Original Article

# Mental Distress and Health Care Use Among Survivors of Adolescent and Young Adult Cancer: A Cross-Sectional Analysis of the National Health Interview Survey

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**BACKGROUND:** The current study was conducted to examine the prevalence and correlates of mental distress among survivors of adolescent and young adult (AYA) cancer and a comparison group. **METHODS:** A total of 875 AYA cancer survivors who were diagnosed between the ages of 15 and 39 years and who were at least 5 years from their initial diagnosis were identified from the 2013 and 2014 National Health Interview Surveys. A comparison group was created. The Kessler nonspecific mental/psychological distress scale was used to examine none/low, moderate, and severe distress. The issues of whether individuals talked to mental health professionals within the previous year and if they could afford mental health care also were examined. Variables (ie, demographics, behavioral [eg, smoking status], comorbidity, and mental health visits) associated with distress among the 2 groups were identified using multinomial logistic regressions. **RESULTS:** Survivors reported mental distress more often than the comparison group (moderate: 23.2% vs 16.9%; and severe: 8.4% vs 3.0% [$P$<.001]). Survivors cited not being able to afford mental health care more often (6.4% vs 2.3%; $P$ = .002). Moreover, 74.7% and 52.2% of survivors, respectively, with moderate and severe distress had not talked to a mental health professional. Contrary to the comparison group, survivors who were current smokers reported severe distress more often compared with nonsmokers (relative risk, 3.59; 95% confidence interval, 1.46-8.84 [$P$ = .01]). Having public and no insurance versus private insurance and report of sleep-related trouble within the previous week were found to be associated with greater distress among survivors. **CONCLUSIONS:** AYA cancer survivors are more likely to demonstrate mental distress than individuals without cancer. Nevertheless, few survivors may be receiving professional mental health services. Survivors need greater access to mental health screening and counseling to address the current gaps in care delivery. *Cancer* 2016;000:000–000. © 2016 American Cancer Society.

**KEYWORDS:** adolescent and young adult cancer, mental distress, mental health care access, kessler's distress scale.

## INTRODUCTION

Individuals with cancer may experience greater mental distress than those without cancer.[1,2] The management of mental distress may be particularly challenging for survivors of adolescent and young adult (AYA) cancer, who are defined as individuals who were diagnosed with cancer between ages 15 and 39 years.[3-6] The AYA age range is a key time of development and social growth,[3] and these patients may undergo psychosocial and social role changes (transitioning to college/work and building families) during the critical time of survivorship,[7] which may increase distress.[8-10] Also, AYA cancer survivors are prone to unhealthy behaviors (eg, cigarette smoking),[11] which may elevate the risk of mental disorders such as depression.[12] Poorer self-reported mental health status has been observed among AYA patients with cancer compared with the general population,[13] and this distress may continue over time.[14]

There may be inadequate treatment for mental health-related illness in the United States.[15-17] Identifying individuals who may be at risk of developing mental illness and examining how best to provide treatment to meet their needs is a critical public health issue.[18-22] Moreover, there is a growing policy-related movement toward reforming the delivery of mental health care (eg, increase the number of child psychiatrists) in the United States.[23] Mental health coverage expansion also is a key element of the Patient Protection and Affordable Care Act.[24] Nevertheless, to the best of our knowledge, there is limited information regarding the mental health status of survivors of AYA cancer, which is a particularly vulnerable patient population, and whether the current system meets their mental health care needs.

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Research indicates that there exists a myriad of factors (demographic, socioeconomic, behavioral [eg, smoking], health [eg, comorbidity], and medical [mental health visitation]) that may be associated with mental distress.[1,2,20,25] For example, cancer survivors who are unmarried or uninsured report greater mental distress that their counterparts.[1] Being a current cigarette smoker and having trouble sleeping also have been associated with poor psychological functioning.[12,26] Cancer survivors have comorbid conditions more often than those without cancer,[11,27] and a greater prevalence of comorbidity also may be associated with adverse mental/emotional well-being and distress.[1] Knowledge of how these factors may affect distress among AYA cancer survivors and their comparison counterparts is scarce.

The current study used the National Health Interview Survey (NHIS) to evaluate the prevalence of nonspecific mental distress among AYA cancer survivors in comparison with individuals without a history of cancer. Related to this, we identified factors that were associated with mental distress both among survivors and the comparison group. We hypothesized that survivors would report distress more often than the comparison group, and that being uninsured and being a current smoker would be associated with greater distress. Our second objective was to examine whether survivors with distress reported using mental health care within the past year and whether they faced affordability barriers in receiving this care. We hypothesized that survivors would report greater needs for mental health care and more affordability barriers to receiving mental health care compared with the comparison group.

