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Material and psychological financial hardship related to employment disruption among female adolescent and young adult cancer survivors

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Abstract

Background—The importance of addressing adverse financial effects of cancer among adolescents and young adults (AYAs) is paramount as survival improves. We examined whether cancer-related employment disruption was associated with financial hardship among female AYA cancer survivors in North Carolina (NC) and California.

Methods—AYA cancer survivors identified through the NC Central Cancer Registry and the Kaiser Permanente Northern/Southern California tumor registries responded to an online survey. Disrupted employment was defined as reducing hours, taking temporary leave, or stopping work completely because of cancer. Financial hardship was defined as material conditions or psychological distress related to cancer. Descriptive statistics and chi-square tests were used to characterize the invited sample and survey respondents. Marginal structural binomial regression models were used to estimate prevalence differences (PDs) and 95% confidence intervals (CIs).

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Results—Among 1,328 women employed at diagnosis, women were a median age of 34 years at diagnosis and 7 years from diagnosis at survey, and 32% had employment disruption. A substantial proportion reported financial hardship related to material conditions (27%) or psychological distress (50%). In adjusted analyses, women with disrupted employment had a 17% higher burden of material conditions (95% CI: 10%, 23%) and an 8% higher burden of psychological distress (95% CI: 1%, 16%) compared to those without disruption.

Conclusions—Financial hardship related to employment disruption among female AYA cancer survivors can be substantial. Interventions to promote job maintenance and transition back to the workforce after treatment, and improved workplace accommodations and benefits, present an opportunity to improve cancer survivorship.

Precis:

Female adolescent and young adult cancer survivors can be particularly vulnerable to adverse employment and financial outcomes. Those with cancer-related employment disruption reported increased financial hardship related to material conditions and psychological distress.

Keywords

Adolescent; Young Adult; Female; Cost of Illness; Employment

INTRODUCTION

Cancer diagnosis can have a substantial impact on a patient's quality of life, including one's ability to work due to physical, psychosocial, and cognitive effects related to cancer and its treatment.^{1–7} This is of concern, as employment remains the primary means of accessing insurance coverage in the U.S. among the nonelderly population.⁸ As a result, cancer patients who face disruptions in their employment may be at increased risk for adverse financial outcomes given the potential compounding effects of losing both income and insurance coverage.

Financial outcomes after cancer are multidimensional and are referred to throughout the literature using varied terminology (e.g., financial toxicity, financial burden).^{9,10} This study focuses on two of the three broad domains that have been conceptualized for the term "financial hardship": (1) material conditions arising from increased out-of-pocket expenses and reduced/lost wages from work disruption during and after treatment; and (2) psychological distress triggered by material conditions.^{10,11} A third domain encompasses the coping behaviors adopted to manage the material conditions (e.g., skipping medications). ^{10,11} These three domains can be highly prevalent among cancer survivors in the U.S., as 12–62% report cancer-related debt, approximately 50% report experiencing any financial distress due to cancer care, and up to 45% report non-adherence to medications because of cost.¹⁰ Such financial hardship has been linked to adverse health outcomes, including reduced quality of life, ^{12–16} poorer mental health, ^{12,13} and an increased risk of death.¹⁷

Adolescent and young adults (AYAs) are a demographic that may be at increased risk for poor employment outcomes and greater financial challenges during and after cancer treatment. For instance, AYAs who are employed full-time earn as little as half that of older

adults,¹⁸ and AYAs disproportionately lack health insurance¹⁹ and experience coverage gaps in insurance.²⁰ Among cancer survivors specifically, younger age at diagnosis is a risk factor for both employment disruption¹ and financial hardship.^{21,22} Risks for poor employment and financial outcomes among female AYAs, in particular, may be further exacerbated by gender inequalities; women are disproportionately employed part-time²³ and in low-wage occupations,²⁴ which, in turn, results in less access to benefits such as health insurance,^{25,26} paid leave,²³ and employer-provided disability insurance.²⁷ Indeed, several systematic reviews suggest that female cancer survivors are at increased risk for employment disruption and financial hardship compared to male cancer survivors.^{1,21,22,28} Thus, studies to examine issues related to employment and financial challenges after cancer specifically among female AYAs are warranted given the unique vulnerabilities of this population relative to survivors who are older or male.

