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Financial anxiety in cancer prevention and cancer control

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Financial anxiety in cancer prevention and cancer control

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Editorial: Financial anxiety in cancer prevention and control

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Editorial on the Research Topic
Financial anxiety in cancer prevention and control

Financial hardship is commonly experienced by patients after a cancer diagnosis and can impede participation in cancer control activities and reduce access to cancer care and survivorship support (Altice et al., 2017; Yabroff et al., 2020). Cancer-related financial hardship can be substantial, with recent research highlighting that this burden continues to grow as insurers increasingly shift the costs of cancer care to patients and their families (Mariotto et al., 2011; Shih et al., 2017; Laviana et al., 2020). Financial hardship is a complex issue that is experienced uniquely across patients and which can be categorized into three broad domains: material, behavioral and psychological. The psychological aspect of financial hardship is a distinct concept that provides additional context on the economic impact of cancer. Sometimes referred to as financial anxiety, this psychological aspect of financial hardship often includes feelings of worry about an individual's money situation such as their income, job security and an ability to afford healthcare and living expenses (e.g., rent, transportation, food) (Prawitz et al., 2006; Peterson and Miller, 2019). While financial anxiety in cancer care can be particularly troubling and impact financial hardship, it has received less attention than more material and behavioral aspects of financial outcomes after cancer. To help move the field forward and address the role of financial anxiety in cancer, this Research Topic on *Financial anxiety in cancer prevention and control* aims to bring together the latest articles from researchers working in the area of psycho-oncology and financial hardship, focused on financial anxiety, financial worry, and financial stress.

The first set of articles in this Research Topic further examine underlying conceptual models and measure development for understanding financial anxiety. Five studies highlight the need to better understand the concepts comprising financial anxiety as well as opportunities for measuring these concepts after cancer diagnosis. Biddell et al. present a novel conceptual model that includes the protective, modifying and hindering multi-level factors that affect financial anxiety and other dimensions of cancer-related financial hardship. Another paper reports on the work of the Emotional wellbeing and Economic Burden (EMOT-ECON) Research Network. The EMOT-ECON conceptual framework is based on the stress appraisal coping models, emphasizing how people with cancer actively respond to the triggers of financial hardship, using coping strategies that can increase or decrease anxiety. Three additional papers report on the development of financial hardship measures for specific populations: older adults in China; Spanish speakers in the United States; and people with prostate cancer in the United States. These measures show that the factors that contribute to financial anxiety and financial hardship can differ by location, age, and cancer type. While we know much about financial hardship and financial anxiety from cancer, the complexity of this public health problem requires rigorously developed conceptual models and measures such as those reported here.

In addition to new methods for understanding and measuring financial anxiety, this issue also highlights new research into the impact of financial anxiety on cancer care and outcomes. One study by Shi et al. examined the association between financial anxiety of individuals with cancer and acute care visits, finding that those with severely depleted material, practical and social coping resources related to the financial impact of their cancer were at greater risk for repeat acute care visits than individuals with more robust coping resources. A second study examined the role of frailty in medical financial hardship, finding that among older cancer survivors in the US, frail cancer survivors were vulnerable to not only material financial hardship but poorer psychological and behavioral hardship outcomes. These studies add to the growing evidence of the role financial anxiety may play in risk for poor outcomes after cancer diagnosis.

Lastly, for nearly a decade, there has been a wealth of research dedicated to documenting and detailing the vast adverse effects that patients experience from the financial hardships associated with cancer and its treatment–commonly referred to as financial toxicity within the field of oncology. More recently, there have been calls by advocates, experts, and professional organizations to move beyond describing cancer-related financial toxicity, toward testing and identifying effective solutions to intervene on this critical issue. While there is no high-level evidence (e.g., Level I-III) showing the effectiveness of any intervention to address financial toxicity, there are approaches that have emerged as potential solutions and which served as the basis for recent clinical trials, including financial navigation (clinicaltrials.gov ID: NCT05018000; NCT04960787; NCT04931251), health insurance navigation (NCT05829070; NCT04448678; NCT04520061); and workforce communication and job retention (NCT03572374) (Smith et al., 2022). Doherty et al. expand this body of clinical trials targeting cancer-related financial hardship, presenting their protocol for Guaranteed Income and Financial Treatment (GIFT), a large randomized controlled trial to test the effectiveness of unconditional cash transfers (UCTs) on financial toxicity, health-related quality of life, treatment adherence, and other cancer outcomes, among cancer patients who have low incomes. This societal-level intervention targets both federal and state policy and public benefit programs to provide UCTs, adding to the prior individual- and health clinic/system-level interventions being assessed for effectiveness against financial toxicity.

There has been tremendous progress in our understanding of cancer-related financial hardship. While most research has focused on material financial hardship, including bankruptcy and going into debt, psychological aspects such as financial anxiety have received less attention. This Research Topic of Frontiers in Psychology, *Financial Anxiety in Cancer Prevention and Cancer Control,* helps fill this knowledge gap by presenting findings from an impressive variety of studies that underscore the complexity of financial anxiety as a component of financial hardship and which provide frameworks, methods, and interventions to guide future research. Importantly, this Research Topic highlights the need for studies to further elucidate the bidirectional associations between the multiple components of financial hardship with both health and health care outcomes, as well as to develop and test multi-level interventions that either directly or indirectly aim to mitigate the financial hardship from cancer.

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The development and validation of a patient-reported outcome measure to assess financial hardship among older cancer survivors in China: hardship and recovery with distress survey

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Background: Financial hardship has been described as a patient's economic experiencefollowing cancer-related treatment. Standardized patient-reported outcome measures(PROM) to assess this distress has not been well-studied, especially among older cancer survivors.

Objective: The aim of this study was to develop and validate PROM for assessing the financial hardship of older cancer survivors in China.

Methods: Items were generated using qualitative interviews and literature review. Items were screened based on Delphi expert consultation and patients' opinions. Item response theory (IRT) and classical test theory (CTT) were used to help reduce items. Retained items formed a pilot instrument that was subjected to psychometric testing. A cut-off score for the new instrument for predicting poor quality of life was identified by receiver operating characteristic (ROC) analysis.

Results: Qualitative interviews and literature review generated 135 items, which were reduced to 60 items because of redundancy. Following Delphi expert consultation and patients' evaluation, 24 items with high importance were extracted. Sixteen items were selected due to satisfactory statistical analysis based on CTT and IRT. Ten items were retained and comprised 2 domains after loadings in exploratory factor analysis (EFA). Internal consistency was satisfactory ($\alpha = 0.838$). Test-retest reliability was good (intraclass correlation, 0.909). The ROC analysis suggested that the cut-off of 18.5 yielded an acceptable sensitivity and specificity.

Conclusions: The PROM for Hardship and Recovery with Distress Survey (HARDS) consists of 10 items that specifically reflect the experiences of financial hardship among older Chinese cancer survivors, and it also showed good reliability and validity in clinical settings.

KEYWORDS

older cancer survivors, health outcome, patient-reported outcome measure, financial hardship, financial toxicity

1 Introduction

Financial hardship is defined as patients often being confronted with negative financial consequences of cancer treatment, which include material hardships (e.g., significant out-of-pocket, loss of income), psychological response measures (e.g., distress, stress due to paying medical bills), and coping behavioral measures (e.g., delaying cancer treatment, skipping medications) (1, 2). Financial hardship has a negative effect on cancer patients' health-related quality of life (HRQoL) and clinical outcomes. Patients with financial hardship were likely to show cancer-related medication nonadherence; worse overall physical, emotional, and social functioning; and decreased well-being (3, 4). Cancer survivors experienced severe and persistent financial hardship long after a cancer diagnosis and regarded it as one of their prime unmet survivorship demands (5).

Although the near-universal population coverage offered by social insurance in China has reduced the proportion of out-of-pocket spending, cancer therapies may still require substantial expenditures even among those with medical insurance. There are two basic health insurance schemes with different reimbursement proportions covering more than 95% of Chinese people, Urban Employee Basic Medical Insurance (UEBMI) and Urban-Rural Resident Basic Medical Insurance (URRBMI) (6). Generally speaking, UEBMI has a better benefits package and lower out-of-pocket costs than URRBMI (7, 8). However, approximately two-thirds of older adults [more than 60 years or older (9, 10)] participate in URRBMI. Patients covered by URRBMI had lower health care utilization and direct medical costs than those covered by UEBMI but paid higher out-of-pocket costs. Therefore, the URRBMI only provides a low level of medical security for members (11). Compared to the experiences of older patients in Western countries, the financial hardship of Chinese patients has been found to be worse (12, 13). Some older cancer survivors borrowed money because of cancer (12). In the context of Chinese culture, the tradition of filial piety is still prominent, meaning that adult children are expected to provide love, respect, material provisions, and physical care to their parents (14). A prior study found that a majority of older patients had to depend on their children to pay for cancer costs; thus, cancer-related financial hardship extended into children's families (15). Therefore, cancer-related financial hardship among older adults is an important challenge for the healthcare system and patients' extended families.