## MATERIALS AND METHODS

### Data

The NHIS is an annual, in-person, nationwide health-related survey of the noninstitutionalized civilian population in the United States.[28,29] The NHIS is an important national resource, and these data have been used previously to evaluate health outcomes (eg, mental health, comorbidity, and behaviors) among cancer survivors.[1,2,11] Multistage sampling, clustering, and stratification are used in the NHIS to collect representative data.[28,30] We used the 2013 to 2014 adult survey data component of the NHIS, which includes information regarding health conditions for adults (ie, those aged ≥ 18 years). The response rates for the NHIS adult surveys were 58.9% and 61.2%, respectively, in 2014 and 2013.[31,32] The adult survey data component was merged with the person-level

data in the NHIS to extract information regarding variables such as insurance status. The Institutional Review Board of the University of Texas Medical Branch deemed that this study did not require a review since the NHIS data are publicly available.

### Survivors and Comparison Group

NHIS participants were asked if they had ever been told by a physician or other health professional that they had cancer or a malignancy of any kind. Information regarding cancer diagnosis and age at the time of diagnosis also was collected. A total of 71,197 adults with nonmissing information regarding cancer diagnosis were identified; 6542 reported having been diagnosed with cancer at any age. We excluded nonmelanoma skin or other unknown skin cancers.[11] Of these, 1047 patients reported being diagnosed with an initial cancer at an AYA age (ie, between ages 15-39 years). Delineating the appropriate age at diagnosis for AYA cancer survivors for conducting health outcomes research may be challenging.[4] We chose to follow the National Cancer Institute's age group of 15 to 39 years at diagnosis to define AYA cancer.[4,5] Previous studies with AYA cancer survivors in the United States also have used this age definition for oncology-based research, including the national AYA Hope Study.[6,11,33-35] We restricted our sample to 877 survivors of AYA cancer who were at least 5 years from their diagnosis. Two individuals with missing information regarding race and ethnicity were excluded, for a final sample of 875 survivors.

We used propensity score matching to create a comparison group following our previously published methodology.[11,35,36] Briefly, a multivariable logistic regression was estimated with 64,655 adults with no history of cancer and 875 AYA survivors. The dependent variable was survivors or a comparison group, and independent variables included sex, age at survey, race and ethnicity, census region, and survey year. We followed the general rule of matching: variables such as marital status and insurance may be affected by a cancer diagnosis (eg, survivors are less likely to be married than their counterparts)[37] and therefore these variables were excluded from propensity score matching.[11,35,38] The predicted values from this regression were used to match 1 closest-score individual without a history of cancer with each survivor, which resulted in a sample of 875 individuals for the comparison group.

### Mental Distress

We used the widely used Kessler nonspecific psychological distress scale (K6) to identify mental distress.[39-42] The K6

**TABLE 1.** Diagnosis Information for Survivors

|  | No. | % |
| --- | --- | --- |
| No. of cancer diagnoses |  |  |
| 1 | 765 | 87.6 |
| ≥2 | 110 | 12.5 |
| Age at time of initial diagnosis, y |  |  |
| 15-19 | 83 | 8.5 |
| 20-29 | 348 | 39.5 |
| 30-39 | 444 | 52.1 |
| Cancer at time of initial diagnosis |  |  |
| Blood[a] | 52 | 6.4 |
| Bone or soft tissue | 13 | 1.3 |
| Brain | 8 | 1.1 |
| Breast | 111 | 12.4 |
| Cervix | 256 | 27.6 |
| Colon or rectum | 22 | 2.3 |
| Kidney, liver, or lung | 19 | 2.4 |
| Melanoma | 66 | 8.3 |
| Ovary and uterus | 168 | 16.8 |
| Stomach, bladder, or pancreas | 17 | 2.5 |
| Testicular or prostate | 31 | 4.5 |
| Thyroid | 41 | 6.1 |
| Esophagus, windpipe, mouth, lip, or throat | 10 | 1.4 |
| Other unspecified | 61 | 6.9 |

[a] Includes leukemia, lymphoma, and other blood cancers.

scale is a validated population-based measure for evaluating distress, and has good precision and strong and consistent psychometric properties.[43] The K6 index has been found to be highly correlated with diagnosed mental disorders/emotional impairment, including mood disorders, depression, and anxiety, as well as mental health care use and expenditures.[39,44-46] This index has been used to evaluate mental distress among diverse and vulnerable populations such as cancer survivors,[1,2,25,47] cancer caregivers,[48] patients with substance abuse problems,[49] and patients with asthma.[50]

The 6-item K6 scale in the NHIS asks respondents how frequently within the past 30 days they felt nervous, hopeless, restless or fidgety, worthless, sad, and that everything was an effort. For each symptom, a value of 0 to 4 is assigned to the responses ranging from "none of the time" to "all of the time." Summing of the responses yields a K6 score ranging between 0 and 24.[39] Thresholds that have been previously validated for detecting none/low, moderate, and severe mental distress are $0 \leq K6 < 5$, $5 \leq K6 < 13$, and $K6 \geq 13$, respectively.[39,43]

### Covariates

Covariates were chosen from available data within the NHIS based on previous literature demonstrating effects on mental distress.[1,2,20,25] Demographic variables included sex, age at survey, race and ethnicity, marital status, and education. Insurance status (any private insurance, only public insurance, and uninsured) in the previous

year, which may affect the ability to access mental health services, also was included.