However, studies to date that have examined employment disruption as a risk factor for financial hardship among cancer survivors have been aggregated by age and gender.^{29,30} To address this gap, our study uses survey data linked to cancer-registry clinical characteristics to examine whether cancer-related employment disruption was associated with an increased prevalence of financial hardship related to material conditions and psychological distress in female AYA cancer survivors in North Carolina and California.

METHODS

Study design and participants

The study uses data from a cross-sectional survey of women diagnosed with one of the five most common AYA cancer types among females (accounting for 75% of all cancers in this population)-breast, thyroid, melanoma, gynecologic (cervical, ovarian, uterine), and lymphoma.³¹ The study sample was identified from the North Carolina (NC) Central Cancer Registry and the Kaiser Permanente Northern and Southern California (KPNC and KPSC) tumor registries, and the research was approved by the Institutional Review Board (IRB) at each site. Eligible participants were diagnosed at ages 15-39 years between 2004-2015 (NC) or 2004–2016 (KPNC/KPSC), were alive and 18 years or older at the time of contact (September 2018 – November 2019), and had a recorded address from the cancer registry or KP membership files. Women identified in the KP system were also required to be enrolled in KPNC or KPSC health plans at the time of contact per IRB requirements that limited direct contact for study participation to current members. Cancer types were identified in the registries by the ICD-O-3 topography and histology codes using the AYA Site Recode ICD-O-3/WHO 2008 definitions.³² Invasive cancer diagnoses and *in situ* breast cancers were included, as women with *in situ* breast cancer may still undergo treatment that can affect employment and financial outcomes.

The survey assessed the impact of one's cancer diagnosis and treatment in relation to a broad range of survivorship topics. The 130-item questionnaire primarily contained fixed response options, with free text response to describe "Other" responses as applicable. The survey was developed in collaboration with oncologists, epidemiologists, psychiatrists, and other public health experts who contributed expertise across broad survey topics including fertility, clinical trial enrollment, health behaviors, financial concerns, caregiving roles,

advance care planning, and information needs. Following cognitive interviews with nine AYA cancer survivors in NC, survey items related to five topic areas (cancer recurrence, contraceptive use, genetic testing, caregiving roles, and information delivery) were rephrased or reordered to ensure clarity and understanding. A copy of the survey is provided as Supplemental material.

Eligible women (n=13,132) were mailed letters inviting participation in the online survey between September 2018 and November 2019 about their cancer-related experiences. A first letter was mailed that introduced the study and provided a website URL with a unique login code to complete the survey using the Qualtrics software system. A second reminder letter was sent approximately 3 weeks later to women who had not yet responded. All respondents provided informed consent for use of their survey responses as specified by each site-specific IRB. In NC and KPNC, consent included linkage with information from the NC Central Cancer Registry and the KPNC tumor registry. KPSC participants were asked separately for permission to link responses with the KPSC tumor registry and other existing health records; the majority of respondents (79%) provided consent for the linkage. For KPSC participants who did not consent to link their survey responses to the tumor registry (n=80), only self-reported cancer characteristics were analyzed. All survey respondents were asked if they would like to enter a drawing for one of forty \$50 Amazon gift cards in appreciation for their time and participation.

Sociodemographic characteristics, receipt of cancer treatment, and cancer recurrence were self-reported in the survey. Clinical cancer characteristics (age and calendar year at diagnosis, cancer type, and summary stage) were collected from the NC Central Cancer Registry or the KPNC/KPSC tumor registries where participant consent was provided. Cancer registry data was also used for survey responders who were missing self-reported data on race/ethnicity or cancer treatment (for n=6 and n=1, respectively).

Exposure assessment

The exposure of interest was employment disruption; therefore, the analytic sample was restricted to women who reported "working part-time" or "working full-time" to the survey question, "When you were diagnosed with [cancer type] in [year], what was your employment/school status?" Employment disruption was defined using the survey item, "At any time since your cancer diagnosis, has your school or employment status changed because of your cancer or its treatment?" Women who reported to fixed responses of "quitting work completely" or "changing work status from full-time to part-time or reducing hours", or a relevant "Other (please describe)" free text response were defined as experiencing an employment disruption. Relevant "Other" free text responses included reporting temporary leave from work during or after treatment, being terminated from employment, or retiring (with the latter two responses subsequently defined as "quitting work completely"), and were re-categorized. Survey items related to employment status and changes in status were adapted from the AYA Hope Survey.³³

