









Financial distress and medical financial hardship among young adult survivors of blood cancer

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Abstract

Background: The long-term financial impact of cancer care has not been adequately addressed in young adults. As part of a remote intervention study, we describe medical financial distress and hardship among young adult survivors of blood cancer at study entry.

Methods: Young adults were recruited from 6 US hospitals. Using a Research Electronic Data Capture link, young adults confirmed their eligibility—namely, currently 18 to 39 years of age, blood cancer diagnosis 3 or more years ago, off active treatment, and not on parent's insurance. Following consent, the baseline assessment was sent. The primary outcome measure, the Personal Financial Wellness Scale, measured financial distress (scored as severe, 1-2; high, 3-4; average, 5-6; and low to no, 7-10). Medical financial hardship encompassed material hardship, psychological impact, and coping behaviors. Descriptive summary statistics and linear regression were used.

Results: Among the 126 participants, 54.5% came from minority racial or ethnic groups. Median time since diagnosis was 10 years (interquartile range = 6-16 years), with 56% having received a diagnosis when they were between 18 and 39 years of age. The overall mean (standard deviation) Personal Financial Wellness Scale score was 5.1 (2.4), but 49% reported severe or high distress. In multi-variable analysis, female sex, Hispanic ethnicity, and lower income were strongly associated with worse Personal Financial Wellness Scale scores. Among participants with severe financial distress ($n = 26$), 72% reported 2 or more household material hardships, had worse scores across all psychological domains, and altered survivorship care because of cost (68%).

Conclusions: Nearly half of long-term young adult cancer survivors reported severe or high levels of financial distress. Individuals with severe or high distress also reported more medical financial hardship than other participants. This finding highlights the need for ongoing financial intervention in this vulnerable population.

ClinicalTrials.gov: [NCT05620979](https://clinicaltrials.gov/ct2/show/study/NCT05620979)

There is increasing recognition that many patients with cancer experience deleterious financial effects, including substantial out-of-pocket expenses; loss or alteration of employment; and, in extreme cases, loss of savings and property. The term *financial toxicity* was coined to describe these impacts (1-4), likened to an acute toxicity of treatment. This conceptualization of medical cost consequences has been critically needed, but the long-term cost consequences survivors continue to face years after the completion of cancer treatment has been underappreciated and understudied. Financial distress and medical financial hardship, described to encompass material burden, psychological impact, and behavioral consequences (5-7), can be long lasting. Similar to

other late effects of cancer treatment (8,9), the potential for long-term financial distress and hardship requires ongoing surveillance, monitoring, and intervention.

Young adult (ie, aged 18-39 years) cancer survivors are especially vulnerable to the long-term financial distress and hardship of cancer and its treatment compared with older adults. First and foremost, survival for the majority of young adults is measured in decades. Second, for survivors of childhood and adolescent cancer aging into the young adult age group or individuals with onset of cancer during young adulthood, the cancer experience collides with key developmental milestones, including educational and vocational attainment, social and financial

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independence, and gradual acquisition and stabilization of finances. Kayser et al. (10) highlighted that young adults are less financially stable than older adults, with financial stressors such as student loan debt, bad credit, and costs associated with starting or raising a family. In contrast to older adults, who are at risk for bankruptcy or consumption of assets, young adults often lack the opportunity to have acquired such assets (11,12) and have historically faced health insurance uncertainty (13).

To explore and alleviate current financial distress and hardship among young adult cancer survivors, we developed a multi-site, 6-month, fully remote, hybrid effectiveness-implementation study (14). Linendoll et al. (14) previously described the study's design, including the United States (US) Health Insurance Portability and Accountability Act-compliant Research Electronic Data Capture (REDCap) (15,16) web-based study database; aims; assessment schedule; and the 3-arm randomized financial navigation intervention. The study's primary outcome measure, the Personal Financial Wellness Scale (17), was used to measure financial distress. The Personal Financial Wellness Scale has demonstrated an association of higher financial distress among younger aged cancer survivors (18-20). This report highlights the financial late effects of the assembled young adult survivors of blood cancer cohort at study entry, describing factors associated with financial distress. We hypothesized that vulnerable participants (eg, traditionally underrepresented racial and ethnic groups) would report greater financial distress. We also present medical financial hardship domains by categorical financial distress level to identify areas of particular concern.

Methods

Assembling the cohort

Enrollment spanned from February 2022 through April 2023, with recruitment staggered across 6 US hospitals. Tufts Medical Center (Tufts Institutional Review Board [IRB] No. 00001828; ClinicalTrials.gov identifier NCT05620979) served as the central site, managing the study database and performing all enrollment, assessment, and intervention procedures (14). Each recruitment site had dedicated young adult champions and served diverse and often underrepresented populations, defined by race, ethnicity, socioeconomic demographics, or geography.