The need for specific instruments to estimate financial hardship has been acknowledged in previous research. In the USA, the Comprehensive Score for financial Toxicity (COST) was developed based on patient-reported outcome measures (PROM), which were validated for measuring financial hardship in cancer patients with advanced cancer and undergoing chemotherapy (16). The Financial Index of Toxicity (FIT) was developed and validated to measure financial hardship for patients with head and neck cancer in Canada (17). The Patient Reported Outcome for Fighting Financial Toxicity of cancer (PROFFIT) was designed for patients undergoing cancer treatment in Italy (18). All of these current instruments were created in relatively wealthy, developed countries in the west (19). In fact, they are not always appropriate for use in China, due to social, economic, and cultural differences between developed and developing countries (20). In particular, older cancer patients have a high risk of occurrence of comorbidities, geriatric syndromes, and disability, which significantly reduced the HRQoL of patients and caused catastrophic expenses (21). In order to alleviate medical economics burdens for older adults with cancer in China, it is essential to gain a thorough understanding of cancer-related financial hardship and its effects.

However, there is no a special instrument to describe the effects of cancer-related financial hardship among older adults in China. This theoretical framework was based on a typology of three broad domains of financial hardship. These three domains cover the following aspects: (i) the material conditions that arise from increased direct and indirect costs, (ii) the psychological response as a result of efforts necessary to cope with the increased costs and (iii) the coping behaviors itself that patients adopt to manage their medical care while experiencing increased expenses (22). The aim of this study was to develop a PROM for assessment of financial hardship among older adults with cancer that captures and integrates the relevant domains of subjective financial distress. The following specific aims guided our study: (1) develop a new measure of financial hardship for older cancer survivors in China; (2) evaluate the reliability and validity of the instrument; (3) validate this new instrument in clinical settings.

2 Materials and methods

2.1 Ethical approval

The approval for this study was provided by the Ethics Committee of the Centre for Health Management and Policy Research at Shandong University (ECSHCMSDU20200901).

Participants who understood the research purposes and provided written informed consent were included. The development and validation of the instrument were performed in accordance with the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) (23). The size and criteria of the sample was shown in the Supplemental Table 1.

2.2 Item generation and instrument development

2.2.1 Item generation

The original item pool was constructed through qualitative interviews and literature reviews. We interviewed 21 older cancer survivors, 20 family caregivers, 6 oncologists, and 8 nurses using purposive sampling to explore the experiences of cancer-related financial hardship among cancer survivors, and ensure adequate representation of the conceptual domain. The early qualitative findings of the project were published (24, 25). A literature review was performed through PubMed, Web of Science, and Cochrane using selected keywords such as “financial hardship”, “financial toxicity”, “financial burden”, “financial stress/distress”, “cancer survivor”, “cost of cancer care” and “patient-reported outcome (PRO)” to extract published items related to measuring financial hardship after cancer treatment. First, the items the research team members jointly analyzed, while checking for redundancy, overlapping content, and ambiguous language. Second, the items were discussed with anyone with a different view until consensus was reached through consolidation, reflection, and theoretical thinking. Finally, if discrepancies could not be resolved, all team members held weekly online meetings to discuss the pending items and further voting produced the final result.

2.2.2 Item importance evaluation

A Delphi method was used to evaluate the feasibility and importance of the items in the pool. A questionnaire was emailed to 23 experts representing diverse expertise in oncology-related fields (e.g., oncology, nursing, psychology, health economics). Experts were asked to rate each item in the initial pool according to (a) rationality and specificity; (b) feasibility and representativeness of implementation into clinical practice (26). Each rating was made on a 0 (low) to 10 (high) scale. To reinforce the understanding of the link between financial hardship and item content, we also invited 40 patients for the importance of the items and cognitive test. We collapsed the options to “important (assign it the value of 1)” and “not important (assign it the value of 0)” to define whether items were important and the mean values of importance scores were calculated. Finally, the items with mean value ≥0.6 (i.e., support rate ≥ 60%) were retained (16).

2.2.3 Item analysis

Older survivors who had received any cancer treatment for at least one consecutive month were included in this step. The item analysis based on Classical Test Theory (CTT) mainly included: critical ratio (CR), reliability analysis, option selection rate analysis, and correlation coefficient. Item Response Theory (IRT) was used to explore the ability and response at every level among the participants. Specifically, two-parametric logistic regression model analysis were used for dichotomous variables and five-point Likert items were analyzed by the Graded Response Model (GRM). We also performed each item’s discriminability and difficulty, item characteristic curve (ICC), item information function (IIF), and scale information function (SIF) to assess internal validity of the instrument. We deleted items with unsatisfactory indicators after group meeting. In Exploratory Factor Analysis (EFA), the factor structure used principal axis factoring analysis. Factors with eigenvalues greater than 1.0 were retained using the Kaiser–Guttman principle. We used a scree plot and parallel analysis to examine the retained factors. Factor loadings over 0.5 showed theoretical and practical significance.

2.3 Instrument validation

2.3.1 Reliability and validity

Internal reliability of the multi-item instrument was assessed by analyzing inter-item correlations and using Cronbach’s α coefficient adjusted by the number of items. An estimate of Cronbach’s $\alpha > 0.70$ was considered to indicate acceptability (17). To analyze the test-retest reliability, the intraclass correlation coefficient (ICC) was estimated by repeating the questionnaire between the patients’ first survey and approximately 2 weeks later, with an ideal level of ICC ≥0.7 (27). Confirmatory factor analysis (CFA) was used to evaluate the overall structural validity of the instrument with criteria for a good model fit identified as: Root Mean Square Error of Approximation (RMSEA) ≤0.080, a value of ≥0.960 for Comparative Fit Index (CFI), and Tucker–Lewis Index (TLI), Goodness of Fit Index (GFI)≥0.900 (27). Convergent validity was evaluated by using the average variance extracted (AVE) and composite reliability (CR). Discriminant validity and criterion validity of the new instrument was also determined.

2.3.2 Identifying a cut-off score

Cut-off scores were determined using receiver operating characteristic (ROC) analyses, which produce a comprehensive assessment of diagnostic values for sensitivity and specificity. Since the ROC curve plots the relationship between the true positive rate (sensitivity) and the false positive rate (1-specificity), it can help in selecting a value with the best predictive power. We assessed the accuracy of this prediction by the area under the ROC curve (AUC). If a value of closer to 1.0 indicates more perfect accuracy, a value ≤ 0.5 shows lower accuracy. The cut-off score of the new instrument was determined by ROC analysis based on its discriminatory ability to predict the first quartile of the PROM 10-item Global Health Scale in measuring for HRQoL (28). With poor quality of life as the health outcome, the financial hardship score was divided into higher and lower financial hardship. Finally, a multivariable logistic regression model was used to examine the relationship between cancer survivors’ characteristics and higher financial hardship. Independent variables included sociodemographic and cancer characteristics.

2.4 Statistical analysis

IRT analysis was performed using R programs to select items. The CTT analyses and EFA were conducted in SPSS 21.0. A parallel analysis was performed in MonteCarlo PCA to determine the most appropriate number of factors to extract. The data was submitted for further CFA using AMOS 24.0 with the maximum likelihood method. The characteristics of the participants such as frequency, percentage, means, and standard deviation were analyzed using descriptive statistics. Independent variables with a P value <0.05 on univariate analysis were entered into a multivariate logistic regression model analysis by adopting the stepwise method. All tests were 2-sided, and a P value < 0.05 was considered statistically significant. ROC and Logistic regression analyses were performed using SAS 9.4. All analyses were performed in 2021.

3 Results

3.1 Item generation and instrument development

3.1.1 Item generation

Literature review yielded 80 candidate items. An additional 43 candidate items were generated by interviews with 21 survivors and 20 family caregivers, while an additional 12 items were generated from feedback from 6 oncologists and 8 nurses. These 135 items were reduced to 60 by the investigators because of redundancy and overlapping content (see Figure 1).

3.1.2 Item importance analysis

Two Delphi rounds were conducted. The response rate of the questionnaire was 82.6% (19/23) in round 1, and 89.5% (17/19) in round 2. In the 2-round Delphi methods, the experts' authority coefficients were more than 0.700; they were 0.800 in round 1 and 0.897 in round 2. Finally, 36 items were deleted and 5 items were added by experts. In total, 29 items were retained. Subsequently, the important support rate of items from the 40 patients ranged from 17.5% to 100%. 5 items were excluded by an important support rate of <60%; finally, 24 items were retained (see the Supplemental Table 2).

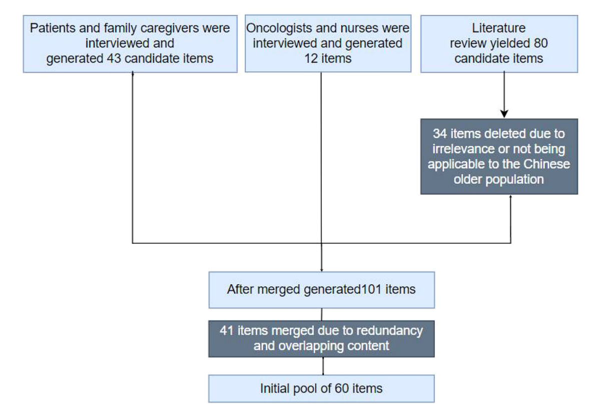

FIGURE 1
Initial items pool.