Outcome assessment

Two domains of financial hardship¹⁰ (material conditions and psychological distress) were examined using survey items from the Medical Expenditure Panel Survey Experiences with Cancer questionnaire.³⁴ Each of the survey items had fixed binary response options (yes/no). Financial hardship related to material conditions was operationalized as a binary outcome based on responses to the following two items: (1) "Have you or anyone in your family had to borrow money or go into debt because of your cancer, its treatment, or the lasting effects of that treatment?" and (2) "Did you or your family ever have to file for bankruptcy because of your cancer, its treatment, or the lasting effects of that treatment?" Women who responded "yes" to either of the two items were defined as experiencing hardship related to material conditions, while women who responded "no" to both items were defined as not experiencing material conditions. Additionally, women who reported having to borrow money or go into debt were asked about the amount of money borrowed or debt incurred, with fixed response options ranging from "less than \$10,000" to "\$100,000 or more." Financial hardship related to psychological distress was operationalized as a binary outcome based on response to the survey item, "Have you ever worried about having to pay large medical bills related to your cancer." Women who responded "yes" were defined as experiencing psychological distress. No data was available on coping behaviors (the third domain of financial hardship).

Statistical analyses

Descriptive statistics were used to characterize the invited sample and survey respondents. Chi-square tests were used to assess differences between these groups. Marginal structural linear binomial regression models with inverse probability of treatment weighting and robust variance³⁵ were used to estimate prevalence differences (PDs) and 95% confidence intervals (CIs) for financial hardship comparing AYA cancer survivors with and without employment disruption. Covariates in adjusted models were determined a priori as confounders using a directed acyclic graph (DAG),³⁶ and were operationalized to ensure positivity in the model used to estimate weights,³⁷ including: cancer type (breast, gynecologic, lymphoma, melanoma, thyroid), age at diagnosis (16-29 years, 30-34 years, 35-39 years), time since diagnosis (3–5 years, 6–9 years, 10–15 years), stage (*in situ*/localized, regional/distant), cancer recurrence (yes, no), race/ethnicity (non-Hispanic white, non-Hispanic other race, Hispanic), educational attainment (high school or less, some college or associate degree, Bachelor's degree or higher), health insurance at diagnosis (yes, no), marital status at diagnosis (never married, married, other), employment type at diagnosis (part-time, fulltime), and caregiving for a child or a sick, elderly, or disabled person at diagnosis (yes, no). Cancer treatment was identified a priori as a confounder, but was not included in the final adjusted model due to its high collinearity with cancer type and stage. Further, a broad age at diagnosis category for women <30 years old was used due to a lack of positivity given cancer type, as few women with breast or gynecologic cancers were diagnosed at younger ages. Though some residual confounding may result, this broader categorization allowed for mutual adjustment of age at diagnosis and cancer type without increasing bias and variance due to nonpositivity.37,38

Stratum-specific estimates (adjusted for the same covariate set as the primary model) were used to assess effect measure modification on the additive (prevalence difference) scale for variables selected *a priori* based on substantive interest—age at diagnosis, time since diagnosis, race/ethnicity, and caregiving for a child or a sick, elderly, or disabled person at diagnosis (including a spouse/significant other, parent, grandparent, sibling, friend, or someone else). For a given modifier, effect measure modification was determined to be present when the effect estimate (the prevalence difference) significantly varied across levels of the modifier (*p* for interaction 0.1).³⁹ Given the exploratory nature of the modification analysis, a more liberal *p* for interaction value was set *a priori* to identify specific groups of women who may be at particular risk and who may warrant further study.

Sensitivity analyses

We conducted two primary sensitivity analyses. First, we assessed the sensitivity of our effect estimates to severity of disruption by stratifying analyses by type of disruption: stopping work completely (n=190), taking temporary leave (n=82), or reducing hours (n=154). Women who reported both stopping work completely and reducing hours (n=19) were only included in the stopping work analysis. The association between cancer-related employment disruption and financial hardship for each exposure group was compared relative to women with no employment disruption (n=907).

Second, we assessed the sensitivity of our estimates to exclusion of AYAs who were both employed and in school part-time or full-time at diagnosis (n=154). School status was assessed in the same survey question as previously described pertaining to employment/ school status at the time of diagnosis (i.e., selection of "part-time student" or "full-time student"). This analysis considers the possibility that women who were in school at diagnosis (in addition to being employed) may be differentially affected by an employment disruption than women who are only employed. Both sensitivity analyses were adjusted for the same covariate set included in the primary model. Analyses were conducted using SAS version 9.4 (SAS Institute, Cary, NC).