Sites screened their clinic database or the electronic health record for off-treatment young adult patients who had been diagnosed with a blood cancer. Sites then shared IRB-approved information about the study that contained a survey link to the eligibility checklist embedded in the study database. Interested young adults had to confirm that they were 18 to 39 years of age and had been diagnosed with blood cancer more than 3 years previously. They had to identify site of care and whether they had been diagnosed when they were younger or older than 18 years of age as well as confirm that they had completed treatment or were on a long-term oral medication. If the young adult checked that they had been diagnosed with another cancer, they were eligible to participate if treatment for the second cancer had been completed or they were taking an oral anticancer medication. The ability to read and understand English and having a primary residence in the US were also required. Young adults were not eligible if they were on their parent's medical insurance. This exclusion criterion was based on concerns that the participant would be less knowledgeable and more financially protected with regard to insurance coverage and its costs (14). If all eligibility criteria were met, the central study team shared the

informed consent form electronically. If the form was not signed after 2 prompts, the contact information was deleted.

Measure dissemination and variables

After provision of consent, an email or text message with a unique survey link to the baseline measures was sent from the study database. Questions were programmed to be optional, enabling participants to skip questions or stop at any time. Participants were sent a \$25 electronic gift card as remuneration upon completion of the primary outcome measure. Up to 2 automated reminders were sent if the assessment was not completed. A final attempt to capture the Personal Financial Wellness Scale was made by phone. If this attempt was unsuccessful, the participant was withdrawn.

Established scoring algorithms were used for validated measures, including instructions about the handling of missing data. Analyses of the 8-item Personal Financial Wellness Scale were categorized based on previous reports (17,20), as follows: severe (ie, overwhelming to extremely high financial distress), 1 to 2; high (ie, very high to high financial distress), 3 to 4; average (ie, average to moderate financial distress), 5 to 6; and low to no financial distress, 7 to 10.

Self-reports of medical interventions beyond frontline therapy and associated with higher costs were combined to create an indicator for adverse clinical features. These features included a history of relapse or salvage therapy, receipt of hematopoietic stem cell transplant, receipt of cellular therapy (ie, chimeric anti-cancer receptor T-cell therapy), or currently taking an oral anti-cancer medication. Similarly, engagement with mental health care was identified by affirmative responses to seeing or seeking a mental health professional or taking a medication for anxiety or depression.

The variables used to describe the 3 domains of medical financial hardship are illustrated in Figure 1. The first domain, material hardship, was defined according to 4 household material challenges—food, utility, rent or mortgage, and transportation (21,22)—experienced over the prior 12 months. Food insecurity was defined as food not lasting often or sometimes. Financial assistance, such as a history of borrowing money or going into debt (23) or receiving financial support within the prior year was also captured. The second domain, psychological impact, was

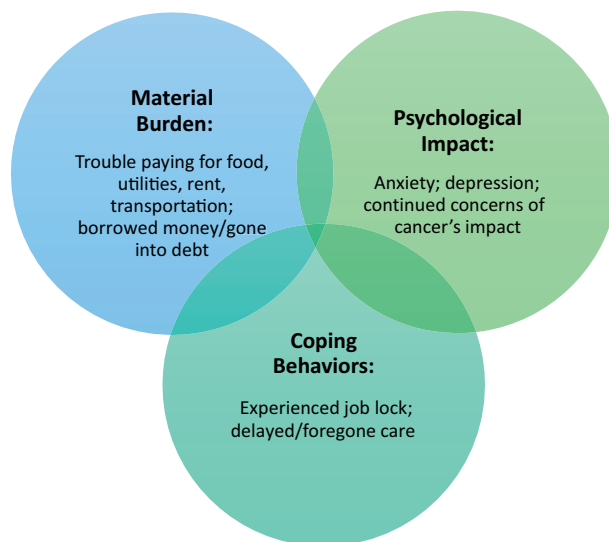


Figure 1. Domains of medical financial hardship explored^a. ^aDiagram Inspiration from (5).

described by scores obtained from 6 Patient-Reported Outcomes Measurement Information System (PROMIS) validated short forms: 1) physical function, 2) fatigue, 3) anxiety, 4) depression, 5) emotional support, and 6) general efficacy, plus the Quality of Life in Neurological Disorders (Neuro-QoL) applied cognition instrument (14,24). Additional items regarding the perceived impact of cancer on education or employment and concern that cancer would limit earnings (23) were also included within this domain. The third domain, coping behaviors, was examined by the participants' decision to stay at their job to keep insurance (23) or modified (ie, delayed, forewent, or changed) survivorship care utilization because of cost (23). Coping behavior items regarding care utilization from the 2017 Medical Expenditure Panel Survey (23) were adapted to focus on current survivorship experiences.

