



Financial burdens during the COVID-19 pandemic are related to disrupted healthcare utilization among survivors of adolescent and young adult cancers

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Abstract

Purpose We examined whether financial burdens occurring during the COVID-19 pandemic impacted healthcare utilization among survivors of adolescent and young adult cancers.

Methods We surveyed survivors enrolled in a patient navigation program to obtain self-reports of delayed/skipped cancer care or other care, changes to medication obtainment, and changes to medication use since the COVID-19 pandemic began. Reported financial burdens were defined as financial toxicity in the past 4 weeks (COMprehensive Score for financial Toxicity [COST] \leq median 21) and material hardships (*range* = 4–11) since March 2020. Adjusted logistic regression models calculated associations and effect modification by gender.

Results Survivors ($n = 341$) were mostly female (61.3%) and non-Hispanic White (83.3%). Nearly 20% delayed/skipped cancer care, 35.2% delayed/skipped other care, 19.1% changed medication obtainment, and 12.6% changed medication use. Greater material hardships were associated with delayed/skipped cancer care (odds ratio (*OR*) = 3.13, 95% *CI* = 1.44–6.81) and other care (*OR* = 2.17, 95% *CI* = 1.18–3.98), and changed medication obtainment (*OR* = 2.72, 95% *CI* = 1.43–5.18) or use (*OR* = 4.49, 95% *CI* = 2.05–9.80). Financial toxicity was associated with delayed/skipped other care (*OR* = 2.53, 95% *CI* = 1.31–4.89) and changed medication obtainment (*OR* = 1.96, 95% *CI* = 1.01–3.83) and medication use (*OR* = 3.73, 95% *CI* = 1.59–8.73). The association of material hardships and any changes in healthcare utilization was greater among female compared to male survivors.

Conclusion Financial burdens experienced during the pandemic impeded survivors' ability to utilize necessary healthcare, with worse impacts among female survivors.

Implications for Cancer Survivors Delayed or skipped healthcare may lead to an increased cancer mortality or severity of therapy-related conditions. Providing resources that enable survivors experiencing financial burdens to continue critical cancer and preventive care during the COVID-19 pandemic is a priority.

Keywords COVID-19 · Healthcare utilization · AYA cancers · Survivorship · Financial toxicity

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Introduction

The COVID-19 pandemic has taken the lives of over 1,000,000 Americans and strained the capacity of healthcare professionals and systems to care for complex patients [1–3]. Healthcare systems have reduced patient loads to limit in-person contact and preserve resources for COVID-19 care, but these changes have limited capacity for cancer care [4, 5]. Shifting to telehealth has been challenging for cancer patients whose care may require laboratory tests or hands-on examination [4, 5]. While some patients are hesitant to start or continue cancer care during the pandemic, expedient cancer care is still a priority. Even a month-long delay in treatment can increase cancer mortality by between 6 and 23% [6, 7]. Survivors of adolescent and young adult cancers, who were diagnosed between the ages 15 and 39 years (AYA survivors), already had financial and insurance-related barriers to utilizing healthcare before the pandemic [8]. COVID-19-related health care challenges may cause additional barriers for AYA survivors, affecting their treatment, management of late effects, and screening for second cancers [9, 10]. Pandemic-related delays in cancer care have been reported in 40% to 60% of surveyed AYA survivors [11].

Before the pandemic, the financial burden of cancer therapy, employment and education disruption, and inadequate access to health insurance impeded healthcare use among AYA survivors [8]. Distress from financial problems due to cancer therapy, defined as financial toxicity, can continue for years after therapy ends [12]. To cope with financial toxicity and out-of-pocket costs, AYA survivors may engage in cost-coping behaviors such as skipping treatments that likely have adverse impacts on their survival [13]. An estimated 71% of AYA survivors have engaged in at least one cost-coping behavior, and those with the greatest financial toxicity had the highest risk for these behaviors [13]. While health insurance can offset some costs, cancer-related unemployment can create gaps in health insurance coverage and can impede survivors' ability to build savings [14]. The pandemic appears to have worsened the prevalence of these financial, health insurance, and employment-related barriers to healthcare in AYA survivors [13, 15].

In addition, historic disparities have existed in healthcare utilization according to sociodemographic characteristics like gender, sexual orientation, insurance coverage, and cancer type, that can disproportionately affect AYA survivors [16–19]. These disparities may have widened during the COVID-19 pandemic, but few studies involving young cancer survivors have addressed this topic. In the midst of the COVID-19 pandemic, we surveyed AYA survivors through the Huntsman-Intermountain Adolescent

and Young Adult (HIAYA) Cancer Care Program about their healthcare utilization, financial burdens, and changes in employment or school that they experienced during the 2020 calendar year. This exploratory study identifies whether these changes were correlated with survivors' self-reported healthcare utilization. We captured four dimensions of healthcare utilization: delayed or skipped cancer care, delayed or skipped other care, adaptive behaviors to obtain lower cost medications, and changes in medication use.