3.1.3 Item reduction

The IRT-based item analysis showed good parameter of discrimination and difficulty among majority of items; ICC, IIF, and SIF were well distributed. The CTT based analysis item CR suggested that the majority of items had good discrimination. The correlation coefficient method indicated that most items had a good correlation with the total score, and some items had a strong correlation (≥0.70, P<0.01). Cronbach's α coefficient indicated that the correlation coefficients of a few items (item 6, item 7, and item 8) were all less than 0.350 after correction, and the Cronbach's alpha if item deleted (CAID) values increased. Finally, 8 items were removed from the items pool following the criteria mentioned in the methods section above (see Table 1).

3.1.4 Exploratory factor analysis

The parallel analysis and scree plot results show two factors would be extracted. Six items were deleted because they did not load on either of the extracted factors. The EFA was then conducted again on the remaining ten items. The Kaiser-Meyer-Oklin value was 0.842, and Bartlett's spherical test P< 0.5. Two factors explained 56% of the variance and were named "subjective financial distress" (items 14,15, 18, 19, and 22) and "objective medical burden" (items 1, 2, 3, 4, and 5) (see Table 2). This new 10-item version was then developed, which was named the "Hardship And Recovery with Distress Survey" (HARDS) (see Supplemental Table 4). The total score range was from 10 (highest financial hardship) to 50 (lowest financial hardship). Figure 2 summarizes the adopted stepwise approach.

3.2 Instrument validation

3.2.1 Reliability analysis

The Cronbach's α for the 10-item instrument was 0.838. The Cronbach's α for factor 1 and factor 2 were comparable at 0.856 and 0.865, respectively. The test-retest reliability of the measure was 0.909 from a sample size of 23 patients who were assessed twice within 14 days. The result of CITC and CAID were shown Table 3.

3.2.2 Validity analysis

The results of CFA showed that the tool had good structural validity; the loading of each factor ranged from 0.548 to 0.884. The corrected model fit indices were ideal (RMSEA=0.075, SRMR=0.041, GFI=0.956, CFI=0.964, TLI=0.949) (see Figure 3). The correlation coefficient between the total score of the COST scale and the HARDS total score of this measuring tool was 0.523 (P<0.01), which indicated that the criterion validity of the HARDS was satisfactory. The AVE of the two factors were 0.555 and 0.558, respectively. The CR value of the two factors were 0.859 and 0.860, respectively.

TABLE 1 Item reduction results using the IRT and CTT.

Item	IRT		CTT					Outcome
	a	b	CITC	Effectiveness*	IIC	TIC	CR	
Item 6	0.517	0.390	0.336	45.4		0.397	<0.001	√
Item 7	1.165	-2.206	0.324	10.7		0.382	<0.001	√
Item 8	0.400	-9.975	0.014	2.0		0.047	>0.050	×
Item 9	1.003	4.017	0.481	3.4		0.473	<0.001	×
Item 10	0.923	4.212	0.375	3.4		0.346	<0.001	×
Item 12	2.361	1.874	0.755	11.7	>0.7	0.738	<0.001	×
Item 14	2.942	1.880	0.750	7.3		0.746	<0.001	√
Item 16	1.976	2.048	0.661	6.8	>0.7	0.626	<0.001	×
Item 20	3.199	1.490	0.762	7.3	>0.7	0.776	<0.001	×
Item 23	3.857	1.676	0.762	8.8	>0.7	0.749	<0.001	×
Item 24	3.824	1.715	0.734	8.8	>0.7	0.714	<0.001	×

"√" represented the selected item;
"×" indicated the item considered to be deleted;
*One of the response options is less than 10%;
a, discrimination parameter, an item should have a discrimination value greater than 0.35;
b, difficulty parameters, the difficulty values should range from −3 to 3;
Abbreviations: CITC, corrected item-total correlation;
IIC, interitem correlation, if the IIC ≥0.7, compared to the two items' importance score in methods 2.2.2, the item with a lower score was deleted;
TIC, total-item correlation;
CR, critical ratio.

3.2.3 Cut-off analysis

The mean score of the HARDS for financial hardship was 20.4 (standard deviation = 6.4). The ROC analysis results suggested this cut-off score of 18.5 could provide a balance between acceptable levels of sensitivity (0.64) and specificity (0.59). When the sample was stratified based on this cut-off score, 42% of samples were defined as having higher financial hardship.

3.2.4 Results of the multivariate regression analysis

The influencing factors of high financial hardship included socioeconomic status (i.e., employment, household income, education, and medical insurance type), social support, loneliness, frailty status, cancer site, out-of-pocket costs, and medical decision-making patterns.

TABLE 2 Factor loadings of the remaining 10-item HARD using EFA.

Item	Extracted factors		Communality
	Subjective financial distress	Objective medical burden	
Item 1	-0.094	**0.640**	0.354
Item 2	-0.018	**0.773**	0.583
Item 3	0.016	**0.781**	0.623
Item 4	0.172	**0.448**	0.312
Item 5	0.016	**0.548**	0.310
Item 14	**0.797**	0.042	0.673
Item 15	**0.884**	-0.123	0.680
Item 18	**0.662**	-0.002	0.437
Item 19	**0.446**	-0.011	0.194
Item 22	**0.544**	0.206	0.459
Percent variance (%)	40.8	15.3	56.1
Factors correlation		0.534	

Factor loadings of ≥ 0.4.in bold.

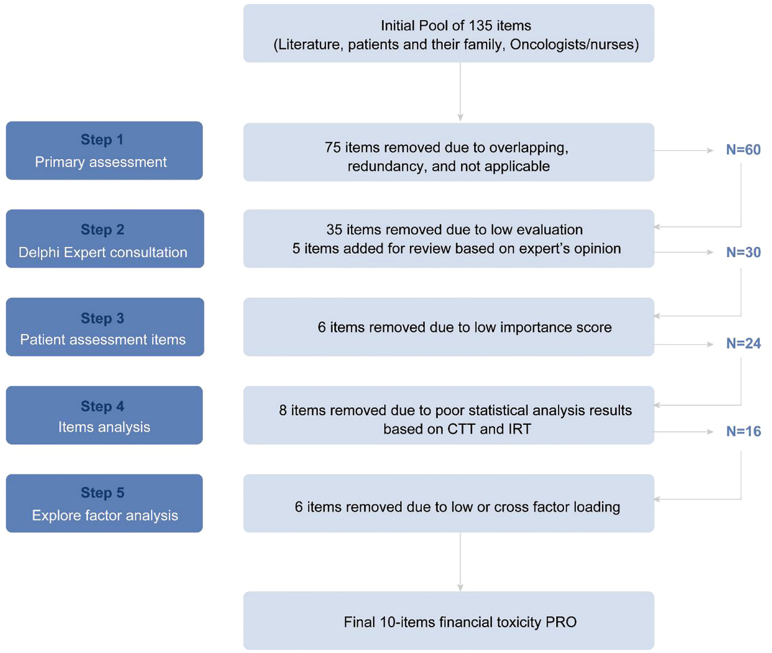

FIGURE 2
Flow chart of items inclusion and deletion.

Higher socioeconomic status of patients was associated with lower financial hardship (OR=0.427, 95%CI:0.326~0.560). Samples with frailty had a higher probability (OR=1.817) of financial hardship than those who were non-frail (see Table 4).

4 Discussion

4.1 Main findings

The HARDS, containing 10 items, is a new tool for measuring cancer related financial hardship for older patients in China, that takes about 5 minutes per patient to measure. The HARDS captures the subjective financial distress and objective medical burden. The HARDS based on PROM can reflect the specificity of older cancer survivors' experiences. The collection and use of PROM such as the HARDS can help with medical decision-making, early identification of financial hardships, and improvements to HRQoL and prognosis. In this study, we used the COSMIN checklist to evaluate the methodological quality of studies on the measurement properties of PROM measuring financial hardship for older cancer survivors (29). And the validity and reliability of the HARDS as a screening tool for financial hardship have been tested. We also determined the cut-off score that predicted a poor outcome for HRQoL, as well as features that characterize older survivors with a high level of financial hardship.

TABLE 3 Results of the reliability analysis.

Item		CITC	CAID
HARD1	I couldn't afford the costs of my cancer treatments and care.	0.465	0.834
HARD2	I don't have enough income, savings, or retirement pension to cover my treatment costs.	0.489	0.832
HARD3	I rely on my children to pay for my medical costs.	0.537	0.830
HARD4	Due to cancer treatment and related long-term impacts on my daily life, I had to borrow money or was in debt.	0.441	0.835
HARD5	I used up all my savings for my cancer treatment.	0.325	0.839
HARD6	I worry that my cancer treatment will affect my family's financial stability.	0.729	0.801
HARD7	I worried about the loss of both my life and money at the end of my cancer treatment.	0.699	0.805
HARD8	If the expected medical cost is higher than I can afford, I would give up the treatment.	0.614	0.817
HARD9	Due to financial reasons, I would choose the medications covered by medical insurance.	0.677	0.809
HARD10	I reduced spending on basics like food or clothing because of the costs of my cancer care.	0.629	0.813

item 1=HARD1, item 2= HARD 2, item 3= HARD 3, item 4= HARD 4, item 5= HARD 5, item 14= HARD 6, item 15= HARD 7, item 18= HARD 8, item 19= HARD 9, item 22= HARD 10; CITC, corrected item-total correlation; CAID, Cronbach's alpha if item deleted.