Statistical analysis

Analyses were restricted to participants who completed the Personal Financial Wellness Scale and demographic measures. Summary statistics (eg, means [standard deviation, SDs], frequencies [percentiles]) were used to describe demographic characteristics and medical history for the entire sample. To identify differences in distress, these variables were then summarized by categorical Personal Financial Wellness Scale score. Because there has been limited use of the Personal Financial Wellness Scale in young adult cancer populations (19), we calculated Cronbach alpha as a measure of internal consistency reliability (>.8 is acceptable for established scales) (25,26). We hypothesized that younger age, female sex, non-White race or Hispanic ethnicity, lower education, lower household income, having public insurance, and adverse clinical features would be associated with greater distress on the Personal Financial Wellness Scale scores.

To test these relationships, we fit univariable linear regression models and a multivariable linear regression model that included all these variables. Models were restricted to participants with complete data; model assumptions, including linearity, were assessed. Finally, we used summary statistics to describe the 3 domains of medical financial hardship by categorical Personal Financial Wellness Scale score. To understand differences in psychological impact reported on PROMIS or Neuro-QoL scales by Personal Financial Wellness Scale category, we relied on the measures' previously established minimal important difference (ie, 1/3-1/2 the SD of 10 or 3-5 units), depending on the particular scale and methods used to estimate it (27-30). A 2-sided alpha of .05 was used, and analyses were performed in SAS Enterprise Guide, version 8.1, software (SAS Institute Inc, Cary, NC).

Results

Assembling the cohort

Of the 363 eligibility checklists submitted (Figure 2), 59% were eligible to participate. The remaining submitters were not eligible (30%), provided duplicate submissions (4%), or did not provide contact information (7%). The most common ineligible responses, not mutually exclusive, were coverage through a parent's or guardian's insurance (45%), being in active treatment (21%), and within 3 years of initial diagnosis (13%). The informed consent form was signed by 71% of eligible young adults, of whom 83% completed baseline measures. The analytic cohort consisted of 126 participants.

Study sample

The mean (SD) age of the cohort was 30.4 (5.2) years, 60.8% of the cohort were female, and 55.5% were either Hispanic (32.5%) or

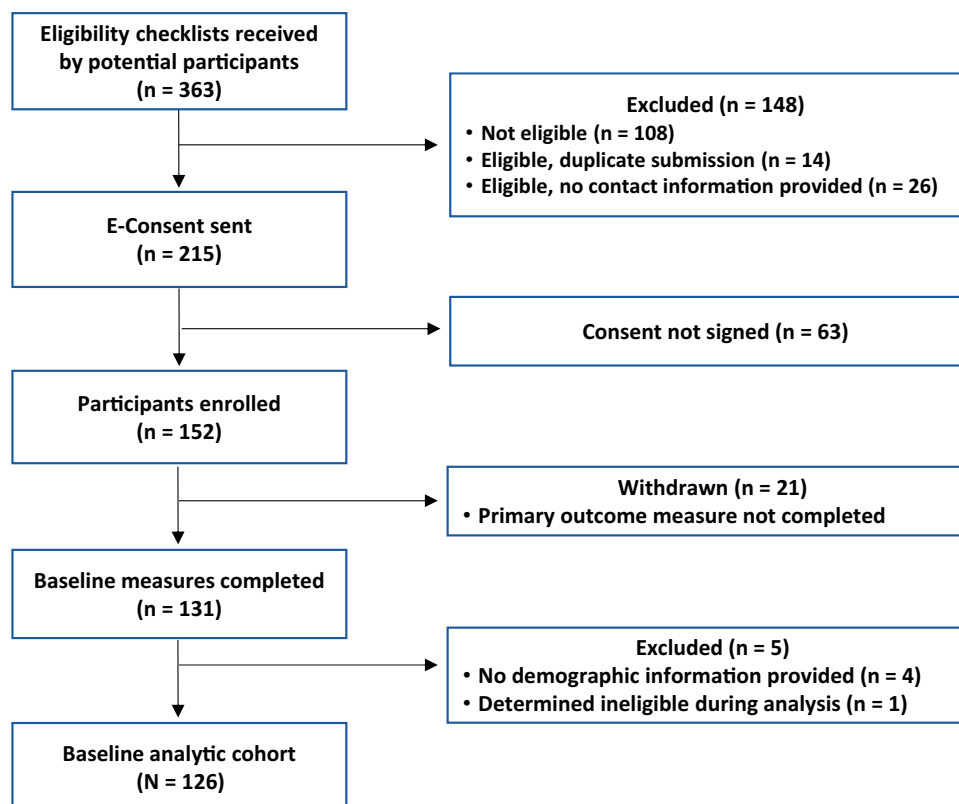


Figure 2. Study analytic cohort CONSORT diagram.