Methods

Study design and population

The Utah-based HIAYA program provides AYA cancer survivors with healthcare navigation, access to research studies, and other support. HIAYA serves Utah patients and patients from the neighboring states that utilize Utah's healthcare network, and patients of community oncology clinics were treated at Intermountain Healthcare. The University of Utah IRB approved this study.

Eligible participants who were enrolled in HIAYA were ≥ 18 years at the time of survey and diagnosed with cancer between 15 and 39 years, and who had an email address in the HIAYA database ($n = 675$) (Supplemental Fig. 1). A one-time survey was emailed to eligible persons in October 2020, and data collection continued until January 2021. Follow-up emails, texts, and mail notifications occurred between October 2020 and January 2021. Participants received a \$20 gift card.

Survey design

We referred to March 2020 as the beginning of the pandemic in the survey. Participants reported demographic items such as age at survey, race, ethnicity, sexual orientation, and gender identity. Diagnosis age was computed from self-reported dates of birth and first cancer diagnosis from medical records. Survey and diagnosis age were grouped by 5-year increments. Race and ethnicity were combined together into White non-Hispanic, Hispanic, and non-Hispanic racial minority. LGBTQ+ identity was determined using self-reported sexual orientation and gender identity. Years since diagnosis were computed using the survey date and cancer diagnosis date.

Receipt of cancer therapy was asked in the survey. Participants indicated yes/no if they received cancer-related therapy since March 2020. Participants reported if they specifically received chemotherapy, surgery, radiation, hormone therapy, immunotherapy, or other therapies related to cancer. We reviewed medical records to identify first cancer

diagnosis and classified diagnoses by the AYA site recode/WHO 2008 definition [20].

Financial burden and changes in employment or schooling

We measured financial burdens as financial toxicity and material hardship. Financial toxicity in the past 4 weeks was measured using 11 items coded on a 5-point Likert scale from the “COMprehensive Score for financial Toxicity” (COST) [12]. As low scores indicated higher toxicity, we divided participants into “high” or “low” by $COST \leq 21$ (median = 21) as done previously [21].

Material hardships that occurred since March 2020 were measured with 11 questions adapted from the Commonwealth tracking survey and other healthcare surveys [22, 23]. We asked participants if their material hardships originated from the COVID-19 pandemic or their cancer treatment and/or side effect costs (Supplemental Fig. 2). We summed the number of material hardships from either cancer or COVID-19 and defined groups as “high” (4–10) or “low” (0–3) by the median ($n = 3$). We also counted material hardships that were caused due to COVID-19 or cancer separately. These were grouped as “high” (2–9) or “low” (0–1) by the median ($n = 1$).

Participants reported their employment and/or school enrollment prior to March 2020. Open-ended and multiple-choice questions asked about changes in work hours, employment, or schooling since March 2020. We created four categories to reflect responses: increased hours, reduced hours, no change and unemployed/caregiver, no change and employed.

Healthcare utilization outcomes

Our outcomes were delayed/skipped cancer care, delayed/skipped other care, changes in medication obtainment, and changes in medication use. Participants reported any delayed/skipped care that was related to cancer and unrelated to cancer (other care) since March 2020 [24]. Participants also reported the types of care that were delayed/skipped and reasons for delaying/skipping care, including provider/facility delays or cancellations. The response options for types of care that were skipped/delayed were oncology, primary care, mental health, urgent care, emergency care, and other specialties as a free-response text answer.

Participants reported changes in medication obtainment or use because of the COVID-19 pandemic [22]. Changes to medication obtainment captured adaptive behaviors to find affordable medications, defined as asking physicians for less expensive medication, shopping for lowest priced pharmacies, replacing prescriptions with over-the-counter options,

purchasing medication abroad, or obtaining medications through Veterans Affairs. Changes to medication use were defined as taking medications prescribed for others, not filling prescriptions, filling only part of prescriptions, or taking less than the prescribed amount.

Statistical analysis

We described the sample by demographics and outcomes. Chi-squared tests compared differences among the outcomes by therapy, survey age, and cancer diagnosis. Melanoma was chosen as the referent group as it can often be treated with less therapy than the other tumor types included in the survey. Logistic regression models were conducted to examine the associations between the outcomes and demographics separately to avoid collinearity, while adjusting for survey age, race/ethnicity, and gender where appropriate. We also used logistic regression to compute the associations of financial burdens or employment/school changes with our outcomes separately, while adjusting for gender, race/ethnicity, survey age, marital status, and health insurance. Confounders were chosen by their impact on the odds ratio, theoretical merit, and maximization of $c \geq 0.7$. For models of delayed/skipped care, we excluded persons with delayed/skipped care due to provider/facility preference (cancer care = 33; other care = 57).