RESULTS

Invited sample and survey respondents

In total, 1,679 eligible AYA cancer survivors responded to the survey (12.8%) (Figure 1). The invited sample (those whose mailings were not returned and not determined to be ineligible, n=13,132) and survey responders had similar distributions of study site and age at diagnosis, though they did vary by cancer type, stage, treatment, race, and ethnicity (all p<.01) (Supplemental Table 1). Notably, survey responders contained a higher proportion of women who were diagnosed with breast cancer (39.9% vs. 35.2% of the invited sample), had more advanced stage disease (40.9% with regional or distant stage disease vs. 35.0% of the invited sample), received chemotherapy (41.9% vs. 36.6% of the invited sample), and were white (83.1% vs. 73.4% of the invited sample).

Among the women who responded to the survey, 80% reported working part-time (n=226; 17%) or full-time (n=1,097; 83%) at diagnosis (5 women were employed but were missing

data on part-time vs. full-time status), and had non-missing data on the exposure and outcomes of interest (n=1,328; 98% of all employed women who responded to the survey). Given the proportion of women in the analytic sample who reported employment disruption and the prevalence of financial hardship among those with no disruption, we had 80% power (α =.05) to detect prevalence differences of 7% and 8% for material conditions and psychological distress, respectively.

Sample characteristics

Table 1 describes clinical and sociodemographic characteristics of the analytic sample. Nearly 60% of participants were residents of North Carolina, while the remaining were enrollees in the KPNC and KPSC health systems. Women were a median age of 34 years at cancer diagnosis (range=16–39 years) and 7 years from diagnosis at time of survey (range=3–15 years). Breast cancer survivors comprised more than 40% of the sample, 39% of respondents were diagnosed with regional or distant stage disease, and 46% received any chemotherapy. Women were majority non-Hispanic white (75%), nearly 12% were Hispanic, and 13% were non-Hispanic black, Asian, or other race.

Employment disruptions

Roughly one-third of women (32%) reported cancer-related employment disruption. Employment disruptions due to cancer or its treatment were categorized as stopping work completely (including free text responses indicating being fired or retiring) (n=190; 14%), reducing work hours (n=154; 12%), or taking temporary leave (n=82; 6%). Five women reported both temporary leave and a reduction in hours.

Employment disruption and financial hardship related to material conditions

Overall, 27% of respondents reported financial hardship related to material conditions, including borrowing money or going into debt (27%) or filing for bankruptcy (3%) because of cancer or its treatment (Table 2). Material conditions differed substantially by employment disruption—reported by 43% of women with disruption compared to 20% among women without disruption. Women with disrupted employment also experienced a higher degree of hardship, with 24% borrowing money or going into debt of \$10,000 or more (vs. 9% among women without disruption) and 9% borrowing money or going into debt of \$25,000 or more (vs. 2.5% among women without disruption). In adjusted analyses, employment disruption was associated with a 17% (95% CI: 10%, 23%) higher prevalence of material conditions on the absolute scale compared to those without employment disruption (Table 2).

Employment disruption and financial hardship related to psychological distress

Half of respondents reported financial hardship related to psychological distress, or worrying about cancer-related medical bills (Table 2). As with hardship associated with material conditions, psychological distress differed by employment disruption—reported by 60% of women with disruption compared to 45% among women without disruption. In adjusted analyses, employment disruption was associated with an 8% (95% CI: 1%, 16%) higher prevalence of psychological distress on the absolute scale compared to those without

employment disruption (Table 2). We examined the sensitivity of our results to inclusion of health insurance source (through own employer, spouse/parent, government, other, or no insurance) as a confounder (rather than a binary indicator of health insurance), but found no substantive differences in effect estimates and a slight increase in variance (material conditions: PD = 16%, 95% CI: 9%, 23%; psychological distress: PD = 7%, 95% CI: -0.4%, 15%).

Effect measure modification

Stratum-specific estimates were used to evaluate effect measure modification on the additive scale by age at diagnosis, time since diagnosis, race/ethnicity, and caregiver status (Figures 2–3; stratum-specific estimates for disaggregated racial/ethnic groups are presented in Supplemental Table 2). For financial hardship related to material conditions, there was a stronger association related to employment disruption among women ages 16–29 years (p for interaction=.07) and 30–34 years at diagnosis (p for interaction=.1) (vs. 35–39 years) and among Hispanics (vs. non-Hispanic whites, p for interaction=.08). For financial hardship related to psychological distress, a stronger association related to employment disruption was observed among women ages 30–34 years (vs. 35–39 years and 16–29 years, p for interaction=.02), those 6–9 years post-diagnosis (vs. 3–5 years, p for interaction<.001; and vs. 10+ years post-diagnosis, p for interaction=.05), and those who were caregivers for others at diagnosis (vs. non-caregivers, p for interaction=.1).