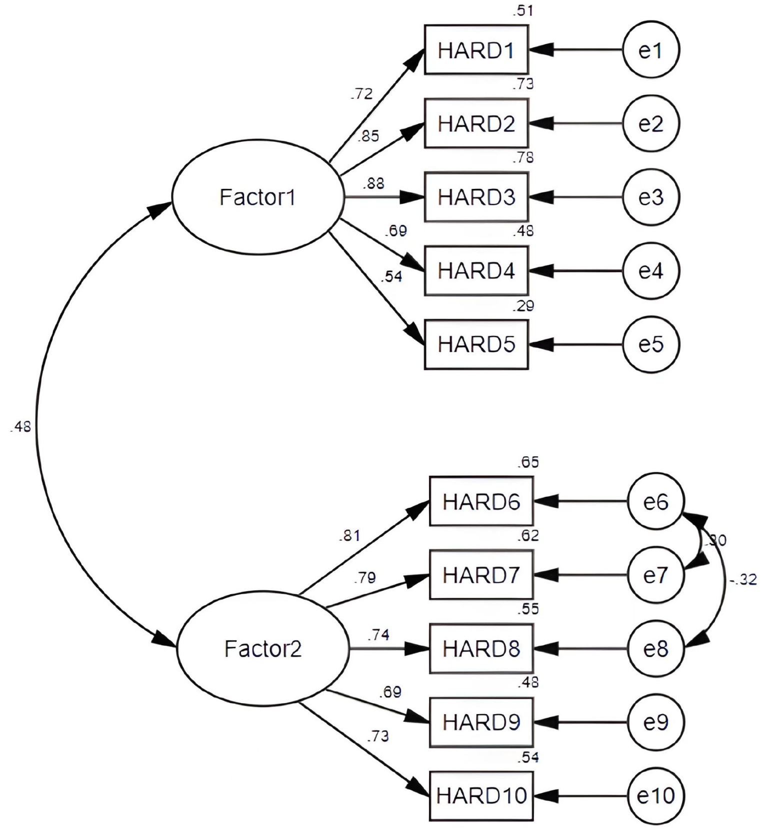

FIGURE 3
A two-factor model for the HARD from confirmatory factor analysis.

Current instruments measuring cancer related financial hardship include the FIT (17), the COST (30), and the Breast Cancer Finances Survey (BCFS) (30, 31). The FIT was designed specifically for head and neck cancer, the COST was designed for patients with advanced cancer, and the BCFS was designed exclusively for breast cancer patients. Applicability of these instruments to other cancer stages and sites may be limited. To our knowledge, the COST is currently the most commonly used validated instrument to measure financial hardship in cancer survivors (31, 32). However, the COST measure has only one family item which is a summary statement (27); thus, the financial hardship on families has not been fully taken into consideration. In this study, cancer-related financial worries and stress among older adults extended into their families, especially those of their adult children. Our instrument assessed financial hardships from the perspectives of both an individual and their family. Therefore, the HARDS captures the family's financial situation and covers material factors, psychological measures, and coping strategies to comprehensively measure financial hardship.

Like other studies that have developed and validated measures of financial toxicity, our study also uses the COST as the gold standard for criterion validity (17, 18, 33). For example, factor analysis and item reduction were performed on the patients as validity testing. The instrument demonstrated reasonably good psychometric properties, which provide useful information for practical applications. Thus, HARDS is a valid, reliable tool. But one of the job-related items of COST "I am concerned about keeping my job and my income" might be less sensitive to older survivors. In China, the older population in rural and urban areas aged 60 were 175 million and 75 million, respectively, and nearly 70% of older people lived in rural areas (34). Rural residents lack pension support and expect to work in agriculture-related activities until relatively late in their lives. Furthermore, older adults in urban areas usually have retired, so their job and salary were rarely affected due to cancer treatment. Despite deleting this job-related item, the rest of 10 items retained were representative of the COST with a score ranging from 0 to 40. The results still indicated that the newly developed HARDS correlated well with the modified COST.

This study also determined a proposed cut-off score for the HARDS measure. The cut-off score predicted an adverse outcome for HRQoL and categorized the level of high or low financial hardship. Forty-two percent of the patients had a high level of financial hardship in our study. A prior study indicated close to 20% of older adults with advanced cancer experience financial hardship in USA (35). In the USA, most respondents were aged 65, and older adults often had Medicare, while lower-income people were enrolled in Medicaid (36). These insurance programs help them pay for medical services, including hospitalization, prescription drugs, home health care, and hospice care. However, China has implemented a basic medical insurance system, in which UEBMI is mandatory for employees in urban areas, while unemployed

TABLE 4 Results of Logistic regression analysis (Reference: Lower financial hardship).

Variables	β	OR (95%CI)	P-value
Socioeconomic status	-0.851	0.427 (0.326, 0.560)	<0.001
Social support	-0.023	0.977 (0.958, 0.997)	0.026
Loneliness (Reference: No)			
Yes	0.394	2.200 (1.024, 4.726)	0.020
Frailty (Reference: No)			
Yes	0.299	1.817 (1.098, 3.007)	0.026
Cancer site (Reference: Lung)			
Esophageal and Stomach	-0.500	0.908 (0.467, 1.765)	0.061
Colorectum	0.267	1.995 (0.783, 4.881)	0.460
Liver and gallbladder	0.796	3.302 (1.504, 7.251)	0.011
Other	-0.156	1.281 (0.651, 2.520)	0.562
Out-of-pocket (/10,000 CNY)	0.050	1.051 (1.021, 1.081)	<0.001
Medical decision making (Reference: Patients)			
Family	-0.546	0.339 (0.135, 0.848)	0.014
Shared	0.254	0.754 (0.316, 1.801)	0.197
Oncologist	-0.245	0.458 (0.169, 1.242)	0.349

Socioeconomic status was defined by education level, occupation, annual household income, and health insurance. It was determined as a continuous variable by principal component analysis;
The Multidimensional Scale of Perceived Social Support (MSPSS) was used to assess social support;
The Groningen Frailty Indicator Scale (GFI) was used to assess the frailty level;
10,000 CNY was approximately US $1,433 as of December 31, 2021.
OR, odds ratio; CI, confidence interval; β, effect estimate.

residents in urban areas and rural residents are covered by the URRBMI (37). In China, most of the older patients are farmers, and they are a relatively disadvantaged population with low incomes. A previous study indicated that older cancer survivors from rural areas have to bear higher hidden costs of transportation and rent for their homes (27). Moreover, rural residents are covered by URRBMI, which has a lower reimbursement ratio than UEBMI. Thus, the cancer-related financial hardship prevalence in rural patients is higher than in those with pension support and prior non-agricultural employment (38). A considerable proportion of older patients still struggle against financial hardship despite the availability of basic health insurance. There is a gap that needs to be addressed between financial hardship and government assistance (39, 40). Therefore, these medical insurance policies need to be constantly improved to alleviate the burden of cancer-related costs.

The strengths of our study included the integration of qualitative interviews with quantitative findings, and the inclusion of a broad stakeholder group with experts from a diverse, yet significant group of oncology-related fields, patients, and their families. This study shows a comprehensive understanding of older cancer survivors and their family members' financial hardship.

4.2 Clinical implications

This study is an original study in the field of cancer survivorship in China that provides evidence for improving the quality of cancer care. The incorporation of financial toxicity assessments into observational research will ensure a patient centered foundation in the evaluation of financial distress, as HARDS is a quick and reproducible measurement that could be used in clinical practice to identify patients early who may be at risk of financial hardship and may benefit most from intervention. Oncology providers (oncologists and nurses) are important agents in patient cancer care experiences, discussions about financial toxicity of cancer care should be initiated by an informed oncologist and managed by the entire healthcare team. The collection and use of the HARDS can help with enhancing shared decision-making between oncologists and patients to reduce costs. Long-term solutions must include policy shifts involving how we set and negotiate anti-cancer prices and insure patients. The HARDS may help increase awareness of patient financial distress and cancer treatment cost sparking discussions among health policy makers and other stakeholders to develop multidisciplinary strategies for mitigating financial toxicity.

4.3 Study limitations

Several potential limitations should be considered in interpreting the results of the study. First, the study findings might not be representative of all older cancer patients, as this study did not include individuals who were not admitted to the hospital and did not receive treatment due to severe financial difficulties. Therefore, the level of financial hardship in older populations may be underestimated. Second, the financial toxicity of PROM in China may differ from older cancer survivors in other countries due to social and cultural differences, so the extrapolation of the instrument may be limited. It needs cross-cultural validation and adaption in other eastern countries. Third, this study used a cross-sectional survey in the instrument validation stage, but the trajectory of cancer and medical treatment for survivors is complicated and long-term; thus, a prospective study is needed to determine how financial toxicity changes over time.

5 Conclusions

In this study, we report the development and validation of the HARDS to measure financial hardship among older cancer survivors in China. This study found that poor quality of life was associated with a higher level of financial hardship, and the severity cut-off score of the new instrument was obtained. Finally, we also identified several influencing factors on higher financial hardship, such as low socioeconomic status, poor social support, loneliness, frailty, high out-of-pocket costs, and more.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material. Further inquiries can be directed to the corresponding author.