Because of the pandemic’s disproportionate financial impact on women [25], we examined the effect modification of the association of material hardship and our outcomes by gender. To improve power, we aggregated all responses into a single outcome (any change in healthcare utilization) which excluded persons who only reported delayed/skipped care due to provider delays/cancellations ($n = 56$). We also aggregated the outcome medication obtainment and use (medication obtainment/use) and delayed/skipped cancer and other care (delayed/skipped cancer or other care). Stratified logistic regression models provided the gender-specific odds ratios and confidence intervals while adjusting for survey age, race/ethnicity, education, and health insurance. Separate models with interaction terms provided the p values for the comparison of gender-specific odds ratios. Odds ratios were significant if their 95% confidence intervals excluded the null and interactions were significant if the type 3 test p value < 0.05 . We also examined the association between changes in employment and our outcomes stratified by gender and in separate models.

Results

We had 341 (50.5%) survivors who participated in the survey (Supplemental Fig. 1). Participants were largely female (61.3%), married/cohabiting (52.5%), non-Hispanic White

Table 1 Characteristics of survivors of adolescent and young adult cancers surveyed from October 2020 to January 2021 ($N=314$)

		<i>n</i>	%
Female		209	61.3
Survey age (years)	18–24	99	29.0
	25–29	74	21.7
	30–34	76	22.3
	35–39	68	19.9
	40–55	24	7.0
Diagnosis age (years)	15–19	51	15.0
	20–24	97	28.5
	25–29	66	19.4
	30–34	61	17.9
	35–40	60	17.6
Race and ethnicity	Hispanic	34	10.0
	Non-Hispanic racial minority	23	6.7
	White, non-Hispanic	284	83.3
LGBTQ+		29	8.5
Marital status	Divorced/widowed/separated	24	7.0
	Married/cohabiting	179	52.5
	Single	127	37.2
Education	≤ High school	42	12.3
	Some college	146	42.8
	College	109	32.0
	Graduate school	43	12.6
Employment or schooling changes during COVID-19 pandemic	Increased hours	67	19.7
	Reduced hours	74	21.8
	No change (unemployed/caregiver)	80	23.5
	No change (employed)	119	35.0
Health insurance	Employer/military/individual	270	79.2
	Public and private coverage	19	5.6
	Public	33	9.7
	Uninsured/unknown	15	4.4
First diagnosis	CNS/other nervous system	42	12.3
	Carcinoma	103	30.2
	Gonadal/related tumors	30	8.8
	Leukemia/lymphoma	104	30.5
	Sarcoma	35	10.3
	Melanoma	20	5.9
Therapy since March 2020	Yes	184	54.0
Years since diagnosis	0–2	207	60.7
	3–10	116	34.0
	11–25	12	3.5

Missing *N*'s: diagnosis age = 6, LGBTQ+ = 16, marital status = 11, education = 1, employment = 1, health insurance = 4, first diagnosis = 7, therapy since March 2020 = 4, years since diagnosis = 6
employment includes school enrollment

(83.3%), 18–29 years old (50.7%), 0–2 years from diagnosis (60.7%), and health insured at the time of survey (79.2%; Table 1). Females composed 83.3% of divorced/widowed/separated persons, 65.9% of married/cohabiting persons, and 79.3% of LGBTQ+ survivors. Carcinomas (30.2%) and

leukemia/lymphoma (30.5%) were the most common diagnoses and 54.0% reported receiving cancer-related therapy since March 2020. Employment/school hours were reduced for 21.8% and increased for 19.7% of survivors. Only 1.2%

Table 2 Changes in healthcare utilization among survivors of adolescent and young adult cancers surveyed from October 2020 to January 2021

	<i>n</i>	%
All	341	
Delayed/skipped cancer care since March 2020		
No	276	80.9
Yes	65	19.1
<i>Facility/provider delayed or canceled care</i>	31	47.7
Types of delayed/skipped cancer care		
Oncology	47	13.8
Primary care	7	2.1
Mental health	9	2.6
Urgent care	2	0.6
Emergency care	1	0.3
Other specialties	16	4.7
Delayed/skipped other care since March 2020		
No	220	64.5
Yes	120	35.2
<i>Facility/provider delayed or canceled care</i>	53	44.2
Types of delayed/skipped other care		
Primary care	81	23.8
Mental health	40	11.7
Urgent care	9	2.6
Emergency care	4	1.2
Dental	18	5.3
Other specialties	33	9.7
Changed medication obtainment ^a		
No	208	61.0
Yes	65	19.1
Changed medication use		
No	237	69.5
Yes	43	12.6

^aAdaptive behaviors to find more affordable medications

Missing *N*'s: therapy=4, delayed/skipped cancer care=1, delayed/skipped not cancer care=1, medication obtainment=68, medication use=61, financial toxicity=2, financial burden=1, employment=1

Italics indicate subgroup percentages

lost health insurance and 4.1% enrolled in Medicaid since March 2020.