We created a comorbidity indicator from individually reported health conditions including asthma/chronic obstructive pulmonary disorders (includes a diagnosis of chronic bronchitis within the past year and emphysema), diabetes, heart diseases (includes coronary heart disease, angina, heart attack, and other heart conditions), liver diseases, kidney diseases, and stroke. Diagnosis of each condition was coded as 0 (no) versus 1 (yes). Responses across all conditions then were summed to create a comorbidity indicator that was evaluated as a categorical variable (none, at least 1, or $\geq 2$ comorbid conditions).[11]

Using the self-reported data, we created an indicator for having no trouble falling or staying asleep versus having trouble falling and staying asleep at least 1 time within the previous week. Smoking status compared current cigarette smokers versus former/never-smokers.[11]

Mental health visitation was examined by asking participants, "During the past 12 months, have you seen or talked to any of the following health care providers about your own health? A mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker (yes or no)." Affordability-related reasons for not accessing mental health care were measured by the response to the question "During the past 12 months, was there any time when you needed mental health care or counseling, but didn't get it because you couldn't afford it? (yes or no)."

For survivors, age at the time of the initial cancer diagnosis, number of diagnoses, and cancer at the time of the initial diagnosis also were evaluated.

### Statistical Analysis

Summary statistics (frequency and weighted percent) of the study variables were estimated. The study variables were compared between survivors and the comparison group using chi-square tests. Bivariate analyses were conducted to compare distress across variables separately for survivors and the comparison group. Results for survey year and census region were excluded for brevity.

To examine the associations between distress and covariates, we estimated multinomial logistic regressions separately for survivors and the comparison group. The dependent variable in these regression models was mental distress (low/none, moderate, or severe), and independent variables included demographics, insurance status, comorbidity, behavioral factors, and mental health care visit. For survivors, we also included age at the time of diagnosis and number of diagnoses as independent variables. To adjust for time and region-specific differences, we included

**TABLE 2.** Characteristics of Survivors and the Comparison Group

| | Survivors | | Comparison Group | | |
| --- | --- | --- | --- | --- | --- |
| | No. | %[a] | No. | %[a] | P |
| Demographics | | | | | |
| Sex | | | | | |
| Male | 180 | 22.7 | 181 | 21.8 | .72 |
| Female | 695 | 77.3 | 694 | 78.2 | |
| Age at survey, y | | | | | |
| 20-39 | 165 | 19.6 | 164 | 19.1 | .97 |
| 40-64 | 512 | 60.9 | 512 | 61.4 | |
| 65-85 | 198 | 19.5 | 199 | 19.5 | |
| Race and ethnicity | | | | | |
| Hispanic | 85 | 9.4 | 86 | 8.4 | .89 |
| Non-Hispanic white | 660 | 79.4 | 661 | 79.4 | |
| Non-Hispanic black | 78 | 6.4 | 78 | 7.2 | |
| Non-Hispanic others | 52 | 4.8 | 50 | 5.0 | |
| Marital status | | | | | |
| Never married | **109** | **9.5** | **109** | **11.8** | **.03** |
| Married or living with partner | **423** | **62.7** | **473** | **67.3** | |
| Divorced, separated, widowed | **342** | **27.8** | **289** | **21.0** | |
| Education | | | | | |
| ≤High school, no diploma | 116 | 11.3 | 100 | 11.0 | .09 |
| High school graduate/GED | 240 | 25.8 | 198 | 21.1 | |
| Some college/Associate's degree | 299 | 33.8 | 274 | 31.1 | |
| ≥Bachelor's degree | 215 | 29.1 | 298 | 36.8 | |
| Socioeconomic characteristics | | | | | |
| Insurance status | | | | | |
| Private | 478 | 59.7 | 560 | 66.7 | .10 |
| Public | 266 | 25.1 | 211 | 21.4 | |
| Uninsured | 129 | 15.2 | 102 | 11.9 | |
| Health-related outcomes and behavior | | | | | |
| Comorbid conditions[b] | | | | | |
| None | **404** | **45.5** | **566** | **65.9** | **<.001** |
| At least 1 | **251** | **29.9** | **230** | **25.6** | |
| ≥2 | **220** | **24.6** | **79** | **8.5** | |
| Trouble falling or staying asleep in the previous wk | | | | | |
| Yes | **327** | **37.9** | **250** | **28.5** | **.002** |
| No | **528** | **62.1** | **603** | **71.5** | |
| Current smokers | | | | | |
| Yes | **271** | **31.2** | **158** | **17.8** | **<.001** |
| No | **599** | **68.8** | **713** | **82.2** | |
| Access to mental health care | | | | | |
| Visited mental health professional within the previous y | | | | | |
| Yes | **149** | **13.9** | **81** | **8.3** | **.003** |
| No | **717** | **86.1** | **786** | **91.7** | |