Author contributions

LL: Conceptualization, data curation, software, writing-original draft, and writing–review, and editing. AZ: Writing, data curation, review, software, and editing. MS: Conceptualization, methodology, formal analysis, and writing–review, and editing. XS: Writing–review, and editing. DS: Writing–review, and editing. JC: Writing–review, and editing. NY: Supervision, and writing–review, and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fonc.2023.1151465/full#supplementary-material

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Facing financial barriers to healthcare: patient-informed adaptation of a conceptual framework for adults with a history of cancer

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Background: Cancer-related financial hardship is associated with negative clinical outcomes, which may be partially explained by cost-related delayed or forgone care in response to financial barriers. We sought to understand patient experiences facing financial barriers to medical care following a cancer diagnosis.

Methods: We conducted virtual, semi-structured interviews in Fall 2022 with 20 adults with a history of cancer who had experienced cancer-related financial hardship in the prior year. We used template analysis within a pragmatic paradigm, combining constructivist and critical realist theoretical perspectives, to analyze interview transcripts and adapt an existing conceptual framework of financial barriers to care.

Results: The majority of interviewees identified as women (70%), non-Hispanic white (60%), and reported an annual household income of <$48,000 (60%). As interviewees sought to overcome financial barriers, they described substantial frustration at the limitations and complexities of United States health and social care systems, resulting in a reliance on a fragmented, uncertain resource landscape. The administrative burden resulting from bureaucratic systems and the advocacy responsibilities required to navigate them ultimately fell on interviewees and their caregivers. Thus, participants described their ability to overcome financial barriers as being influenced by individual and interpersonal factors, such as social support, comfort asking for help, time, prior experience navigating resources, and physical and mental health. However, participants noted health system organizational factors, such as whether all new patients proactively met with a social worker or financial navigator, as having the potential to lessen the administrative and financial burden experienced.

Conclusion: We present an adapted conceptual framework outlining multi-level factors influencing patient experiences coping with financial barriers to medical care. In addition to influencing whether a patient ultimately delays or forgoes care due to cost, financial barriers also have the potential to independently affect patient mental, physical, and financial health.

KEYWORDS

cancer, financial toxicity, financial burden, access to care, financial barriers

1. Introduction

A cancer diagnosis and subsequent treatment in the United States can impose substantial costs, both medical (i.e., out-of-pocket costs) and non-medical (e.g., transportation, lost income), on patients and their families. As a result, it is estimated that almost half of individuals with a history of cancer experience financial hardship, including material conditions, psychological response, and coping behaviors (Altice et al., 2017; Zheng et al., 2019; Jiang et al., 2022). More specifically, 70% of adults ages 18–49 with a history of cancer report one or more domains of financial hardship, followed by 63.2% of those ages 50–64, and 38.7% of those 65 years and older (Zheng et al., 2019). As such, "financial toxicity" has emerged as a term over the past decade to relate the financial consequences of cancer treatment to other treatment toxicities routinely monitored and addressed (Zafar and Abernethy, 2013).

Cancer-related costs, compounded by underlying financial vulnerability, may lead patients to experience financial barriers to accessing and paying for medical care during active treatment and into survivorship. Almost 20% of adults with a history of cancer report forgoing medical care and/or prescription medications due to cost (Weaver et al., 2010). Financial access barriers may lead to missed appointments (Maldonado et al., 2021), treatment and medication nonadherence or delays (Knight et al., 2018), and forgone surveillance and preventive care. Furthermore, the burdens of cost-related care interference are not experienced equally, with a higher prevalence among uninsured or publicly insured patients (al Rowas et al., 2017; Amin et al., 2021), patients of color (Weaver et al., 2010; Wheeler et al., 2018), and low-income patients (Amin et al., 2021). As such, understanding and addressing patient financial hardship, and how such hardship influences access to care (Levesque et al., 2013), is a necessary step toward promoting equitable cancer care delivery (Tucker-Seeley, 2023).

Conceptual frameworks describing the impact of financial hardship on patients with cancer have identified delayed and forgone care as a coping behavior to reduce costs (Altice et al., 2017; Jones et al., 2020); however, conceptual clarity surrounding cost-related care interference is lacking. Though not developed among patients with cancer, Campbell and colleagues developed a conceptual framework of the role of financial barriers to healthcare in contributing to health outcomes among patients with cardiovascular-related chronic disease in Canada (Campbell et al., 2016). This framework, developed using grounded theory, conceptualizes both the causes of perceived financial barriers and the factors influencing the extent to which perceived financial barriers to healthcare translate into care avoidance, adverse healthcare events, and negative clinical outcomes (Campbell et al., 2016).

Given notable differences between a cancer diagnosis and chronic cardiovascular conditions, as well as the Canadian versus United States healthcare systems, there is a need to adapt and update this model to reflect patient experiences with financial barriers to healthcare following a cancer diagnosis in the United States. The United States healthcare system does not provide universal healthcare coverage and consists of both public and private payers. Private health insurance coverage is most commonly obtained through employers, public Medicaid coverage is provided to low-income individuals meeting eligibility criteria through states, and public Medicare coverage is provided to individuals with disabilities and adults over 65 years of age through the federal government.

This study builds off of Campbell and colleagues' conceptual framework of financial barriers, as well as prior qualitative analyses documenting cancer-related financial hardship, to understand the experiences of patients with cancer facing financial barriers to healthcare in the United States (Amir et al., 2012; Timmons et al., 2013; Schröder et al., 2020). Using the conceptual framework of financial barriers as a guide, we specifically probed on patient perceptions of factors influencing the extent to which perceived financial barriers resulted in delayed and forgone medical care. Ultimately, a better understanding of how patients experience financial barriers to care serves to inform patient-centered approaches to reducing cost-related cancer outcome disparities.

2. Materials and methods

2.1. Study design/research approach

In order to capture in-depth patient experiences, we conducted qualitative interviews with individuals with a history of cancer living in the United States. We then conducted a qualitative analysis using a hybrid inductive and deductive template analysis approach (King and Brooks, 2017; King et al., 2018). Template analysis is an established qualitative thematic analysis approach involving the iterative development of a coding template and subsequent thematic interpretation that can be used in the context of a range of qualitative paradigms (King and Brooks, 2017; King et al., 2018). Our overarching approach to this research study was pragmatism, which involves the combination of approaches for the purposes of understanding a given research problem (Moon and Blackman, 2014). The first stage of analysis was largely inductive, and we approached this phase with a constructivist theoretical perspective, focusing on meaning-making from participant lived experiences within their social environments (Moon and Blackman, 2014). Given that there is an existing conceptual framework of patient experiences facing financial barriers to healthcare developed using grounded theory (Campbell et al., 2016), we then layered on this framework deductively as a way of situating the knowledge generated through participant experiences into the existing body of knowledge on this topic. Lastly, in line with a critical realist qualitative paradigm, we structured the meaning gleaned from our qualitative inquiry into an adapted conceptual framework intended for further use and revision. The critical realist paradigm allowed this conceptualization to inform our codebook development and thematic interpretation. Themes resulting from the hybrid inductive/deductive template analysis then informed the adaptation of this conceptual framework for adults with a history of cancer. A critical realist approach is particularly well suited to health services research in that it seeks to recognize and acknowledge objective health outcomes while remaining open to variation in how participants experience and understand those outcomes (Ritchie et al., 1994; Archer et al., 1998; Clark et al., 2007; King et al., 2018).

2.2. Participants

Potential interview participants were identified through the Patient Advocate Foundation (PAF), a national non-profit organization providing financial assistance and social needs navigation services to patients with serious and chronic illness. Individuals were considered eligible if they met the following criteria: (1) diagnosed with cancer (any site), or received active cancer treatment, in the prior one to 5 years, (2) age 18 or older at the time of diagnosis, (3) completed a survey administered in English by PAF in May 2022 and indicated willingness to be contacted for future research, and (4) experienced cancer-related financial hardship in the past 365 days (self-reported via screener questionnaire). Patients receiving the PAF survey received assistance from PAF between July and December 2020.

A total of 218 individuals met the first three eligibility criteria based on data collected from the PAF survey. From this subset, PAF emailed a screener questionnaire to waves of purposively sampled individuals in order to maximize diversity with regard to age, race, ethnicity, gender, and sexual orientation. Of the 218 eligible individuals, 111 were emailed. Potential participants were considered to have experienced cancer-related financial hardship if they self-reported experiencing difficulty paying for medical care or prescription medications, reducing spending on basic necessities (e.g., food, housing) to get needed medical care or prescription medications, or delaying or forgoing medical care because it cost too much in the past 365 days. Eligible individuals were then emailed by a member of the study team (CB) to schedule an interview. Participants were also given the option to schedule by phone. Additionally, two participants, who also met all eligibility criteria, were referred to the study via snowball sampling. Participants were compensated for their time with a $25 electronic gift card. The institutional review board approved this study (UNC-CH IRB#22-0467).

2.3. Data collection

A member of the research team (CB) conducted virtual, audio-only semi-structured interviews between August and November 2022. Interview questions were guided by an in-depth, semi-structured interview guide, which was informed by Jones and colleagues' conceptual framework of financial burden in adult cancer survivors (Jones et al., 2020) and Campbell and colleagues' conceptual framework of financial barriers to care in adults with chronic cardiovascular conditions (Campbell et al., 2016). The guide was refined through pilot testing with three patient advocates recruited from PAF's Patient Insight Institute Experts by Experience Advisory Committee. The complete interview guide is included in Supplemental Appendix 1.