Sensitivity analyses

The relation between employment disruption and financial hardship was examined stratified by type of disruption, relative to women with no disruption (Table 3). Stopping work, taking temporary leave, or reducing hours were each associated with an increased prevalence of material conditions and psychological distress. In other sensitivity analysis, adjusted effect estimates remained substantively unchanged—though moved slightly away from the null—when women who reported being both employed and in school at diagnosis were excluded (material conditions: PD = 18%, 95% CI: 10%, 25%; psychological distress: PD = 10%, 95% CI: 2%, 18%).

DISCUSSION

Employment disruption among female AYA cancer survivors across two states was associated with a 17% higher prevalence of financial hardship related to material conditions (borrowed money, went into debt, or filed for bankruptcy) and an 8% higher prevalence of psychological distress (worried about medical bills), relative to no employment disruption. The relationship between employment disruption and material conditions was particularly pronounced among women diagnosed at a younger age (<35 years) and Hispanic women, while the relationship between employment disruption and psychological distress was stronger among women ages 30–34 years, those 6–9 years post-diagnosis, and caregivers. Findings also highlight the severity of material conditions related to employment disruption: 24% of women with disruption borrowed or went into debt of at least \$10,000 and 9% borrowed or went into debt of at least \$25,000, relative to 9% and 2.5%, respectively, among women with no disruption.

Prevalence of material and psychological financial hardship in our study sample overall (27% and 50%, respectively) corresponds to national prevalence estimates from the 2015–2017 National Health Interview Survey, in which 29% of adults ages 18–64 reported material conditions and 47% reported psychological distress related to medical financial hardship.⁴⁰ Our study further highlights the substantial increase in prevalence of these domains of financial hardship after an employment disruption—among women in our study with a disruption, 43% reported material conditions and 60% reported psychological distress.

Our results also align with two recent studies that observed an increased likelihood of financial hardship associated with employment change. Among cancer survivors ages 18-64 years who were employed at or after diagnosis, those with an employment change (vs. no change) had a 24.5% higher probability of making financial sacrifices, 29% higher probability of material financial hardship, and 12% higher probability of psychological financial hardship.^{29,30} These associations were substantially modified by sex; compared to those without employment change, females with change had a 31% higher probability of material hardship (vs. 24% in males) and an 18% higher probability of psychological hardship (vs. no effect in males).³⁰ Our study expands on this literature by providing estimates for the relation between employment disruption and financial hardship that are adjusted for confounding clinical variables, including cancer stage, and by exploring patient and clinical characteristics that may modify this association. Notably, our study is the first published study to our knowledge to investigate employment disruption and financial hardship specifically among female AYAs—a population of cancer survivors who may be at particular risk for poor financial outcomes given their age (e.g., lower accumulated wealth) and gender (e.g., disparities in employment type and wages).

Our examination of modification by specific patient and clinical characteristics revealed findings that warrant further exploration. Notably, AYAs <35 years (vs. 35–39) and Hispanic women (vs. non-Hispanic whites) experienced a stronger negative effect of employment disruption on material conditions. More detailed assessment of factors such as pre-diagnosis financial stability and employer-provided benefits (e.g., availability of paid sick leave) may provide further insight regarding potential contributors to the particular vulnerability of these groups. Moreover, women who were caregivers for a child or a sick, elderly, or disabled person at diagnosis (vs. non-caregivers) experienced a stronger negative effect of employment disruption on psychological distress. Further investigation of the emotional, social, physical, and economic burden associated with caregiving—while simultaneously undergoing treatment for a new cancer diagnosis-may help inform psychosocial and psychoeducational interventions targeted towards AYA cancer survivors with caregiving roles.⁴¹ Also of note, we observed that even transient disruption to work or a reduction in hours without complete removal from the workforce was associated with significant material and psychological hardship—findings that should be considered when classifying at-risk patient populations for potential interventions that aim to limit adverse financial outcomes after cancer.

