 2009; **28**:147–156.
 38. Parker PA, *et al.* Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho-Oncology* 2003; **12**:183–193.
 39. Reeves WC, *et al.* Mental illness surveillance among adults in the United States, in *Morbidity and Mortality Weekly Report*, C.f.D.C.a. Prevention, Editor, Centers for Disease Control and Prevention: Atlanta, GA. p. 1–32, 2011.
 40. Adolescent and Young Adult Oncology Progress Review Group. Closing the gap: research and care imperatives for adolescents and young adults with cancer, in *Report of the Adolescent and Young Adult Oncology Progress Review Group* August 2006. (Available from: http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf), US Department of Health and Human Services, National Institutes of Health, National Cancer Institute; and the LiveSTRONG Young Adult Alliance, NIH Publication No. 06-6067: Bethesda, MD.
 41. Ferrari A, *et al.* Starting an adolescent and young adult program: some success stories and some obstacles to overcome. *J Clin Oncol* 2010; **28**(32):4850–4857.
 42. Bleyer A, Viny A, Barr RD. Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years: SEER Incidence and Survival, 1975–2000, National Cancer Institute, NIH Pub. No. 06-5767: Bethesda, MD, 2006.
 43. Barakat LP, Alderfer MA, Kazak AE. Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *J Pediatr Psychol* 2006; **31**(4):413–419.
 44. Stanton AL, Bower JE, Low CA. Posttraumatic growth after cancer. In *Handbook of Posttraumatic Growth: Research and Practice*, Calhoun L, Tedeschi R, (eds.), Lawrence Erlbaum Associates, Inc.: Mahwah, 2006; 138–175.
 45. Bonanno GA, Diminich ED. Annual research review: positive adjustment to adversity – trajectories of minimal-impact resilience and emergent resilience. *J Child Psychol Psych* 2013; **54**(4):378–401.
 46. Haase JE. The adolescent resilience model as a guide to interventions. *J Pediatr Oncol Nurs* 2004; **21**(5):289–299.
 47. Butow PN, *et al.* Review of adherence-related issues in adolescents and young adults with cancer. *J Clin Oncol* 2010; **28**(32):4800–4809.
 48. Sansom-Daly U, *et al.* A systematic review of psychological interventions for adolescents and young adults living with chronic illness. *Health Psychol* 2011. DOI: 10.1037/a0025977.
 49. Seitz DC, Besier T, Goldbeck L. Psychosocial interventions for adolescent cancer patients: a systematic review of the literature. *Psycho-Oncology* 2009; **18**(7):683–690.
 50. Institute of Medicine. *From Cancer Patient to Cancer Survivor: Lost in Transition*, Hewitt M, Greenfield S, Stovall E (eds.), National Academies Press: Washington, DC, 2006.
 51. Recklitis CJ, Rodriguez P. Screening childhood cancer survivors with the brief symptom inventory-18: classification agreement with the symptom checklist-90-revised. *Psycho-Oncology* 2007; **16**:429–436.
 52. Parry C, Chesler M. Thematic evidence of psychosocial thriving in survivors of childhood cancer. *Qual Health Res* 2005; **15**(8):1055–1073.
 53. Woodgate RL. A review of the literature on resilience in the adolescent with cancer: part II. *J Pediatr Oncol Nurs* 1997; **16**(2):78–89.