Interviews were conducted until thematic saturation was achieved in relation to the primary research questions (Malterud et al., 2016; Saunders et al., 2018). All interviews were audio-recorded, transcribed using an online transcription tool and then cleaned and quality checked against audio files. Sociodemographic information for interview participants was collected in the electronic survey administered by PAF in May 2022 and included: age category, race, ethnicity, gender, sexual orientation, education, employment status, marital status, household income category, self-described rurality, health insurance status, cancer type, and time since diagnosis.

2.4. Data analysis

To maximize reflexivity, the template analysis took place concurrently with data collection. The research team first engaged in data immersion, or familiarization, by writing analytic memos following each interview and developing a qualitative matrix organized by participant and interview domain (Miles et al., 2015). This matrix included key patient characteristics hypothesized to influence the experience of financial barriers to care.

Second, two independent coders (CB, AW) analyzed interview transcripts in Dedoose version 9.0.62 (SocioCultural Research Consultants, LLC Dedoose, 2022); using a codebook developed via a hybrid inductive and deductive approach (Saldaña, 2013; Miles et al., 2015). In first cycle coding, CB conducted open coding on 20% of the interviews ($n = 4$), during which transcript segments were categorized based on emergent ideas, both descriptive and thematic. Codes resulting from open coding were condensed into a coding scheme by combining similar codes and grouping codes within broader categories (Saldaña, 2013; Miles et al., 2015). CB also developed an unconstrained coding matrix based on the conceptual framework of financial barriers to care for adults with chronic cardiovascular conditions (Campbell et al., 2016). This deductive coding matrix was incorporated into the inductively developed code structure, and the resulting codebook was applied to another 20% of interviews. Codes were developed for relevant sections of text that could not be categorized within the existing scheme, and the updated codebook was reviewed and refined by other research team members.

In second cycle coding, CB and AW used consensus coding to apply this coding scheme to all transcripts, including those used in first cycle coding. CB and AW first independently coded a single transcript and then compared code applications, reflected on unrecognized assumptions or interpretations, resolved disagreements, and updated the codebook as needed. Once consensus was achieved, CB applied the codebook to all remaining interviews, and AW reviewed code applications, noting additional codes that should be applied and points of disagreement, with the ultimate goal of ensuring critical thinking in the code application process. A third coder (RA) was consulted in the case that disagreements could not be resolved. The final codebook is included in Supplemental Appendix 2.

Finally, coded excerpts were interpreted in relation to the original research questions, identifying resonant themes across interviews. Though analysis took place throughout the coding process, the review of coded excerpts took place after all code assignments were finalized. Particular attention was given to "pressure points," defined as positive or negative experiences that change how an individual navigates a system (Schaal et al., 2016; Black, 2022), in order to connect individual experiences to systemic factors. Transcripts were marked by participant characteristics (i.e., cancer type and year of diagnosis, age, race, ethnicity, annual income, marital status, health insurance status at diagnosis and currently) such that excerpts were viewed in the context of interviewees' identities and life circumstances. Resulting themes were used to adapt an existing conceptual framework of patient experiences facing financial barriers to care (Campbell et al., 2016), which was then revised iteratively through discussions with the research team and patient advocates, including attendees of the 2022 Patient Insight Congress, a gathering of advocates, healthcare professionals, and researchers hosted by the Patient Advocate Foundation.

3. Results

We completed 20 audio-only interviews averaging 43 min (range: 28–60 min; intended interview length: 30–45 min). Of the 20 adults interviewed, 70% identified as women (25% men, 5% gender non-conforming); 55% had a college degree; and 55% were single, divorced, or separated. The majority of interviewees identified as non-Hispanic white (60%), followed by Black or African American (20%), Hispanic or Latino (10%), Asian (5%), and Native Hawaiian or other Pacific Islander (5%). When asked to report their annual household income, 20% reported making less than $24,000, 40% between $24,000 and $47,999, and 35% $48,000 or more (5% did not disclose). Interviewees were diagnosed with a range of cancer types (with breast cancer most common, 40%) between 2012 and 2020 (median time since diagnosis = 4.5 years). At the time of diagnosis, the majority of interviewees were privately insured (60%), and 15% were uninsured. At the time of the interview, Medicare was the primary insurer for 55% of participants, followed by private insurance (35%) and Medicaid (10%) (Table 1).

Cancer-related financial hardship led to the majority of interviewees either delaying or forgoing medical care, including diagnostic procedures (30%), primary cancer treatment (30%), supportive medications and therapies (50%), surveillance/monitoring (5%), and care for other conditions (30%) (Table 2). For example, one interviewee described forgoing supportive medications – "There were a couple meds that I could not afford to get… I just had to pick and choose…" (05: 56–75 years old, Stage 3 multiple myeloma). Direct causes of delayed and forgone care included out-of-pocket medical cost uncertainty, services or medications not being covered by insurance, prohibitive patient cost sharing (i.e., deductible, coinsurance, co-pays), and uninsurance. Non-medical cost barriers, such as not being able to take time off work or afford transportation to access care, were reported as challenges, but less commonly identified as causing participants to delay or forgo care.

In addition to describing experiences delaying and forgoing care due to cost, interviewees described in-depth the causes of the financial barriers experienced, their process of coping with or attempting to overcome these barriers, and the consequences of this process, on both delayed and forgone care, as well as their physical, emotional, and

TABLE 1 Characteristics of interviewed adults with a history of cancer (N=20).

Participant characteristics	*N* (%)
Age	
19–35	2 (10%)
36–55	9 (45%)
56–75	9 (45%)
Race/ethnicity	
Non-Hispanic White	12 (60%)
Black or African American	4 (20%)
Hispanic White	2 (10%)
Asian	1 (5%)
Native Hawaiian or other Pacific Islander	1 (5%)
Gender	
Woman	14 (70%)
Man	5 (25%)
Gender non-conforming	1 (5%)
Sexual orientation	
Heterosexual	17 (85%)
LGBTQIA+	2 (10%)
Prefer not to say	1 (5%)
Education	
HS, GED, Other	2 (10%)
Some college or 2-year degree	7 (35%)
College degree or more	11 (55%)
Marital status	
Single, divorced, or separated	11 (55%)
Married or partnered	9 (45%)
Annual household income	
Less than $24,000	4 (20%)
Between $24,000 and $47,999	8 (40%)
$48,000 or more	7 (35%)
Prefer not to say	1 (5%)
Current employment status	
Disabled, not able to work	9 (45%)
Retired or not employed	4 (20%)
Employed full-time by someone else	3 (15%)
Self-employed	3 (15%)
Employed part-time by someone else	1 (5%)
Cancer type	
Breast	8 (40%)
Multiple myeloma	3 (15%)
Blood	3 (10%)
Head and neck	2 (5%)
Other*	4 (20%)
Time since diagnosis	
1–2 years	7 (35%)
3–4 years	5 (25%)
5–6 years	5 (25%)
More than 6 years	3 (15%)
Insurance at diagnosis	
Private	12 (60%)
Medicare/medicaid/tricare	5 (25%)
Uninsured	3 (15%)
Current insurance	
Medicare	11 (55%)
Private	7 (35%)
Medicaid	2 (10%)

*Other includes colorectal, lung, ovarian, and gastrointestinal.

TABLE 2 Types of cost-related delayed and forgone care described by interviewees with a history of cancer.

Type of care	Illustrative quotation
Diagnostic	"When I was initially diagnosed with cancer, it was due to a diagnostic mammogram, which I delayed because I did not have $300 to pay for it…and so while my cancer was caught, you know, in stage two, I do go back and think about, I should have just done that diagnostic mammogram." (13: 36–55 years old, Stage 2 breast)
Cancer treatment	"I know what cancer is, and it just all hit me that I would not be able to follow through with any of it without money." (12: 56–75 years old, Stage 3 multiple myeloma)
Supportive care	"There were a couple meds that I could not afford to get…I just had to pick and choose…I would sacrifice the pain med and another one until I could work out how I could afford to get that thing." (05: 56–75 years old, Stage 3 multiple myeloma)
Surveillance	"So I'm actually due to have [an MRI] coming up in a few months, but I'm not going to have insurance anymore… it's quite possible I'm not going to be able to get that this year, which really sucks because I definitely need it." (09: 36–55 years old, Stage 3 breast)
Other medical care	"I went to CVS to get my [multiple sclerosis] prescription refilled and it was gonna cost $395. So I just refused. I said, well, I'll just have to go without it." (06: 56–75 years old, blood)