Abbreviation: GED, General Education Development.
[a] The National Health Interview Survey sampling design was incorporated to compute weighted percentages. Bold type indicates statistical significance.
[b] Please see the text for the list of comorbidities.

survey year and region (Northeast, Midwest, South, and West) as previously done.[36] We reported the relative risk ratios (RR) (ie, the probability of having moderate and severe distress compared with none/low distress) and 95% confidence intervals.

NHIS sampling procedures were accounted for by using adult survey weights, strata, and primary sampling unit, and sampling weights from 2013 to 2014 were divided by 2.[51] The "SVY" package was used to estimate the weighted results; "PSMATCH2" command was used to implement propensity score matching.[52] Two-sided statistical significance was considered for an α at the .05 level.

All analyses were conducted using Stata statistical software (version 13.0 SE; StataCorp LP, College Station, Tex).

## RESULTS

### Participant Characteristics

The majority of survivors (87.6%) were diagnosed with 1 cancer (Table 1). Cervical, breast, or ovarian/uterine cancers accounted for 56.8% of all diagnoses. Greater than one-half of patients were diagnosed at ages 30 to 39 years. The mean time since the initial diagnosis was 23 years (standard deviation, 13.9 years).
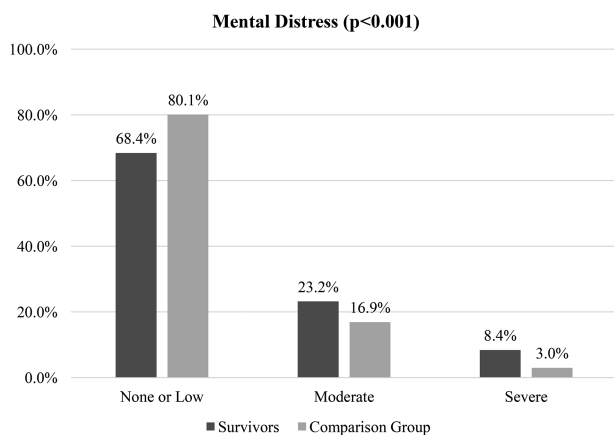
**Figure 1.** Mental distress among survivors and the comparison group. The percentage on the y-axis indicates the weighted percentage of individuals.

In Table 2, survivors reported comorbid conditions, trouble falling/staying asleep, and being a current smoker more often than the comparison group. More survivors reported having seen a mental health professional than the comparison group (13.9% vs 8.3%; $P = .003$).

### Mental Distress and Covariates

Figure 1 demonstrates the increased prevalence of mental distress in survivors (moderate, 23.2% and severe, 8.4%) compared with the comparison group (moderate, 16.9% and severe, 3.0%) ($P<.001$). Many survivors (moderate, 74.7% [155 survivors] and severe, 52.2% [47 survivors] vs none/low, 94.2% [515 survivors]; $P<.001$) and the comparison group individuals (moderate, 81.3% [126 individuals] and severe, 58.1% [20 individuals] vs none/low, 95.2% [640 individuals]; $P<.001$) at risk of distress had not seen a mental health professional within the previous year (data not shown). Survivors were significantly more likely to report that they could not afford mental health care (6.4% [59 survivors] vs 2.3% of the comparison group [20 individuals]; $P = .002$). Among survivors who reported not being able to afford mental health care, those with moderate and severe distress (45.7% [21 survivors] and 38.8% [26 survivors], respectively) reported this affordability barrier more often than those without distress (15.4% [12 survivors]) ($P<.001$).

Bivariate analyses indicated that survivors diagnosed at younger ages were more likely to report distress than those diagnosed at older ages (Table 3). Survivors with > 1 cancer were more likely to report distress. Similar to the comparison group, survivors who were married/living with a partner were less likely to report distress than those who were never married or were divorced, separated, or

widowed. A lower educational level was found to be associated with distress among survivors only. Public or no insurance, the presence of comorbidities, trouble sleeping within the previous week, being a current cigarette smoker, or having seen a mental health professional within the previous year were found to be associated with higher reports of distress in both groups.