Delayed/skipped cancer care (19.1%) was less common than delayed/skipped other care (35.2%) (Table 2). Provider/facility preference was responsible for delays/skips in 47.7% of cancer and 44.2% of other care. Oncology (13.8%) was the most commonly delayed/skipped type of cancer care. Primary care (2.1%) and mental health (2.6%) that were related to cancer were the least commonly delayed/skipped cancer care. For other care, primary care (23.8%) was most commonly delayed/skipped. Nearly 20% of survivors changed their medication obtainment and 12.6% changed their medication use. Financial burdens due to cancer (39.9%) or

COVID-19 (54.8%) were the most common type of reported material hardship (due to any cause = 77.5%). Other common material hardships included taking money out of savings (due to any cause = 63.2%, COVID-19 = 22.9%, cancer = 32.0%) and spending ≥ 10% of income on medical expenses (due to any cause = 38.4%, COVID-19 = 4.7%, cancer = 31.4%).

Odds ratios for delayed/skipped other care were greater among female survivors ($OR = 2.41$, 95% $CI = 1.26–4.62$) compared to males and among married/cohabiting survivors ($OR = 2.34$, 95% $CI = 1.15–4.76$) relative to single survivors (Table 3). Changing medication obtainment odds ratios were elevated among divorced/widowed/separated survivors ($OR = 3.32$, 95% $CI = 1.08–10.2$) and inverse among survivors with employer/military/individual health insurance ($OR = 0.42$, 95% $CI = 0.21–0.82$) relative to their comparison groups. Odds ratios for changes to medication use were elevated among LGBTQ+ survivors ($OR = 3.51$, 95% $CI = 1.35–9.11$) but inverse among married/cohabiting survivors ($OR = 0.31$, 95% $CI = 0.13–0.73$). We found no significant results by cancer diagnosis or self-reported cancer therapy since March 2020.

Financial burdens had significant impacts on delayed/skipped cancer and other care appointments. Odds of reporting a delayed/skipped cancer care appointment were greater among survivors with high material hardships due to any cause, from COVID-19, and from cancer (any cause, $OR = 3.13$, 95% $CI = 1.44–6.81$; COVID-19, $OR = 6.09$, 95% $CI = 2.04–18.10$; cancer, $OR = 5.36$, 95% $CI = 1.96–14.70$) (Table 4). Delayed/skipped other care appointments were associated with high financial toxicity ($OR = 2.53$, 95% $CI = 1.31–4.89$) and high material hardship from any cause, from COVID-19, and from cancer (any cause, $OR = 2.17$, 95% $CI = 1.18–3.98$; COVID-19, $OR = 2.67$, 95% $CI = 1.29–5.53$; cancer, $OR = 2.17$, 95% $CI = 1.02–4.59$).

Odds ratios for changes in medication obtainment were elevated among survivors with high financial toxicity ($OR = 1.96$, 95% $CI = 1.01–3.83$) and high material hardship due to any cause, from COVID-19, and from cancer (any cause, $OR = 2.72$, 95% $CI = 1.43–5.18$; COVID-19, $OR = 3.08$, 95% $CI = 1.41–6.75$; cancer, $OR = 3.08$, 95% $CI = 1.41–6.71$). Odds ratios for changing medication use were elevated among survivors with high financial toxicity ($OR = 3.73$, 95% $CI = 1.59–8.73$) and high material hardship from any cause, COVID-19, and cancer (any cause, $OR = 4.49$, 95% $CI = 2.05–9.80$; COVID-19, $OR = 3.63$, 95% $CI = 1.41–9.35$; cancer, $OR = 2.93$, 95% $CI = 1.18–7.27$) relative to their comparison groups. Participants whose employment/school hours were increased ($OR = 4.54$, 95% $CI = 1.44–14.30$) or reduced ($OR = 3.66$, 95% $CI = 1.23–10.90$) had higher odds of changing their medication use relative to employed survivors with no changes.

Table 3 Multivariable associations of demographic and clinical characteristics of survivors of adolescent and young adult cancers and changes in healthcare utilization during the COVID-19 pandemic