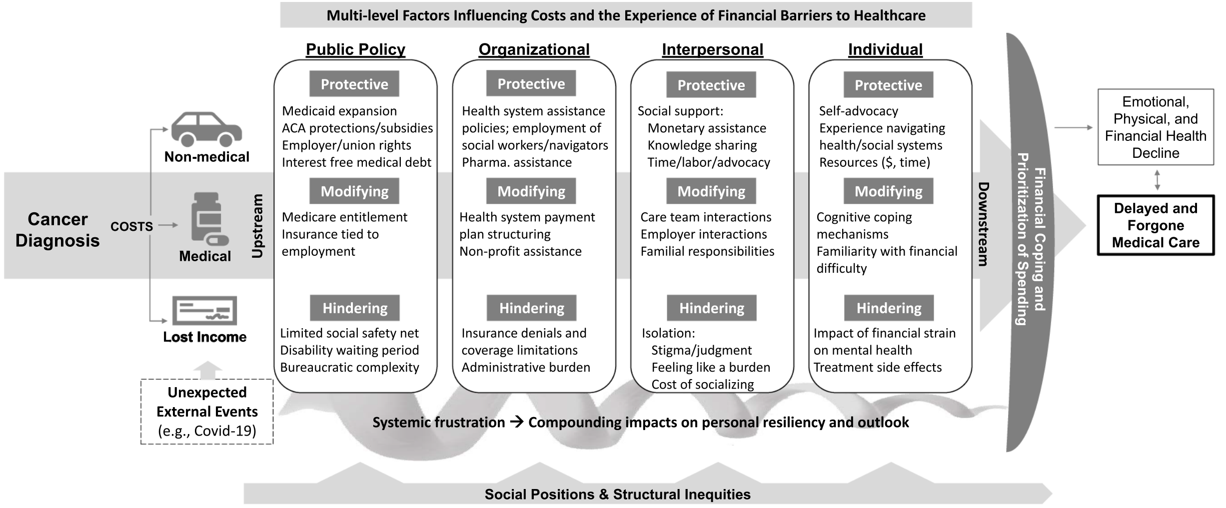

FIGURE 1
This framework displays for understanding the experience of financial barriers to healthcare by adults with a history of cancer. This framework displays the multi-level factors influencing patient experiences facing financial barriers to healthcare. Protective factors lessened the causes and consequences of financial barriers, hindering factors exacerbated them, and modifying factors had the potential to be either protective or hindering.

financial health. Figure 1 organizes emergent themes into a conceptual model of the multi-level protective, modifying, and hindering factors influencing patients' experiences facing financial barriers to medical care. Protective factors lessened the causes and consequences of financial barriers, hindering factors exacerbated them, and modifying factors had the potential to be either protective or hindering (Campbell et al., 2016). This model serves as an organizing framework for the factors we identified as influencing patient experiences of financial barriers to care in our analysis. Additionally, it presents an opportunity to stimulate future research on this topic. Below, we describe emergent qualitative themes, organized by model component.

3.1. Costs

Figure 1 depicts costs incurred as a consequence of cancer leading to financial barriers to care. In addition, factors influencing patient experiences facing financial barriers can also affect the magnitude of the costs incurred (e.g., the time required to find and navigate resources and medical care leading to more time off work). The amount and impact of cancer-related costs were also influenced by unexpected external events, most notably the Covid-19 pandemic. Interviewees described no longer being able to rely on childcare from family members and public transportation, thus increasing non-medical costs. The pandemic also caused several interviewees and their caregivers to lose employment, leading to insurance churn and lost income. *"When I lost my job [due to Covid-19], I felt the full effect of cancer and my job and just, everything just fell apart"* (17: 36–55 years old, Stage 4 breast).

3.2. Multi-level factors influencing costs and the experience of financial barriers to healthcare

3.2.1. Public policy factors

Though interviews focused on participants' individual experiences, the influence of policies in both protecting interviewees from financial burden and exacerbating it shone through, with

TABLE 3 Public policy factors influencing the experience of financial barriers to healthcare.

Factor	Illustrative quotation
Protective	
Medicaid expansion	"I did not really have any issues with, with Medicaid that, like I said, it was, everything was covered, you know?" (01: 56–75 years old, Stage 2 lung)
Affordable Care Act protections and subsidies	"I was really worried that you know I wasn't gonna get covered, because I was going to graduate soon, so I could not be I did not want to be diagnosed or have it on the radar because I was afraid I wasn't going to get the pre-existing condition protection." (02: 36–55 years old, Stage 4 breast)
Employer/union rights	"Because I had been with the, the college for over 20 years, I was able to carry that health insurance with me and for my wife afterwards… it was a union contract from 15 years previous." (15: 36–55 years old, Stage 3 multiple myeloma)
Interest-free medical debt	"There's no interest on medical debt…. I knew how the laws worked with medical debt. You know because the hospital, they can be like really kind of bullies…" (04: 36–55 years old, Stage 4 colorectal)
Modifying	
Medicare entitlement	"And you know, with Medicare, the copay for part B is like 20%. That copay for my treatment was about $2,000 to $3,000 every 3 weeks. And if it got to the point where I'm trying to figure out how to pay for this." (01: 56–75 years old, Stage 2 lung)
Insurance tied to employment	"So, when I lost my job like I said, that was not the time to lose my job because I'm, you know, I'm not married. So no health insurance. And it was like, Okay, this is how I'm gonna die. I'm gonna die of Covid because, you know, Covid wiped my job out." (17: 36–55 years old, Stage 4 breast)
Hindering	
Limited social safety net	"The amount that [social security disability] gives you per month is not really a livable amount, and then they limit you on what you can earn per month." (05: 56–75 years old, Stage 3 multiple myeloma)
Disability waiting period	"You have to wait 6 months to get any kind of disability payments and then 2 years for Medicare, which is pretty frustrating because at that point, you are in a bad situation… I just think they are hoping that people will die off or not need it anymore." (04: 36–55 years old, Stage 4 colorectal)
Bureaucratic complexity	"And then I did the paperwork [for SNAP] because there's supposed to be an exception for people with disabilities. But now with the Covid shutdown, you have to do everything online and the application is like 40 pages. When they looked at it, I tried to call them back and said, you did not read the part that says I'm disabled, which increases the income level, but they did not know about that. So I still have that appointment to visit in person." (01: 56–75 years old, Stage 2 lung)

particular emphasis on the shortcomings of governmental protections. Each key protection mentioned came with caveats. For example, though Medicaid provided comprehensive coverage for those able to qualify, participants expressed frustration over the strict eligibility criteria, particularly in non-expansion states ["*when I tried [to apply for Medicaid] first, my husband and I were not eligible because he was still working… [and made] like a hundred dollars more than the limit*" (12: 56–75 years old, Stage 3 multiple myeloma)]. Similarly, the Patient Protection and Affordable Care Act provided important protections for individuals with pre-existing conditions; however, threats of these protections being overturned still led one interviewee to reflect, "*I did not want to be diagnosed…because I was afraid I wasn't going to get the pre-existing condition protection*" (02: 36–55 years old, Stage 4 breast). Other avenues of acquiring insurance, such as Medicare entitlement for individuals with qualifying disabilities and employer-sponsored insurance, also came with notable limitations, such as administrative delays, prohibitive out-of-pocket costs, and insurance churn. Additional factors at the public policy level are outlined in Table 3, along with illustrative quotations.

3.2.2. Organizational factors

Organizational factors related to healthcare systems, insurance companies, pharmaceutical manufacturers, and non-profit organizations. Protective organizational factors included healthcare system financial assistance programs and the employment of a sufficient number of social workers and financial navigators to assist patients in understanding and coping with the cost of care. As described by one interviewee, "*the oncology unit has social workers attached to it…when you first have a cancer diagnosis they sort of flood you with resources*" (07: 56–75 years old, Stage 4 breast). Financial assistance programs through pharmaceutical manufacturers, and the connection to these resources through care team members, were also protective. The availability of payment plans through healthcare systems could be protective, warding off collections and medical debt, but several interviewees described instances in which they felt pressured by the healthcare system to pay more than they could afford each month – "*the hospital, they can be really kind of bullies…like you are going to pay this or we'll send you to collections*" (04: 36–55 years old, Stage 4 colorectal). Non-profit assistance was similarly an important resource, but it was not guaranteed and often came with very specific eligibility criteria, complex applications, and funding limits ["*if they do not have the availability in your disease fund, then you are out of luck*" (20: 56–75 years old, blood)].

Insurance denials, processing delays, and coverage limitations were described as sources of substantial frustration by the majority of interviewees. This frustration was underscored by a sense of injustice that insurance coverage determinations ultimately determined care decisions instead of their oncologist or other care team members. Outstanding denied charges and concerns about future denials weighed heavily on interviewees, particularly in instances in which accessing treatment was a matter of survival. "*Whether the insurance company does not approve a new drug or a clinical trial or anything like that is terrifying to me… that's always in the back of my mind*" (10: 19–35 years old, Stage 4 breast). Though caused by organizational practices and policies, the administrative burden of communicating between the fragmented landscape of organizations providing and paying for medical care was ultimately felt by patients and their

TABLE 4 Organizational factors influencing the experience of financial barriers to healthcare.