In multinomial analyses (Table 4), survivors with $\geq 2$ cancer diagnoses were found to have 2.1 times the risk of reporting moderate distress than survivors with only 1 cancer. Severe distress was not found to be associated with the number of cancer diagnoses. Being non-Hispanic white was associated with a 0.39 times lower risk of severe distress than being Hispanic among survivors. Compared with survivors with private insurance, the risk of moderate distress was 2.48 and 1.93 times greater, respectively, if the survivor had public insurance or no insurance, whereas insurance status was not found to be associated with severe distress. The risk of moderate (RR, 1.61) or severe (RR, 2.09) distress significantly increased if the survivor had $\geq 2$ comorbid conditions. Among survivors, being a current smoker was found to be associated with a 3.59 times higher risk of having severe distress, but no difference in the risk of moderate distress was observed.

In the comparison group, sex, age, race/ethnicity, and marital status were not found to be associated with distress, and educational attainment was associated with lower risks of severe mental distress. Sleep-related problems and visiting a mental health professional within the previous year were associated with greater distress (moderate and severe) among both the groups.

## DISCUSSION

We investigated the prevalence of nonspecific mental distress among AYA cancer survivors in the NHIS data, and identified gaps in mental health care delivery for this important population. The prevalence of severe mental distress among survivors was approximately 3 times than that in the comparison group (8.4% vs 3.0%). Survivors also were at risk of moderate distress more often than the comparison group (23.2% vs 16.9%). Although survivors used mental health care more frequently than the comparison group, an overwhelming majority of survivors (86%) had not talked to a mental health professional within the previous year, suggesting that there may be mental health concerns that are undertreated in this population. Each year, > 70,000 AYA individuals are diagnosed with cancer in the United States,[3] and as per our estimates, many of these survivors may be at risk of developing mental distress in the future and not receive adequate mental health care. The results of the current study point toward the