The development of survivorship care interventions that promote self-management and assist with transitioning back to or remaining in the workforce after cancer diagnosis may help

temper or prevent the effects of employment disruption on financial hardship. Such interventions should be informed by a multidisciplinary understanding of the factors that contribute to employment changes, including physical, psychosocial, and cognitive effects related to cancer and its treatment,^{1,11} and could be targeted to higher risk groups such as younger AYAs.

The effects of cancer-related employment disruption may also be reduced or prevented altogether by more flexible work accommodations and sick leave policies. For instance, the perception of employer accommodation and flexible working arrangements can increase the likelihood of returning to work after diagnosis.¹ Further, some employees in the U.S. are provided up to 12 weeks of leave for serious medical conditions under the Family and Medical Leave Act (FMLA); though unpaid, it can protect an employee's job status and group health insurance coverage.⁴² However, FMLA does not apply to small businesses (<50 employees), which account for nearly half of the American workforce.⁴³ FMLA also requires 12 months of employment within a company to qualify, which may particularly disadvantage AYAs who, in general, have been in the workforce for a shorter duration compared to older adults.

When employment disruption does occur, the availability of state laws such as disability insurance to replace lost wages may help mitigate the financial impact of that disruption.⁴⁴ Adverse financial outcomes may be further compounded by loss of employment-based health insurance, though these adverse outcomes may be tempered by increased access to health insurance coverage resulting from the 2010 Affordable Care Act (ACA). Uninsured rates among nonelderly adults with cancer have significantly declined since implementation of the ACA, particularly in Medicaid expansion states (currently enacted in 36 states and the District of Columbia⁴⁵).^{46–48} Further, dependent coverage provisions have resulted in increased health insurance coverage and health care access among young adults ages <26 years, in general,⁴⁹ and specifically among young adults with cancer.⁵⁰ Though the potential impact of the ACA was beyond the scope of this study, future studies should explore how AYAs have utilized specific provisions of the ACA prior to and after cancer diagnosis to access health insurance—particularly after loss of employment-based insurance—and how that coverage may mitigate financial hardship related to material conditions, psychological distress, and coping behaviors.

A primary limitation of our study is the suboptimal response rate (12.8%), which likely reflects the long time since cancer diagnosis for much of the invited sample, as more than 35% were at least 10 years removed from date of diagnosis. Also, contact with the invited sample was limited to two survey invitation postal mailings, and the survey was only available in an English-language online format. However, the response rate is representative of other studies that have recruited AYA cancer survivors, with enrollment rates <15% commonly observed among this demographic.^{51,52} Recruitment of AYA cancer survivors may be improved in future studies through more intensive recruitment and follow-up protocols (e.g., phone call reminders in addition to mailings), multi-modal response options (e.g., web and phone), availability of non-English language study materials, and guaranteed incentives (vs. a raffle format). Non-response in our study may underestimate the impact of cancer-related employment disruption on financial hardship, particularly given that racial

and ethnic minorities were less likely to respond—groups who may be at higher risk for employment and financial challenges after cancer diagnosis.^{53–56}

Availability of sociodemographic and clinical covariates was robust given the study's utilization of both self-reported survey data and linkage to cancer registries, but we lacked data on pre-diagnosis income/assets, type of employment, and leave benefits-factors that may influence a woman's employment status after diagnosis and subsequent financial hardship.^{55,57} We also lacked information on time since last cancer treatment—a valuable characteristic to consider in relation to employment and financial outcomes given potential differences in treatment duration by cancer type; however, we were able to adjust for time since diagnosis and cancer type. Additionally, misclassification of the outcome is a concern given the complexity of constructs related to financial challenges after cancer. Our operationalization of financial hardship used three items from the Medical Expenditure Panel Survey (MEPS) Experiences with Cancer questionnaire (two items related to material conditions and one item related to psychological distress), each of which had been systematically assessed prior to inclusion in MEPS and had been evaluated in cognitive testing.³⁴ Nevertheless, there are likely additional indicators of material conditions and psychological distress not captured in our study, including, for instance, crowd-funding to raise money to pay medical or other bills, or having to reduce spending on essential needs, such as food and other health care-potentially resulting in an underestimation of the prevalence of financial hardship in our sample.