non-Hispanic non-White (22.0%) (Table 1). Fifty-six percent of the sample had been diagnosed between the ages of 18 and 39 years; the remainder were diagnosed at younger than 18 years of age. The median time since diagnosis was 10 years (interquartile range [IQR]=6-16 years). Lymphoma (Hodgkin or non-Hodgkin) was the most common diagnosis (54.0%), followed by leukemia (46.0%, acute or chronic); 37.3% of participants were characterized as having adverse clinical features; and 54.4% reported engagement with mental health care. Although most participants (79%) resided in the same state as their site of care (ie, California, Texas, South Carolina, Massachusetts), the overall cohort was drawn from 18 states.

Financial distress

The overall mean (SD) summary score of the Personal Financial Wellness Scale was 5.1 (2.4). The Cronbach alpha for the total scale was .94, demonstrating excellent internal consistency. When categorizing Personal Financial Wellness Scale results, 20.6% of participants were severely distressed (scores 1-2), 28.6% were highly distressed (scores 3-4), 26.2% were average (scores 5-6), and 24.6% reported low to no financial distress (scores 7-10).

Factors associated with financial distress

As hypothesized, female sex and Hispanic ethnicity were associated in univariable analysis with lower Personal Financial Wellness Scale scores (ie, worse distress), whereas higher education, being employed, higher income, and private insurance were associated with better Personal Financial Wellness Scale scores (ie, less distress) (Table 2). In multivariable analysis, adjusting for other factors, female sex, Hispanic ethnicity, and higher income remained strongly associated with Personal Financial Wellness Scale scores. Specifically, female participants had worse financial distress than male participants ($\beta = -0.9$, Standard Error [SE] = 0.4, $P = .04$), Hispanic participants had worse financial distress than non-Hispanic White participants ($\beta = -1.1$, SE = 0.5, $P = .03$), and participants with higher incomes had less financial distress than participants with incomes below \$20 000 per year ($\beta = 2.6$, SE = 0.7, $P < .01$).

Medical financial hardship: material burden

Household material hardship over the prior 12 months was endorsed by 43.6% of the sample (21.0% with 1 insecurity; 22.6% with ≥ 2 insecurities) (Table 3). The most often endorsed type of

Table 1. Baseline demographic characteristics and medical history, by categorical Personal Financial Wellness Scale score^a