**TABLE 3.** Bivariate Analyses for Mental Distress

| | Survivors No. (%) | | | | Comparison Group No. (%) | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| | Mental Distress | | | | Mental Distress | | | |
| | None/Low | Moderate | Severe | *P* | None/Low | Moderate | Severe | *P* |
| Sex | | | | | | | | |
| Male | 134 (75.6) | 29 (16.7) | 17 (7.7) | .21 | 150 (84.5) | 24 (12.4) | 7 (3.1) | .29 |
| Female | 436 (66.4) | 187 (25.1) | 72 (8.6) | | 535 (78.9) | 135 (18.2) | 24 (3.0) | |
| Age at survey, y | | | | | | | | |
| 18-39 | 96 (64.2) | 51 (27.4) | 18 (8.5) | .30 | **133 (82.5)** | **28 (16.5)** | **3 (0.9)** | **.01** |
| 40-64 | 326 (67.2) | 123 (23.1) | 63 (9.7) | | **378 (76.5)** | **107 (19.1)** | **27 (4.4)** | |
| 65-85 | 148 (76.6) | 42 (19.1) | 8 (4.4) | | **174 (89.1)** | **24 (10.3)** | **1 (0.6)** | |
| Age at diagnosis, y[a] | | | | | | | | |
| 15-19 | **41 (53.3)** | **30 (38.5)** | **12 (8.2)** | **.05** | - | - | - | |
| 20-29 | **215 (66.2)** | **87 (23.6)** | **46 (10.2)** | | - | - | - | |
| 30-39 | **314 (72.6)** | **99 (20.3)** | **31 (7.1)** | | - | - | - | |
| Cancer diagnosis frequency[a] | | | | | | | | |
| 1 | **515 (71.6)** | **182 (21.4)** | **68 (7.0)** | **<.001** | - | - | - | |
| ≥2 | **55 (46.2)** | **34 (35.8)** | **21 (18.0)** | | - | - | - | |
| Race and ethnicity | | | | | | | | |
| Hispanic | 48 (58.4) | 26 (33.0) | 11 (8.6) | .12 | 67 (77.0) | 14 (16.8) | 5 (6.2) | .74 |
| Non-Hispanic white | 443 (70.5) | 157 (21.9) | 60 (7.6) | | 521 (80.1) | 120 (17.3) | 20 (2.7) | |
| Non-Hispanic black | 52 (70.5) | 17 (16.1) | 9 (13.4) | | 60 (81.9) | 15 (16.0) | 3 (2.1) | |
| Non-Hispanic others | 27 (51.2) | 16 (35.0) | 9 (13.9) | | 37 (83.7) | 10 (12.4) | 3 (3.8) | |
| Marital status | | | | | | | | |
| Never married | **67 (58.8)** | **31 (29.4)** | **11 (11.8)** | **<.001** | **80 (76.7)** | **25 (18.2)** | **4 (5.1)** | **.01** |
| Married, living with partner | **311 (76.8)** | **88 (18.5)** | **24 (4.7)** | | **394 (83.6)** | **66 (14.6)** | **13 (1.8)** | |
| Divorced, separated, widowed | **191 (52.7)** | **97 (31.6)** | **54 (15.7)** | | **207 (70.4)** | **68 (23.8)** | **14 (5.8)** | |
| Education | | | | | | | | |
| ≤High school | **58 (50.0)** | **34 (33.4)** | **24 (16.6)** | **<.001** | 70 (74.5) | 22 (18.7) | 8 (6.9) | .11 |
| High school graduate/GED | **152 (61.5)** | **58 (25.9)** | **30 (12.6)** | | 149 (77.4) | 44 (20.6) | 5 (2.0) | |
| Some college/Associate's degree | **191 (68.9)** | **82 (24.1)** | **26 (7.0)** | | 214 (78.3) | 48 (17.8) | 12 (3.9) | |
| ≥Bachelor's degree | **166 (82.1)** | **40 (14.4)** | **9 (3.5)** | | 249 (84.9) | 43 (13.5) | 6 (1.6) | |
| Insurance status | | | | | | | | |
| Private | **372 (81.7)** | **85 (14.6)** | **21 (3.7)** | **<.001** | **454 (82.7)** | **95 (15.9)** | **11 (1.4)** | **.01** |
| Public | **130 (45.1)** | **88 (38.6)** | **48 (16.3)** | | **160 (76.4)** | **41 (17.9)** | **10 (5.6)** | |
| Uninsured | **68 (56.2)** | **41 (30.0)** | **20 (13.8)** | | **70 (73.3)** | **22 (19.5)** | **10 (7.1)** | |
| Comorbid conditions | | | | | | | | |
| None | **303 (80.4)** | **82 (15.9)** | **19 (3.7)** | **<.001** | **464 (82.1)** | **90 (16.1)** | **12 (1.8)** | **.04** |
| At least 1 | **162 (64.2)** | **61 (27.3)** | **28 (8.6)** | | **170 (78.8)** | **46 (15.6)** | **14 (5.5)** | |
| ≥2 | **105 (51.5)** | **73 (31.6)** | **42 (16.9)** | | **51 (68.6)** | **23 (27.2)** | **5 (4.3)** | |
| Trouble falling or staying asleep within the previous wk | | | | | | | | |
| No | **414 (80.8)** | **95 (15.7)** | **19 (3.5)** | **<.001** | **518 (88.2)** | **77 (11.1)** | **8 (0.7)** | **<.001** |
| Yes | **136 (46.2)** | **121 (36.9)** | **70 (17.0)** | | **146 (57.8)** | **81 (33.1)** | **23 (9.1)** | |
| Current smokers | | | | | | | | |
| No | **429 (76.7)** | **135 (19.3)** | **35 (4.0)** | **<.001** | **572 (82.4)** | **121 (15.2)** | **20 (2.4)** | **.01** |
| Yes | **136 (49.8)** | **81 (32.0)** | **54 (18.2)** | | **109 (68.6)** | **38 (25.8)** | **11 (5.7)** | |
| Visited mental health professional within the previous y | | | | | | | | |
| No | **515 (74.6)** | **155 (20.3)** | **47 (5.1)** | **<.001** | **640 (83.0)** | **126 (15.1)** | **20 (1.9)** | **<.001** |
| Yes | **46 (28.4)** | **61 (42.5)** | **42 (29.1)** | | **37 (46.5)** | **33 (38.4)** | **11 (15.1)** | |

Abbreviation: GED, General Education Development.
[a] Age at the time of diagnosis and cancer diagnosis frequency are only applicable to survivors. Bold type indicates statistical significance

need to evaluate and develop distress tools specifically for AYA oncology in an attempt to identify targeted strategies for treating psychological illness.

Mental distress may substantially impact survivors' functioning at the work, household, and family level,[39] and it may be particularly challenging for those diagnosed with cancer at AYA ages. An earlier study with NHIS data reported that 5.6% of survivors of adult-onset cancer had severe mental distress,[1] which is lower than the percentage

we observed among AYA cancer survivors (8.4%). Survivors of AYA cancer are at risk of encountering psychosocial changes during treatment/survivorship that may increase the potential for mental distress.[3] Greater distress among survivors also may be caused by treatment-related fatigue and the psychological effects of a cancer diagnosis (eg, fear of disease recurrence/death).[1] Periodic mental health and social well-being screenings are components of survivorship guidelines because of recognition of the