Models		Delayed/skipped care from March 2020 to January 2021		Changes to medication obtainment or use because of the COVID-19 pandemic	
		Cancer care	Other care	Obtainment ^a	Use
		OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
1 Gender	Female	0.83 (0.39–1.76)	2.41 (1.26–4.62)*	1.17 (0.62–2.20)	1.49 (0.71–3.15)
	Male	1	1	1	1
2 Marital status	Divorced/widowed/separated	1.65 (0.37–7.36)	1.56 (0.42–5.82)	3.32 (1.08–10.2)*	0.55 (0.14–2.10)
	Married/cohabitating	1.28 (0.54–3.05)	2.34 (1.15–4.76)*	0.64 (0.31–1.33)	0.31 (0.13–0.73)*
	Single	1	1	1	1
3 Sexuality	LGBTQ+	2.25 (0.65–7.80)	0.64 (0.20–2.10)	1.72 (0.62–4.73)	3.51 (1.35–9.11)*
	Cis-heterosexual	1	1	1	1
4 Education	≤High school	0.77 (0.14–4.34)	0.77 (0.22–2.68)	2.63 (0.68–10.1)	0.60 (0.11–3.11)
	Some college	1.32 (0.37–4.69)	0.95 (0.38–2.38)	1.53 (0.50–4.68)	1.01 (0.29–3.52)
	College	0.93 (0.26–3.38)	1.15 (0.46–2.88)	1.39 (0.45–4.36)	0.80 (0.22–2.93)
	Grad school	1	1	1	1
5 Health insurance	Employer/military/individual	0.60 (0.26–1.42)	0.76 (0.37–1.56)	0.42 (0.21–0.82)*	0.50 (0.23–1.08)
	Public, uninsured, unknown	1	1	1	1
6 Diagnosis age (years)	15–19	0.32 (0.02–4.61)	0.21 (0.03–1.35)	0.69 (0.11–4.28)	1.32 (0.15–11.5)
	20–24	1.38 (0.14–13.5)	0.24 (0.04–1.32)	0.85 (0.16–4.66)	1.19 (0.15–9.65)
	25–29	1.30 (0.16–10.6)	0.22 (0.05–1.07)	1.11 (0.23–5.28)	1.26 (0.18–8.87)
	30–34	2.43 (0.53–11.1)	0.46 (0.12–1.73)	1.45 (0.41–5.07)	1.53 (0.30–7.86)
	35–40	1	1	1	1
7 Diagnosis	CNS and nervous system	0.66 (0.16–2.81)	0.50 (0.12–2.11)	1.42 (0.24–8.37)	1.02 (0.08–12.7)
	Carcinoma	0.58 (0.15–2.21)	0.76 (0.23–2.53)	1.61 (0.30–8.57)	2.46 (0.28–21.9)
	Gonadal or related tumors	0.39 (0.06–2.56)	0.20 (0.03–1.27)	1.66 (0.24–11.7)	5.74 (0.51–64.2)
	Leukemia or lymphoma	0.35 (0.09–1.37)	1.32 (0.41–4.29)	1.67 (0.33–8.47)	2.66 (0.31–22.7)
	Sarcoma	0.47 (0.09–2.56)	1.66 (0.42–6.56)	0.96 (0.14–6.35)	3.61 (0.36–36.7)
	Melanoma	1	1	1	1
8 Therapy since March 2020	No	0.88 (0.41–1.89)	1.42 (0.78–2.60)	1.37 (0.74–2.52)	1.74 (0.84–3.62)
	Yes	1	1	1	1

^aAdaptive behaviors to find more affordable medications

Models for cancer care exclude $n=33$ and other care exclude $n=57$ with delayed/skipped care due to provider/facility preference. Persons with no information on medication obtainment ($n=68$) or use ($n=61$) were excluded

Model 1 controls for survey age and race/ethnicity. Models 2–7 control for gender, survey age, and race/ethnicity

OR, odds ratio; CI, confidence interval. * $p<0.05$

We found significant effect modification of the association of high material hardship and adverse changes in any healthcare utilization by gender (Fig. 1; p value interaction = 0.03). Females with high material hardship had an odds ratio of 3.63 (95% CI = 1.81–7.29) of changing any healthcare utilization compared to females with low material hardship, while the odds ratio among males did not significantly differ by material hardship (OR = 1.17, 95% CI = 0.39–3.47). Odds ratios for female-only analyses were consistently elevated and significant for all other outcomes, including changes in medication obtainment/

use (OR = 4.80, 95% CI = 2.26–10.19) and delayed/skipped cancer or other care (cancer, OR = 3.71, 95% CI = 1.89–7.28; other care, OR = 3.15, 95% CI = 1.50–6.63). We found no significant differences in the effect estimates for the association of changes in employment and our outcomes stratified by gender.

In a post hoc analysis, we found no significant correlations between demographics and delayed/skipped care among persons with delays/skips that were due to provider/facility preference. We examined the effect modification of the association of material hardship and changes in

Table 4 Multivariable associations of financial burden and employment changes of survivors of adolescent and young adult cancers and changes in healthcare utilization during the COVID-19 Pandemic