Characteristic	All participants	Severe distress (score 1-2)	High distress (score 3-4)	Average distress (score 5-6)	Low to no distress (score 7-10)
Total, No. (%)	126 (100)	26 (20.6)	36 (28.6)	33 (26.2)	31 (24.6)
Demographic characteristics					
Current age, mean y, (SD)	30.4 (5.2)	30.0 (5.5)	30.3 (5.1)	29.6 (4.8)	31.8 (5.3)
Female sex, No. (%)	76 (60.3)	19 (73.1)	26 (74.3)	16 (48.5)	15 (48.4)
Race or ethnicity, No. (%)					
Hispanic	40 (32.5)	12 (48.0)	15 (44.1)	8 (24.2)	5 (16.1)
Non-Hispanic non-White	27 (22.0)	6 (24.0)	8 (23.5)	6 (18.2)	7 (22.6)
Non-Hispanic White	56 (45.5)	7 (28.0)	11 (32.4)	19 (57.6)	19 (61.3)
Currently partnered, No. (%)	81 (65.3)	12 (48.0)	21 (60.0)	27 (81.8)	21 (67.7)
Dependent children, No. (%)	46 (36.8)	8 (30.8)	14 (40.0)	14 (42.4)	10 (32.3)
Highest level of education, No. (%)					
<4-y college degree	45 (36.3)	14 (56.0)	17 (48.6)	9 (27.3)	5 (16.1)
4-y college degree or more	79 (63.7)	11 (44.0)	18 (51.4)	24 (72.7)	26 (83.9)
Currently a student, No. (%)	26 (21.3)	8 (32.0)	10 (28.6)	2 (6.3)	6 (20.0)
Currently employed, No. (%)	103 (82.4)	18 (69.2)	26 (74.3)	30 (90.9)	29 (93.6)
Total income, No. (%)					
<\$20 000	34 (28.8)	10 (41.7)	14 (41.2)	4 (13.8)	6 (19.4)
\$20 000-\$39 999	22 (18.6)	7 (29.2)	5 (14.7)	8 (27.6)	2 (6.5)
\$40 000-\$79 999	26 (22.0)	6 (25.0)	10 (29.4)	9 (31.0)	1 (3.2)
\geq \$80 000	36 (30.5)	1 (4.2)	5 (14.7)	8 (27.6)	22 (71.0)
Type of insurance, No. (%)					
Private	81 (64.8)	14 (53.9)	16 (45.7)	25 (75.8)	26 (83.9)
Any public	40 (32.0)	12 (46.2)	16 (45.7)	7 (21.2)	5 (16.1)
Other/uninsured	4 (3.2)	0 (0.0)	3 (8.6)	1 (3.0)	0 (0.0)
Medical history					
Age at diagnosis, No. (%)					
\leq 17 y	56 (44.4)	11 (42.3)	16 (44.4)	18 (54.6)	11 (35.5)
18-39 y	70 (55.6)	15 (57.7)	20 (55.6)	15 (45.5)	20 (64.5)
Time since diagnosis, median y, (Interquartile range)	10 (6-16)	10 (6-13)	9 (5-14)	11 (8-15)	10 (5-18)
Diagnosis ^b No. (%)					
Leukemia (including acute and chronic)	57 (46.0)	14 (53.9)	18 (50.0)	17 (51.5)	8 (27.6)
Lymphoma (including Hodgkin and non-Hodgkin)	67 (54.0)	12 (46.2)	18 (50.0)	16 (48.5)	21 (72.4)
Adverse clinical features, ^c No. (%)	47 (37.3)	12 (46.2)	12 (33.3)	14 (42.4)	9 (29.0)
Relapse/treatment failure	26 (20.8)	9 (34.6)	3 (8.6)	8 (24.2)	6 (19.4)
Hematopoietic stem cell transplant	35 (28.0)	11 (42.3)	8 (22.9)	10 (30.3)	6 (19.4)
Treated with cellular therapy	14 (11.2)	1 (3.9)	4 (11.4)	5 (15.2)	4 (12.9)
Currently taking oral anticancer medication	4 (3.2)	0 (0.0)	1 (2.9)	2 (6.1)	1 (3.2)
Mental health care, ^d No. (%)	68 (54.4)	22 (88.0)	17 (47.2)	15 (45.5)	14 (45.2)

^a Item-level missingness may result in fewer responses than the column number indicates.

^b Two participants with other blood cancer diagnoses are not listed here, given cell size suppression.

^c Adverse clinical features includes relapse or treatment failure, hematopoietic stem cell transplant, treatment with cellular therapy (ie, chimeric antigen receptor T-cell therapy), or currently taking oral anticancer medication.

^d Responded yes to at least 1 of the following: seeing mental health professional, looking for mental health professional, or taking medication for anxiety or depression.

household material hardship was food insecurity (33.9%). Among participants who reported severe financial distress, 72.0% had 2 or more household material hardships (compared with 0.0% in the low to no financial distress group). Of the entire sample, more than one-third (36.6%) had borrowed money or gone into debt at some point or had received financial support (39.2%) within the previous year. In addition, 64.0% of participants who reported severe financial distress had borrowed money or gone into debt (compared with 16.1% in the low to no distress group).

Table 2. Univariable and multivariable linear regression model for factors associated with financial distress, by Personal Financial Wellness Scale score, n = 115^a

	Univariable model		Multivariable model	
	β (SE)	P ^b	β (SE)	P ^c
Current age, y	0.1 (0.1)	.25	-0.1 (0.1)	.33
Female sex	-1.3 (0.5)	.01	-0.9 (0.4)	.04
Race or ethnicity				
Hispanic	-2.0 (0.5)	<.01	-1.1 (0.5)	.03
Non-Hispanic non-White	-0.7 (0.6)	.20	-0.7 (0.5)	.18
Non-Hispanic White	(Referent)	—	—	—
Highest level of education				
<4-y of college	(Referent)	—	—	—
≥4-y college degree	1.8 (0.5)	<.01	0.8 (0.4)	.07
Currently employed	2.0 (0.6)	<.01	0.9 (0.6)	.11
Total income				
<\$20 000	(Referent)	—	—	—
\$20 000-\$39 999	0.2 (0.6)	.77	0.3 (0.6)	.67
\$40 000-\$79 999	0.2 (0.5)	.76	0.2 (0.6)	.71
≥\$80 000	3.2 (0.5)	<.01	2.6 (0.7)	<.01
Type of insurance				
Private	1.5 (0.5)	<.01	-0.4 (0.5)	.41
Any public/other/uninsured	(Referent)	—	—	—
Years since diagnosis				
<10	(Referent)	—	—	—
≥10	0.3 (0.5)	.53	-0.2 (0.4)	.68
Adverse clinical features				
Absent	(Referent)	—	—	—
Present	-0.7 (0.5)	.14	-0.7 (0.4)	.11

^a Restricted to participants with complete data on all these variables.