**TABLE 4.** Multinomial Logistic Regression Results for Mental Distress[a]

| | Survivors | | | | | | Comparison Group | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Moderate Distress | | | Severe Distress | | | Moderate Distress | | | Severe Distress | | |
| | RR | 95% CI | *P* | RR | 95% CI | *P* | RR | 95% CI | *P* | RR | 95% CI | *P* |
| Sex | | | | | | | | | | | | |
| Male (reference) | | | | | | | | | | | | |
| Female | 1.30 | 0.63-2.68 | .48 | 0.76 | 0.31-1.86 | .54 | 1.52 | 0.72-3.23 | .27 | 0.71 | 0.27-1.81 | .47 |
| Age at survey, y[b] | 0.72 | 0.47-1.12 | .14 | 0.86 | 0.45-1.63 | .64 | 0.75 | 0.51-1.09 | .13 | 1.08 | 0.58-2.01 | .81 |
| Age at diagnosis, y[b] | 1.01 | 0.97-1.05 | .67 | 0.99 | 0.93- 1.04 | .61 | - | | | - | | |
| Cancer diagnosis frequency | | | | | | | | | | | | |
| 1 (reference) | | | | | | | | | | | | |
| ≥2 | **2.10** | **1.00-4.40** | **.05** | 1.97 | 0.74-5.24 | .18 | | - | | | - | |
| Race and ethnicity | | | | | | | | | | | | |
| Hispanic (reference) | | | | | | | | | | | | |
| Non-Hispanic white | 0.52 | 0.23-1.17 | .11 | **0.39** | **0.16-0.96** | **.04** | 0.90 | 0.41-1.96 | .79 | 0.39 | 0.10-1.54 | .18 |
| Non-Hispanic black | 0.35 | 0.11-1.13 | .08 | 0.52 | 0.14-1.88 | .31 | 0.78 | 0.20-2.98 | .71 | 0.24 | 0.02-3.28 | .28 |
| Non-Hispanic others | 1.55 | 0.48-4.99 | .46 | 1.75 | 0.44-6.95 | .42 | 0.69 | 0.24-1.96 | .48 | 0.70 | 0.07-6.74 | .76 |
| Marital status | | | | | | | | | | | | |
| Never married (reference) | | | | | | | | | | | | |
| Married or living with partner | 0.68 | 0.32-1.42 | .30 | 0.41 | 0.15-1.10 | .08 | 1.15 | 0.55-2.42 | .71 | 0.61 | 0.17-2.13 | .43 |
| Divorced, separated or widowed | 1.18 | 0.51-2.75 | .70 | 1.35 | 0.47-3.87 | .57 | 1.84 | 0.83-4.08 | .13 | 1.57 | 0.30-8.32 | .60 |
| Education | | | | | | | | | | | | |
| ≤High school, no diploma (reference) | | | | | | | | | | | | |
| High school graduate/GED | 0.90 | 0.42-1.95 | .79 | 1.20 | 0.40-3.59 | .74 | 0.73 | 0.34-1.59 | .43 | **0.17** | **0.03-0.87** | **.03** |
| Some college/Associate's degree | 0.61 | 0.30-1.23 | .17 | 0.41 | 0.15-1.13 | .09 | 0.80 | 0.36-1.75 | .57 | 0.37 | 0.09-1.55 | .17 |
| ≥Bachelor's degree | 0.47 | 0.21-1.04 | .06 | 0.34 | 0.09-1.28 | .11 | 0.60 | 0.25-1.43 | .25 | **0.24** | **0.06-0.94** | **.04** |
| Insurance status | | | | | | | | | | | | |
| Private (reference) | | | | | | | | | | | | |
| Public | **2.48** | **1.35-4.58** | **.004** | 2.01 | 0.74-5.45 | .17 | 0.86 | 0.46-1.61 | .64 | 1.67 | 0.62-4.47 | .30 |
| Uninsured | **1.93** | **0.99-3.74** | **.05** | 1.78 | 0.59-5.35 | .31 | 0.93 | 0.46-1.88 | .83 | 3.57 | 0.90-14.1 | .07 |
| Comorbid conditions[b] | **1.61** | **1.22-2.14** | **.001** | **2.09** | **1.31-3.32** | **.002** | 1.08 | 0.72-1.62 | .71 | 1.28 | 0.70-2.33 | .4 |
| Trouble falling or staying asleep within the previous wk | | | | | | | | | | | | |
| No (reference) | | | | | | | | | | | | |
| Yes | **3.58** | **2.21-5.81** | **<.001** | **6.5** | **3.11-13.72** | **<.001** | **4.03** | **2.43-6.68** | **<.001** | **21.0** | **7.90-56.01** | **<.001** |
| Current smokers | | | | | | | | | | | | |
| No (reference) | | | | | | | | | | | | |
| Yes | 1.62 | 0.90-2.91 | .11 | **3.59** | **1.46-8.84** | **.01** | 1.64 | 0.84-3.20 | .15 | 1.82 | 0.55-6.00 | .32 |
| Visited mental health professional within the previous y | | | | | | | | | | | | |
| No (reference) | | | | | | | | | | | | |
| Yes | **3.46** | **1.65-7.26** | **.001** | **6.88** | **2.64-17.89** | **<.001** | **4.50** | **2.21-9.19** | **<.001** | **14.2** | **5.64-35.86** | **<.001** |