In consideration of the limitations discussed here, future studies that examine employment and financial outcomes among AYA cancer survivors would benefit by assessing more detailed information on factors such as dependent status at diagnosis (e.g., level of parental financial support), household income (e.g., whether the affected individual was the primary wage-earner), health insurance throughout treatment (e.g., loss of coverage after an employment disruption), employer-provided sick leave benefits and other disability insurance, demands of unpaid caregiving roles (e.g., financial and time commitments), and a broad range of indicators for financial hardship (e.g., assessing the use of crowd-funding to pay bills, and coping behaviors such as forgoing medical care due to cost). Such data can be used to inform potential targets of intervention, including the implementation of stronger workplace accommodation policies (e.g., sick leave benefits, flexible working arrangements) that can mitigate employment disruption, and survivorship programs designed to assist with maintaining employment or transitioning back to the workforce after a disruption that are targeted to groups who may be at particular risk of material or psychological financial hardship after a disruption (e.g., younger cancer survivors, Hispanics, and caregivers). Longitudinal cohort studies of AYA cancer survivors can further broaden our understanding of how employment disruption after cancer diagnosis and treatment affects immediate and long-term financial stability, and how that, in turn, may impact quality of life and physical and mental health outcomes.

Conclusions

Financial hardship associated with cancer-related employment disruption among female AYAs can be substantial, particularly among women diagnosed at a younger age, Hispanics,

and those with caregiving responsibilities. Assistance returning to work after treatment and workplace accommodation policies present an important opportunity to lessen financial hardship and improve cancer survivorship care among AYAs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Flow diagram of survey participation



Figure 2.

Stratum-specific estimates for the association between employment disruption and material conditions on the additive (prevalence difference) scale



Figure 3.

Stratum-specific estimates for the association between employment disruption and psychological distress on the additive (prevalence difference) scale

Table 1.

Respondent characteristics, overall and by employment disruption^a

	Overall		No disruption to employment		Disruption to employment	
	n	%	n	%	n	%
Respondents	1,328		907	68.3	421	31.7
Site						
North Carolina	770	58.0	549	60.5	221	52.5
California (KPNC/KPSC)	558	42.0	358	39.5	200	47.5
Median age at diagnosis, years (SD)	34.0 (5.1)		34.0 (5.0)		34.0 (5.4)	
Median time since diagnosis, years (SD)	7.0 (3.6)		7.0 (3.5)		7.0 (3.7)	
Median age at survey, years (SD)	41.0 (6.2)		41.0 (6.1)		40.0 (6.5)	
Age at diagnosis						
16–18	4	0.3	3	0.3	1	0.2
19–24	107	8.1	66	7.3	41	9.7
25–29	198	14.9	132	14.5	66	15.7
30–34	377	28.4	260	28.6	117	27.8
35–39	642	48.3	446	49.2	196	46.6
Cancer type						
Breast	554	41.7	342	37.7	212	50.4
Thyroid	296	22.3	233	25.7	63	15.0
Melanoma	191	14.4	174	19.2	17	4.0
Lymphoma	138	10.4	54	6.0	84	20.0
Gynecologic (cervical, uterine, ovarian)	149	11.2	104	11.5	45	10.7
Summary stage						
In situ	58	4.6	51	5.9	7	1.7
Localized	690	54.7	516	60.0	174	43.2
Regional	451	35.7	267	31.1	184	45.7
Distant	63	5.0	25	2.9	38	9.4
Unknown	66		48		18	
Treatment received						
Surgery only	417	31.4	358	39.5	59	14.0
Radiation without chemotherapy	285	21.5	220	24.2	65	15.5
Any chemotherapy	613	46.2	321	35.4	292	69.5
No surgery, radiation, or chemotherapy	12	0.9	8	0.9	4	1.0
Unknown	1		0		1	
Cancer recurrence						
Yes	155	11.7	93	10.3	62	14.7
No	1,172	88.3	813	89.7	359	85.3
Unknown	1		1		0	
Race/ethnicity						
Non-Hispanic white	999	75.2	706	77.8	293	69.6
Non-Hispanic black	76	5.7	43	4.7	33	7.8