^b Global P values for categorical variables in univariable analysis: race or ethnicity <.01, total income <.01.

^c Global P values for categorical variables in multivariable analysis: race or ethnicity = .18, total income <.01.

Medical financial hardship: psychological impact

Although most of the overall sample's mean PROMIS and Neuro-QoL scores were similar to the US general population average (SD) score of 50 (10), the mean [SD] anxiety domain score (55.2 [10.3]) (Table 4) was half an SD higher (ie, worse anxiety), equal to the minimal important difference. Participants with higher levels of financial distress reported worse scores across all domains. Comparing the severe financial distress group with the low to no distress group on negatively worded domains, mean (SD) scores for fatigue were 58.2 (9.5) vs 44.7 (7.9); for anxiety, they were 64.6 (9.5) vs 48.1 (7.9); and for depression, they were 59.0 (10.7) vs 45.7 (6.0). For each of these comparisons, the magnitude of difference between PROMIS scores was greater than a full SD difference. The same pattern was seen in the positively worded domains, with comparable magnitudes of difference between the severe and low to no financial distress groups. Specifically, participants with severe financial distress reported lower mean [SD] levels of physical function (46.5 [6.2]) vs 56.1 [2.9]), less emotional support (50.5 [9.0] vs 57.7 [6.0]), lower general self-efficacy (46.1 [10.0] vs 56.0 [8.3]), and worse cognitive function (47.4 [8.9] vs 54.5 [7.6]) compared with the low to no distress group.

Nearly half the participants (46.4%) endorsed that cancer continued to affect their education or employment. The perceived impact was greater among individuals in the severe distress group than individuals in the low to no distress group (84.0% vs 32.3%). Similarly, 46.0% of the sample were concerned that cancer would limit their earnings, with higher levels of concern in the severe (56.0%) and high (65.7%) distress groups than in the low to no distress (22.6%) group.

Medical financial hardship: coping behaviors

Many (29.6%) participants endorsed staying at their job to keep insurance (Table 5). Nearly half the sample (44.8%) reported making a decision (eg, delay) within the previous year that affected their survivorship care because of cost, with specialist care being the most commonly affected (32.0%). Making this decision because of the cost of care was more commonly reported by the severe (68.0%) and high (63.9%) distress groups than the low to no (16.1%) distress group. Individuals in the severe distress category (60.0%) were more likely to have delayed or forgone mental health-care services than any other type of care.

Table 3. Material hardship, by categorical Personal Financial Wellness Scale score^a

	All participants, No. (%)	Severe distress (score 1-2), No. (%)	High distress (score 3-4), No. (%)	Average distress (score 5-6), No. (%)	Low to no distress (score 7-10), No. (%)
Total	126 (100)	26 (20.6)	36 (28.6)	33 (26.2)	31 (24.6)
Household material hardship					
No. of household material hardships in past 12 mo					
None	70 (56.5)	1 (4.0)	16 (45.7)	23 (69.7)	30 (96.8)
1	26 (21.0)	6 (24.0)	10 (28.6)	9 (27.3)	1 (3.2)
≥2	28 (22.6)	18 (72.0)	9 (25.7)	1 (3.0)	0 (0.0)
Food insecurity ^b	42 (33.9)	21 (84.0)	13 (37.1)	8 (24.2)	0 (0.0)
Utility insecurity	12 (9.8)	8 (32.0)	3 (8.8)	0 (0.0)	1 (3.2)
Rent/mortgage insecurity	24 (19.5)	15 (60.0)	9 (25.7)	0 (0.0)	0 (0.0)
Lack of reliable transportation	15 (12.1)	8 (32.0)	4 (11.4)	3 (9.1)	0 (0.0)
Financial assistance					
Ever borrowed money or gone into debt	45 (36.6)	16 (64.0)	14 (41.2)	10 (30.3)	5 (16.1)
Family ever borrowed money or gone into debt	34 (27.4)	10 (40.0)	15 (42.9)	7 (21.2)	2 (6.5)
Received any financial support to help pay for cancer survivorship care or living expenses in the past 12 mo	49 (39.2)	14 (53.9)	14 (40.0)	12 (36.4)	9 (29.0)

^a Item-level missingness may result in fewer responses than the column number indicates.

^b Food not lasting "often true" or "sometimes true" collapsed as insecurity.