Models		<i>n</i>	Delayed/skipped care from March 2020 to January 2021		Changes to medication obtainment or use because of the COVID-19 pandemic		
			Cancer care	Other care	Obtainment ^a	Use	
			<i>OR</i> (95% <i>CI</i>)	<i>OR</i> (95% <i>CI</i>)	<i>OR</i> (95% <i>CI</i>)	<i>OR</i> (95% <i>CI</i>)	
1	Financial toxicity	High: COST score ≤ 21	168	1.75 (0.79–3.91)	2.53 (1.31–4.89)*	1.96 (1.01–3.83)*	3.73 (1.59–8.73)*
		Low: COST score > 21	171	1	1	1	1
2	Material hardship, any cause	High: 4–11	136	3.13 (1.44–6.81)*	2.17 (1.18–3.98)*	2.72 (1.43–5.18)*	4.49 (2.05–9.80)*
		Low: 0–3	204	1	1	1	1
3	Material hardship due to COVID-19	High: 2–9	106	6.09 (2.04–18.10)*	2.67 (1.29–5.53)*	3.08 (1.41–6.75)*	3.63 (1.41–9.35)*
		Low: 0–1	131	1	1	1	1
4	Material hardship due to cancer	High: 2–9	90	5.36 (1.96–14.70)*	2.17 (1.02–4.59)*	3.08 (1.41–6.71)*	2.93 (1.18–7.27)*
		Low: 0–1	144	1	1	1	1
3	Employment or schooling changes during COVID-19 pandemic	Increased hours	67	0.89 (0.29–2.72)	0.77 (0.30–1.96)	1.18 (0.44–3.17)	4.54 (1.44–14.30)*
		Reduced hours	74	2.64 (0.98–7.10)	1.40 (0.58–3.36)	2.08 (0.88–4.88)	3.66 (1.23–10.90)*
		No change (unemployed/caregiver)	80	0.39 (0.10–1.62)	1.44 (0.64–3.20)	0.60 (0.23–1.59)	1.06 (0.29–3.85)
	No change (employed)	119	1	1	1	1	

^aAdaptive behaviors to find more affordable medications

Models for cancer care exclude $n=33$ and other care exclude $n=57$ persons with delayed/skipped care due to provider/facility preference. Persons with no information on medication obtainment ($n=68$) or use ($n=61$) were excluded

All models adjust for gender, survey age, marital status, education, health insurance type, and race/ethnicity

OR, odds ratio; *CI*, confidence interval

COST, “COmprehensive Score for financial Toxicity”

Missing $N=104$ for hardship missing due to COVID-19 and $N=107$ responses for hardship due to cancer

* $p < 0.05$

healthcare utilization by LGBTQ+. The interaction term was significant, but the small sample size and resulting wide confidence intervals indicate that the results are not reliable.

Discussion

The COVID-19 pandemic had adverse impacts on healthcare utilization among survivors of AYA cancer, for whom healthcare is necessary to manage chronic conditions and prevent second neoplasms [9, 10]. We found that survivors of AYA cancers with high financial burdens had nearly threefold increases in their odds of delaying or skipping healthcare appointments. While provider-initiated delays/cancellations were a large reason for delayed/skipped care, our results provide strong support for the role of pandemic-related financial barriers in impeding healthcare utilization. Survivors who were females, married, and LGBTQ+ appear to be at risk for pandemic-related decreases in healthcare utilization.

Even before the COVID-19 pandemic, AYA survivors had high rates of treatment nonadherence [26, 27], and financial toxicity was a significant risk factor for nonadherence [14, 22]. In our study, financial toxicity and material hardship had significant impacts on delayed/skipped cancer care. Even a 4-week delay in starting care increases mortality from treatable cancers that are diagnosed among AYAs, including breast, cervical, and colorectal cancer [6, 7]. In this study, financial burdens were the only significant contributing factors to delayed/skipped cancer or other care. Over a third of surveyed survivors delayed/skipped other care while nearly 20% delayed/skipped cancer care, perhaps due to perceptions that cancer care was of greater importance. While receiving timely cancer care is important for cancer survival, primary care is still needed to detect preventable diseases, cancer screenings, and administration of vaccines including COVID-19 vaccines. The lower percent of delayed/skipped cancer care suggests that AYA survivors may have a higher need or feel more pressure to pay for cancer care than other types of healthcare during the COVID-19 pandemic.