Abbreviations: 95% CI, 95% confidence interval; GED, General Education Development; RR, relative risk ratio.
[a] The base outcome for these ratios is none/low mental distress. Ages at time of study and diagnosis were included as continuous variables. Age at diagnosis and diagnosis frequency were included only for survivors. Regressions were adjusted for survey year and region. Bold type indicates statistical significance.
[b] Included as a linear term.

connection between mental health and quality of life.[53,54] Despite these guidelines, the identification of mental distress in survivors may be problematic because providers may lack the resources and/or time to effectively screen and refer patients to mental health care.

Engagement with mental health services represents a substantial challenge. Individuals who reported having talked to a mental health professional within the previous year had more distress, suggesting that some survivors are accessing services. Unfortunately 75% and 52% of survivors with moderate and severe mental distress, respectively, had not talked to mental health professionals within the previous year. Of concern are the survivors'

reports of not being able to afford mental health care. The data from the current study were accrued after implementation of the Patient Protection and Affordable Care Act, yet 15% of the survivors were without insurance. Survivors may be impacted financially by a cancer diagnosis, which may increase the potential for mental distress.[55] Previous recommendations that uninsured survivors be referred to free-of-charge community mental health services[20] may not be an adequate strategy. The current mental health workforce is inadequate for survivor needs, even if patients are able to pay.[56]

In our bivariate analysis, AYA cancer survivors diagnosed at older ages reported severe distress less often than

those diagnosed at younger ages, although age at diagnosis was not found to be statistically significant in our multivariable regression. The developmental and mental health care needs of patients diagnosed at younger ages (ages 15-19 years or ages 20-29 years) may be different from those of patients diagnosed at older ages (ages 30-39 years). Patients diagnosed at younger ages may struggle with their performance at school or when starting college, potentially leading to stress, whereas older patients may be at risk of employment and job-related stress. Using the age range of 15 to 39 years at diagnosis may capture the breadth of concerns that may influence the likelihood of distress across the AYA age spectrum. In addition, because the literature historically has focused on pediatric cancer survivors or survivors of cancers diagnosed at older ages, it is extremely important to investigate the full AYA age range to begin to identify age-specific needs for this important population.

Survivors with comorbidities were more likely to report distress, which is consistent with an earlier study of cancer survivors.[1] Survivors and individuals in the comparison group who reported problems with falling/staying asleep reported mental distress more often.[26] Hispanic survivors were more likely to report severe mental distress than non-Hispanic white survivors, which has been observed among the general population.[57] It also is very important to note that currently smoking survivors reported severe distress more often than those who did not smoke currently, unlike the comparison group. This is crucial because >30% of AYA cancer survivors were current smokers, and this group is approximately 4 times more likely to report severe distress. Our previous research has shown that survivors of AYA cancer who currently smoke cigarettes are at a greater risk of reporting comorbidities and poorer general health,[11] and the results of the current study extend that by reporting greater mental distress among cigarette smokers.

As is the case with most survey-based studies, the current study findings regarding mental distress and receipt of mental health care services may be influenced by self-report bias. The NHIS data used in the current analysis were not specifically collected for cancer survivors. Therefore, cancer diagnoses in the NHIS may not represent the national incidence. For example, the survivor population in the current study was predominantly female, similar to previous surveys of this population.[36,58] These skewed data may bias cancer diagnoses when compared with medical registry data.[59] However, mental distress, risk-taking behaviors, and receipt of mental health care services are not captured by cancer registries,

and the NHIS data provide important preliminary and prevalence-based insights for designing future studies that may use more accurate and refined data to assess the mental health concerns of AYA cancer survivors.

Future studies should investigate how mental distress differs by diagnosis and treatment. Sample size limitations prevented subanalysis by cancer type, and the NHIS does not include treatment information. We examined mental health using a cross-sectional data set; however, mental health lies along a continuum, and may change over time. We recommend future longitudinal examination of the course and influences of mental distress among AYA cancer survivors.

The current study evaluated nonspecific mental distress among survivors of AYA cancer in comparison with individuals without cancer. Survivors reported distress at greater rates than the comparison group. Nevertheless, few survivors reported seeing mental health professionals. Cancer survivorship and primary care physicians should be aware of the high risk of mental distress in this population. Formal counseling from mental health professionals must be financially possible when needed. Alternatives, including mental health awareness/counseling from medical professionals or online help/recovery tools, may integrate mental health care into primary care settings,[60] and promote mental health among AYA cancer survivors.

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