Table 4. Psychological impact, by categorical Personal Financial Wellness Scale score^a

Characteristic	All participants	Severe distress (score 1-2)	High distress (score 3-4)	Average distress (score 5-6)	Low to no distress (score 7-10)
Total, No. (%)	126 (100)	26 (20.6)	36 (28.6)	33 (26.2)	31 (24.6)
PROMIS/Neuro-QoL domain, mean (SD)^b					
Physical function	51.3 (6.7)	46.5 (6.2)	50.0 (6.7)	52.0 (6.7)	56.1 (2.9)
Fatigue ^c	50.7 (9.9)	58.2 (9.5)	52.0 (9.3)	49.2 (8.8)	44.7 (7.9)
Anxiety ^c	55.2 (10.3)	64.6 (9.5)	56.3 (9.4)	53.5 (8.0)	48.1 (7.9)
Depression ^c	50.6 (10.0)	59.0 (10.7)	51.7 (10.2)	47.8 (8.3)	45.7 (6.0)
Emotional support	53.9 (8.2)	50.5 (9.0)	52.2 (7.9)	54.9 (8.4)	57.7 (6.0)
General self-efficacy	51.1 (9.7)	46.1 (10.0)	50.1 (9.9)	51.6 (8.4)	56.0 (8.3)
Cognition function	51.6 (8.2)	47.4 (8.9)	51.5 (7.8)	52.3 (7.5)	54.5 (7.6)
Ongoing perception of cancer's impact, No. (%)					
Cancer impacts on education/employment					
No impact	66 (53.6)	4 (16.0)	18 (51.4)	23 (71.9)	21 (67.7)
Impact on education only	11 (8.9)	6 (24.0)	1 (2.9)	2 (6.3)	2 (6.5)
Impact on employment only	27 (22.0)	8 (32.0)	8 (22.9)	4 (12.5)	7 (22.6)
Impact on education and employment	19 (15.5)	7 (28.0)	8 (22.9)	3 (9.4)	1 (3.2)
Concerned that cancer would limit earnings	57 (46.0)	14 (56.0)	23 (65.7)	13 (39.4)	7 (22.6)

^a Item-level missingness may result in fewer responses than the column number indicates. PROMIS = Patient-Reported Outcomes Measurement Information System; Neuro-QoL = Quality of Life in Neurological Disorders.

^b PROMIS and Neuro-QoL scores are standardized to have mean (SD) of 50 (10).

^c Higher scores indicate worse-than-average responses for negatively worded concepts (ie, greater fatigue, greater anxiety, greater depression).

Table 5. Coping behaviors, by categorical Personal Financial Wellness Scale score^a

Characteristic	All participants, No. (%)	Severe distress (score 1-2), No. (%)	High distress (score 3-4), No. (%)	Average distress (score 5-6), No. (%)	Low to no distress (score 7-10), No. (%)
Total	126 (100)	26 (20.6)	36 (28.6)	33 (26.2)	31 (24.6)
Stayed at job to keep insurance	37 (29.6)	8 (30.8)	10 (28.6)	11 (33.3)	8 (25.8)
Changed cancer survivorship care because of cost in the past 12 mo					
Any survivorship care ^b	56 (44.8)	17 (68.0)	23 (63.9)	11 (33.3)	5 (16.1)
Tests	26 (20.8)	6 (24.0)	12 (33.3)	6 (18.2)	2 (6.5)
Specialist visits	40 (32.0)	10 (40.0)	19 (52.8)	8 (24.2)	3 (9.7)
Prescription medication	15 (12.0)	4 (16.0)	7 (19.4)	4 (12.1)	0 (0.0)
Other (nonprescription) treatment	19 (15.3)	8 (32.0)	8 (22.9)	3 (9.1)	0 (0.0)
Mental health care	28 (22.4)	15 (60.0)	8 (22.2)	3 (9.1)	2 (6.5)
Other changes	7 (5.8)	1 (4.2)	3 (8.3)	3 (9.4)	0 (0.0)

^a Item-level missingness may result in fewer responses than the column number indicates.

^b Any survivorship care: Responded yes to at least 1 of the following: tests, specialist visits, prescription medication, other (nonprescription) treatment, mental health care, or other.

Discussion

We sought to characterize financial distress and medical financial hardship among a broadly assembled young adult blood cancer survivor cohort. Recruitment at the 6 diverse young adult clinical programs successfully resulted in a cohort of 54.5% individuals from minority racial or ethnic groups, who were a median of 10 years from initial diagnosis. Financial distress, as self-reported on the Personal Financial Wellness Scale, was broadly distributed across the full range of the measure's scale, from severe to no distress. In particular, 49% of our young adult participants reported severe or high financial distress vs the previously reported 30% of the general noncancer adult population (17). In multivariable linear regression analysis, female sex and Hispanic ethnicity were associated, as hypothesized, with more financial distress, as was lower income. Participants who reported severe or high financial distress reported experiencing higher levels of medical financial hardship, defined by greater material hardship and psychological impact, and demonstrated concerning coping behaviors compared with young adults who had less financial distress.