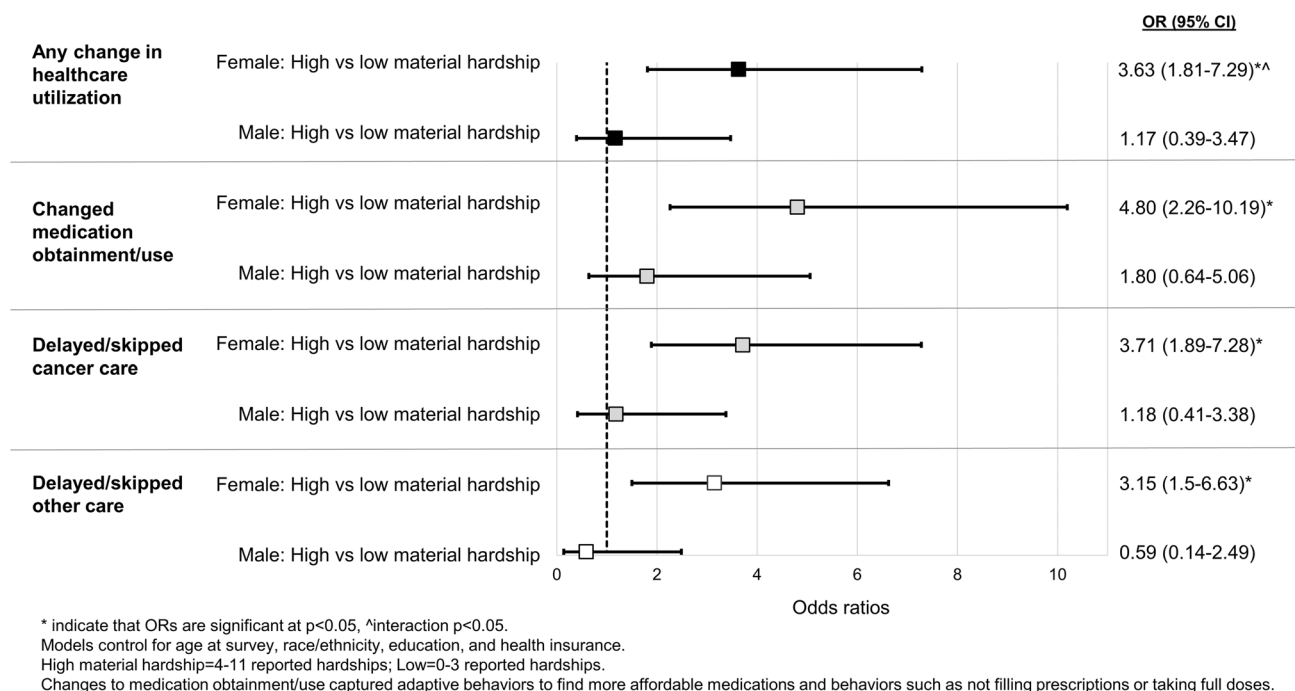


Fig. 1 Effect modification of the association of material hardship and healthcare utilization by gender among survivors of adolescent and young adult cancers during the COVID-19 pandemic

Adherence to recommended medication use is necessary as many chemotherapies have transitioned from intravenous administration to oral ingestion [28], and medications may also be needed to manage therapy-related effects [29]. Our results support that pandemic-related financial burdens were major barriers to medication adherence among AYA survivors, increasing the odds of changing medication obtainment by fivefold relative to survivors with fewer financial burdens. Our survey questions about medication obtainment captured adaptive behaviors to find affordable medications. The cost of prescription medications in the USA rose even before the pandemic began, with cancer drugs being among the most expensive [30].

AYA survivors in the USA have limited protections against drug price increases and are responsible for drug costs that may or may not be covered by health insurance policies [30]. As medication costs during the COVID-19 pandemic may increase due to supply chain interruptions [31], adaptations to locate affordable medications may not be effective in the face of global supply problems. These pandemic-related barriers to obtaining and using medications will require more follow-up to document their full impact on AYA survivors.

Patterns in healthcare utilization appear to vary based on relationship status and sexual orientation/gender identity. Married/cohabiting survivors had two-fold odds of reporting delayed/skipped other care, but inverse odds of changing medication use relative to single persons. During the

COVID-19 pandemic, women had increased responsibilities due to school and daycare closures [32]. In addition to their regular employment, women were more likely to be tasked with the at-home education and care of children [33, 34]. While many employed women left their jobs to cope with these added pressures [35, 36], nationwide, women were also more likely to be laid off or underemployed during the pandemic [25]. This loss of income may have increased material hardships experienced by the family as a whole while adding to demands on women's time.

Prior to the pandemic, financial burdens were a risk factor for delayed/skipped healthcare appointments among families with children [37]. The combination of time limitations due to childcare responsibilities and the rise of pandemic-related material hardships may explain why the odds ratio for delayed/skipped other care was greater among married/cohabiting females relative to single persons. The inverse odds of changing medication use among married persons may be due to having a stable caregiver who helps manage medications or supports self-management of medications [38].

Divorced/widowed/separated survivors and LGBTQ+ survivors appear to be more vulnerable to pandemic-related changes in medication obtainment and use, respectively. Divorced persons may experience poorer health and greater health expenditures relative to married persons [39, 40]. This may be due to the lack of social support, financial resources, or access to a partner's health insurance [39,

40]. Greater healthcare expenditures, competing needs of dependents, social isolation, and financial problems brought on by the pandemic may have led to these changes in medication obtainment among divorced/widowed/separated survivors. In our study, divorced/widowed/separated had a three-fold increase in their odds of changing how their medication was obtained, signaling a potential need to obtain medications at a lower cost than prior to the pandemic.

LGBTQ+ survivors also faced social and/or financial challenges in forms of social isolation [41], discrimination by employers [42], and greater rates of poverty before and during the pandemic [43]. In addition, LGBTQ+ persons have difficulty finding non-stigmatizing and nondiscriminatory cancer care [44, 45]. These multiple forces may have impeded LGBTQ+ survivors from using necessary medication, showing nearly fourfold increases in changing medication use relative to cis-heterosexual persons in this study [46, 47].