	Overall		No disruption to employment		Disruption to employment	
	n	%	n	%	n	%
Non-Hispanic Asian ^b	82	6.2	46	5.1	36	8.6
Non-Hispanic other race	17	1.3	10	1.1	7	1.7
Hispanic	154	11.6	102	11.2	52	12.4
Educational attainment						
High school graduate or less	62	4.7	36	4.0	26	6.2
Some college or associate degree	389	29.4	250	27.7	139	33.2
Bachelor's degree or higher	871	65.9	617	68.3	254	60.6
Unknown	6		4		2	
Employment status at diagnosis						
Part-time	226	17.1	133	14.7	93	22.1
Full-time	1,097	82.9	770	85.3	327	77.9
Unknown	5		4		1	
Marital status at diagnosis						
Married, or living with partner	966	72.7	675	74.4	291	69.1
Never married	272	20.5	168	18.5	104	24.7
Divorced, separated, or widowed	90	6.8	64	7.1	26	6.2
Caregiver for others at diagnosis						
Yes	673	50.8	455	50.2	218	52.0
No	652	49.2	451	49.8	201	48.0
Unknown	3		1		2	
Health insurance at diagnosis						
Not insured	33	2.5	12	1.3	21	5.0
Medicaid or other public assistance program	47	3.5	17	1.9	30	7.1
Private or other	1,247	94.0	878	96.8	369	87.9
Unknown	1		0		1	

 a Data were based on self-report survey response, except for age at diagnosis, time since diagnosis, age at survey, cancer type, and stage, which were derived from each site's corresponding cancer registry. Cancer registry data was also used for survey respondents who were missing self-reported data on race/ethnicity (n=6) or treatment (n=1).

 $b_{\mbox{Includes Native Hawaiian and other Pacific Islander.}$

SD=standard deviation

Table 2.

Financial hardship due to cancer, overall and by employment disruption

	Overall, n=1,328		No employment n=90	t disruption, 17	Employment disruption, n=421		Adjusted PD ^d (95% CI)
	n	%	n	%	n	%	
Borrowed money or went into debt ^a	356	26.8	177	19.5	179	42.5	
<\$10,000	164	12.3	89	9.8	75	17.8	
\$10,000 - \$24,999	118	8.9	56	6.2	62	14.7	
\$25,000+	61	4.6	23	2.5	38	9.0	
Filed for bankruptcy	34	2.6	17	1.9	17	4.0	
Material conditions ^b	364	27.4	184	20.3	180	42.8	0.17 (0.10, 0.23)
Psychological distress ^{C}	662	49.8	410	45.2	252	59.9	0.08 (0.01, 0.16)

^aDue to missing data on amount of money borrowed/debt incurred, the sum of the sample sizes from the monetary categories may sum to less than the total number who borrowed money or went into debt.

^bBorrowing money, going into debt, or filing for bankruptcy due to cancer or its treatment.

^cWorrying about medical bills related to cancer.

 d^{A} Adjusted for cancer type, age at diagnosis, years since diagnosis, cancer stage, cancer recurrence, race/ethnicity, educational attainment, health insurance at diagnosis, marital status at diagnosis, employment type at diagnosis, and caregiver status at diagnosis. Estimates exclude respondents missing information on any model covariates (n=77).

PD=prevalence difference; CI=confidence interval

Table 3.

Cancer-related employment disruption and financial hardship, stratified by type of disruption^a

	Unadjusted PD (95% CI)	Adjusted PD ^b (95% CI)
Stopped work vs. no disruption $^{\mathcal{C}}$		
Material conditions	0.30 (0.22, 0.37)	0.19 (0.08, 0.31)
Psychological distress	0.19 (0.11, 0.26)	0.15 (0.03, 0.27)
Temporary leave vs. no disruption		
Material conditions	0.16 (0.06, 0.27)	0.16 (0.03, 0.29)
Psychological distress	0.17 (0.06, 0.28)	0.13 (-0.009, 0.26)
Reduced hours vs. no disruption		
Material conditions	0.17 (0.09, 0.25)	0.15 (0.04, 0.25)
Psychological distress	0.09 (0.005, 0.18)	0.09 (-0.02, 0.20)

^aSample size by type of disruption: stopped work, n=190; temporary leave=82; reduced hours, n=154; no disruption=907. Temporary leave and reduced hours analyses include 5 women who reported both types of disruption. 19 women who reported both stopping work and reducing hours are only included in the stopping work analysis.

^bAdjusted for cancer type, age at diagnosis, years since diagnosis, cancer stage, cancer recurrence, race/ethnicity, educational attainment, health insurance at diagnosis, marital status at diagnosis, employment type at diagnosis, and caregiver status at diagnosis.

 c Adjusted analysis for stopped work vs. no disruption excludes one extreme outlier (weight of 29.6) given a bias-variance tradeoff analysis.³⁷

PD=prevalence difference; CI=confidence interval

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