More than one-third (33.9%) of the overall sample reported food insecurity. Individuals with severe or high levels of financial distress reported substantial material hardship. Over the prior year, 84.0% of severely financially distressed participants reported food insecurity, and 60.0% reported rent or mortgage insecurity. A substantial proportion of participants who reported severe distress had directly borrowed some amount of money (64.0%) or reported that their family had borrowed money or gone into debt (40.0%). Ketterl et al. (31) found that 14.4% of young adults or their families had borrowed \$10 000 or more in their study. An impact on finances within the previous year was felt by 53.9% of severely distressed, 40.0% of high distressed, and 36.4% of average distressed participants who needed financial support to help pay for survivorship care or living expenses.

Greater rates of fatigue, anxiety, and depression were reported by young adults in the severe and high financial distress groups compared with their counterparts with less financial distress. They also reported worse physical function, emotional support, general self-efficacy, and cognitive function than participants with average and low to no financial distress, based on minimal

important difference estimates for between-group differences. Of further concern, despite the median decade that had passed since diagnosis, cancer continued to have a perceived negative impact on work and/or school for nearly half the cohort (46.4%).

A similar proportion of participants in all distress groups (severe, 30.8%; high, 28.6%; average, 33.3%; low to no, 25.8%) reported job lock, defined as remaining in an employment position to retain insurance benefits. This phenomenon has previously been described in cancer survivor cohorts (32–34). The significant proportion (>60%) of young adults with severe or high levels of financial distress who reported an impact on their cancer survivorship care because of cost within the previous year is worrisome. Survivors should be educated about potential treatment late effects and be engaged in long-term care per oncologic guidelines—of particular importance for the participants with adverse clinical features (37.3%) because their treatment indicates greater need for ongoing care, but this care may then put them at increased risk for additional medical debt. Participants with severe financial distress were more likely to report engagement with mental health care (88.0%) but strikingly were also more likely to have delayed or foregone that care (60.0%). Mental health concerns have been well documented in young adult cancer survivors (35–37). For young adults who have a mental health-care professional or are taking medication but cannot sustain these costs, this translates to inadequate mental health care. Interestingly, participants who reported high financial distress reported greater impact on their survivorship care in the areas of testing, specialist visits, and prescription medication than any other distress group. Participants in low to no financial distress were much less likely to report an impact on care utilization.

We acknowledge lessons learned in our recruitment process and limitations in this study. Local recruitment site IRBs had divergent determination about their role in this centrally managed, fully remote study, ranging from the request for full review to decline of review (as not human subject research), which affected the rollout of the study. Importantly, the study was developed and implemented during the COVID-19 pandemic, which potentially had both positive (eg, familiarity with teleconnection) and negative impacts (eg, additional stressors, such as furloughed study staff, more limited access to care for participants).

Given our aim to explore and alleviate financial distress through a financial navigation intervention in a young adult survivor cohort, eligibility criteria were mainly confined to treatment history and independent insurance coverage. Even when casting this wide net, close to half of young adults reported severe or high financial distress. Participants who reported severe or high financial distress also described more medical financial hardship than their less distressed counterparts.

Results of our 6-month intervention will be shared because it is imperative to understand the range of financial issues that survivors are dealing with and what steps, if any, they have taken to mitigate the impact. The status of participants at study entry provides a sobering snapshot of financial distress among young adult survivors. These findings highlight the ongoing need to investigate and address the financial late effects of cancer to optimize the outcomes for this vulnerable population.

Data availability

The data underlying this article are available in the article.

Author contributions

Susan K. Parsons, MD, MRP (Conceptualization; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Visualization; Writing—original draft; Writing—review & editing); Rachel Murphy-Banks, MA (Conceptualization; Investigation; Methodology; Project administration; Resources; Supervision; Validation; Visualization; Writing—original draft; Writing—review & editing); Angie Mae Rodday, PhD, MS (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Visualization; Writing—review & editing); Michael E. Roth, MD (Resources; Writing—review & editing); Kimberly Miller, PhD, MPH (Resources; Writing—review & editing); Nadine Linendoll, PhD, MDiv, GNP (Writing—review & editing); Randall Chan, MD (Resources; Writing—review & editing); Howland E. Crosswell, MD (Resources; Writing—review & editing); Qingyan Xiang, PhD (Data curation; Writing—review & editing); David R. Freyer, DO, MS (Resources; Writing—review & editing).

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Conflicts of interest

The authors have no conflicts of interest.

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