The pandemic had disproportionate adverse financial and employment impacts on women [25], and these financial issues appear to have impacted female survivors' healthcare utilization based on the degree of their material hardship. None of these patterns was seen among male survivors. Financial burdens from COVID-19 and cancer played a large role in our findings, but social pressures may have also contributed to the associations. In our study, women composed nearly the entire group of divorced/widowed/separated and LGBTQ+ persons, as well as a large percent of married survivors. Because we saw significant differences in healthcare utilization among survivors in these groups, the differential impacts of material hardships experienced by females may also be explained by marital status and LGBTQ+ identity.

Our findings differ from a prior national survey reporting that 60% of AYA survivors had delayed cancer care [11], potentially because the HIAYA patient navigation services may have had a protective effect and/or due to differences in the geographic scope of the surveys. Despite access to patient navigation services, one-fifth of AYAs in our sample still reported that the COVID-19 pandemic had severe effects on their finances and ability to utilize healthcare. Our study provides strong support for the profound impacts that the COVID-19 pandemic had on delayed/skipped healthcare utilization among AYA survivors that may not be able to be addressed through patient navigation services alone. The HIAYA participants were predominantly non-Hispanic White, for whom the impact of the COVID-19 pandemic was less generally severe than racial and ethnic minorities [48]. Thus, we can infer that impacts on healthcare utilization among minority AYA survivors likely have been more severe than reported by our sample.

Socioeconomic disparities in healthcare utilization are not new, but the results of our study suggest that the

COVID-19 pandemic heightened these disparities. Prior to the pandemic, AYA survivors already experienced systematic inequalities in health insurance coverage, cancer care delivery and healthcare access, and employment discrimination that influence their health outcomes [49, 50]. During the pandemic, AYAs from historically marginalized groups (e.g., women, LGBTQ+) appeared to be the most vulnerable to the financial impacts of the pandemic and disruptions in healthcare. Thus, addressing the challenges posed by COVID-19 for these groups requires a systematic approach that considers and addresses the fundamental causes of socioeconomic disparities in the US healthcare system, such as lack of insurance access.

Some of the COVID-19 economic policies, such as the federal stimulus checks and other financial aids, were passed to provide households with some relief from the financial impacts of the pandemic [51]. These policies may have lessened the socioeconomic disparities in cancer health outcomes among AYA survivors. Understanding how financial assistance like the stimulus checks was used by AYAs during the COVID-19 pandemic can shed light on how to implement financial interventions in future pandemics.

As pandemics of infectious diseases are expected to increase in frequency with climate change [52], steps should be taken to intervene and provide support to these marginalized groups during future pandemics. Since females were most affected by the financial impacts of the pandemic, ensuring that women are able to secure an income and continuity of services that enable employment or alleviate stress among women (e.g., childcare) may be critical pieces to supporting their healthcare access. Medication use among LGBTQ AYAs was the most impacted during the pandemic. While this suggests that ensuring continuous access to providers, pharmacies, and prescriptions during pandemics may be a challenge for this group, more studies are needed in this population.

Limitations of the study included our small sample for LGBTQ+ survivors and limited information about active treatment for cancer late effects. We did not ask participants about their stage of cancer at diagnosis. While stage may be correlated with healthcare utilization [53–56], we were primarily interested in how the pandemic affected patients currently in treatment versus not in treatment. We also do not have information about the number of dependents belonging to each participant, nor more detailed information about their work history or household income prior to the pandemic. But we do have detailed information about their reported financial burdens and the origin of those financial burdens. Like all cross-sectional studies, the causal nature of these associations between financial burdens relative to the changes in healthcare utilization cannot be determined due to temporality. Nonetheless, this

study reports important associations that shed light on the COVID-19 pandemic's impact on AYA cancer survivors' use of healthcare.

Our strengths include our sample recruited from a multisite, health systems-based AYA patient navigation program, and highly detailed questionnaire about healthcare utilization.

Conclusion

Financial problems originating from the COVID-19 pandemic had adverse impacts on healthcare utilization among AYA survivors, with female, divorced/widowed/separated, and LGBTQ+ survivors having elevated risk.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s11764-022-01214-y>.

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Author contribution Judy Ou conducted the analyses, contributed to the study aims, and was the primary writer. Austin Waters and Heydon Kaddas conducted data cleaning and management and contributed to the analysis. Austin Waters, Perla Vaca Lopez, and Karely Mann distributed the survey. Karely Mann, Perla Vaca Lopez, Echo Warner, John Anderson, Nicole Ray, Douglas Fair, and Tomoko Tsukamoto contributed to the survey creation and manuscript review. David Gill and Lauri Linder reviewed the manuscript. Anne Kirchhoff was the principal investigator and was responsible for overseeing the study activities and for financial support for all activities.

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Declarations

Ethics approval The University of Utah IRB approved this study.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare no competing interests.

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