Factor	Illustrative quotation
Protective	
Health system assistance policies	"… sometimes the hospitals, if you even just ask for assistance, will give you some somewhat of a reduced bill." (04: 36–55 years old, Stage 4 colorectal)
Employment of social workers and navigators	"The oncology unit has social workers attached to it…when you go into [health system] and you first have a cancer diagnosis, they sort of flood you with resources." (07: 56–75 years old, Stage 4 breast)
Pharmaceutical assistance	"I need the med to stay alive, but it's so expensive that you cannot afford it without a grant or, or something. You know, this ain't gonna work. So I guess at this point, it, it has worked itself out. But yeah, about every 10, 11 months I have to worry about it." (05: 56–75 years old, Stage 3 multiple myeloma)
Modifying	
Health system payment plan structuring	"I chose to go on a payment plan and I pay $5 a month… I used to see [my hematologist] every couple of months, but she said she did not need to see me for 6 months. And I'm wondering if that has anything to do with…I do not have any clue if she knew that I had put myself on the $5 a month payment plan." (06: 56–75 years old, blood)
Non-profit assistance	"Nonprofits. Yeah. Those really have been what have kept us afloat. It's sad to say that it's not been, you know, our, our government or any kind of, you know system. It's been nonprofits that have really been there." (04: 36–55 years old, Stage 4 colorectal)
Hindering	
Insurance denials and coverage limitations	"It's so crazy how one insurance will say, you can take this medicine and then another insurance will say, nope, you gotta take this medicine. And to me, that's like, why do not you just listen to what my doctor wants me to take?" (09: 36–55 years old, Stage 3 breast)
Administrative burden	"I've had to fight [with insurance] to get some medicines that help me get through the day." (03: 19–35 years old, Stage 4 breast)

caregivers ["*it wound up being a lot on me just going back and forth with different people in the insurance company*" (09: 36–55 years old, Stage 3 breast)]. An overview of organizational factors and illustrative quotations are included in Table 4.

3.2.3. Interpersonal factors

Interactions with care team members and employers had the potential to be either protective or hindering, depending on their quality. Positive interactions were characterized by interviewees feeling as though their financial concerns were seen and understood. Additionally, both care team members and employers had the potential to use the power associated with their positions in support of the patient. For example, interviewees described care team members advocating to insurance and pharmaceutical companies ["*my oncologist was pretty savvy – she was able to go to manufacturers and get different chemotherapies for me*" (14: 36–55 years old, Stage 3 ovarian)] and initiating disability applications on their behalf. They also described employers allowing scheduling flexibility around medical appointments. Familial responsibilities, particularly related to providing for children, could also be either protective or hindering, serving as a motivator or source of stress. "*I have to try to keep everything good for my family*" (04: 36–55 years old, Stage 4 colorectal).

Interviewees referenced the benefit of social support in protecting them from the full weight of financial barriers through direct monetary assistance [*"we did not go without because of our family"* (16: 36–55 years old, Grade 4 head and neck)]; knowledge sharing about available resources [*"a lot of my information I got thankfully from my support groups on Facebook"* (10: 19–35 years old, Stage 4 Breast)]; and time, labor, and advocacy [*"my mom helped me start the [disability] application process"* (13: 36–55 years old, Stage 2 breast)]. In contrast to social support, isolation – whether due to perceived stigma, not wanting to place burden on others, or not being able to afford socializing – worsened the experience of financial barriers. An overview of interpersonal factors and illustrative quotations are included in Table 5.

3.2.4. Individual factors

The most notable protective factor at the individual level was the ability to advocate on behalf of one's own financial concerns to care team members, the health system billing office, insurance companies, and government social assistance programs. Underlying this tendency toward self-advocacy was a comfort asking for help (which interviewees described as requiring *"laying down pride"* (08: 36–55 years old, blood) and adjusting to a loss of independence). Additionally, self-advocacy required a baseline resource and health insurance literacy, facilitated for several interviewees by prior work in case management, insurance, or a healthcare system. Familiarity with financial difficulty and navigating social assistance systems in the past also facilitated this baseline knowledge. Furthermore, advocating for oneself required time, with several interviewees describing the process of searching for and applying for resources as akin to a full-time job. "*I cannot imagine how many people have given up because they did not have the time or energy to [navigate resources]*" (18: 56–75 years old, Stage 1 head and neck).

Interviewees described varying cognitive approaches to coping with the experience of financial barriers, ranging from avoidance and resignation ["*I wanted it to all go away*" (02: 36–55 years old, Stage 4 breast)] to being proactive and facing problems head on ["*the brain fog is clearing up and now I can be more active in finding solutions to my problems*" (01: 56–75 years old, Stage 2 lung)]. An underlying belief that resources were available facilitated problem-focused coping, whereas feelings of despair and overwhelm led to avoidance and resignation.

Physical, mental and emotional health challenges were described as limiting one's capacity to overcome financial barriers to care. Physical and mental side effects of the cancer and treatment, most notably fatigue and "brain fog," made the process of finding resources and completing complex applications more difficult. "*You're fighting cancer, you just had pneumonia, do you really want to fight with insurance companies on the phone?*" (15: 36–55 years old, Stage 3 multiple myeloma). Further, financial strain often led to or exacerbated mental health challenges, which in turn limited one's ability to

TABLE 5 Interpersonal factors influencing the experience of financial barriers to healthcare.

Factor	Illustrative quotation
Protective	
Social support: Monetary assistance	"We did not go without because of our family." (16: 36–55 years old, Grade 4 head and neck)
Social support: Knowledge sharing	"A lot of my information I got thankfully from my support groups on Facebook." (10: 19–35 years old, Stage 4 breast)
Social support: Time, labor, and advocacy	"I've had a lot of advocates fight for me, my husband, my mother, my mother-in-law." (03: 19–35 years old, Stage 4 breast)
Modifying	
Care team interactions	"I have gone through a couple navigators. The one that really helped me…the key thing that made her so great…was that she was a social worker.… And then she left and I'm left with a new navigator, and she does not know anything.… I feel really lost without my old navigator right now." (02: 36–55 years old, Stage 4 breast)
Employer interactions	"I had been there so long, and was such a good employee, that [supervisor] worked with me. I was able to do my chemo on a Friday, so I had all weekend to recover and then I was back Monday. And if my duties needed to be light, he would work with me." (17: 36–55 years old, Stage 4 breast)
Familial responsibilities	"And I'm a single mom. I have a daughter, and so I need to make sure that she's fed and taken care of." (09: 36–55 years old, Stage 3 Breast)
Hindering	
Isolation: Stigma/judgment	"And the one thing I'm concerned about is like the stigma of lung cancer.… I cannot tell my family because they have been telling me that I need to stop smoking for years." (01: 56–75 years old, Stage 2 lung)
Isolation: Feeling like a burden	"And you know, I just try to make sure that I do not have to inconvenience someone to the extent where financially they gotta be a, you know, it's gonna be a burden on them as well." (19: 56–75 years old, Stage 1 breast)
Isolation: Cost of socializing	"Everybody's like, let us just go out to lunch. And I'm like, if I could afford to go out to lunch, I would be there, but I just, I cannot… I was going to the ovarian cancer support group. The only person in the financial boat that I'm in is me. Everybody else has a lot of money. So I actually quit that group because I just, I wasn't feeling comfortable." (14: 36–55 years old, Stage 3 ovarian)

overcome financial barriers. In addition to material financial burden, emotional health challenges stemmed from feeling discouraged and alone in the process of applying for resources, the psychological effect of seeing the cost of treatment needed to survive, reliance on an unreliable system, and concerns about the future (e.g., passing debt onto family members, the potential of treatment not being covered). An overview of factors operating at the individual level are included in Table 6, along with illustrative quotations.

3.3. Systemic frustration

The hindering policy and organizational factors described above, paired with the precarity of existing protections, led many interviewees to express frustration toward governmental policies, insurance companies, and health systems. One interviewee described the complexity of the healthcare system as being *"designed to where you'll give up"* and *"a comedy of errors designed not to pay"* (18: 56–75 years old, Stage 1 head and neck), perceiving an intentionality motivating the financial barriers they experienced. This frustration toward the systems and policies influencing cancer care costs had the potential to affect individual resiliency and outlook. For some interviewees, systemic frustration led to individual despair; in contrast, other interviewees reflected substantial frustration at the systemic level but maintained an individual determination fueled by motivation to survive and be around for family members. The extent to which interviewees felt that their financial challenges were seen and valued – whether by care team members, non-profit organizations, or friends and family – influenced the extent to which systemic frustration led to despair at an individual level. Additionally, having success finding resources, even if they were limited in nature, reinforced interviewees' determination and belief that they could overcome the financial barriers experienced. *"All I needed was just a little bit of help to buy me time to get my stuff together because I'm a fighter, I'm gonna figure it out"* (17: 36–55 years old, Stage 4 breast).

3.4. Financial coping and prioritization of spending

In the face of resource constraints, interviewees described a somewhat constant process of having to prioritize how to allocate money, whether between medical care and household necessities [*"I had to choose between putting gas in the car or getting the medications"* (08: 36–55 years old, blood)], different types of medical care (e.g., primary treatment versus supportive therapies or medications), or spending for oneself or one's children [*"I would sacrifice anything of mine before my kids would want for something"* (05: 56–75 years old, Stage 3 multiple myeloma)]. Though this process happened at the individual level, it resulted from the cumulative impact of multi-level factors and was shaped by interviewees' resiliency and outlook.

Interviewees, particularly those who had not experienced financial difficulty in the past, described the impact of this prioritization process on their mental health. *"Sometimes I get very anxious because of not knowing which [necessity] you are gonna take care of…"* (06: 56–75 years old, blood). Others pointed out that forgoing household necessities, such as spending less on groceries or not paying for needed car repairs, instead of medical care also had an impact on their health and ability to get to their appointments. *"If I do not pay my car note…I need that to get to and fro because at one time my car was about to break down and I'm thinking, how am I gonna even get to treatment?"* (19: 56–75 years old, Stage 1 breast).

TABLE 6 Individual factors influencing the experience of financial barriers to healthcare.

Factor	Illustrative quotation
Protective	
Self-advocacy	"Nobody else is gonna help you unless you do it yourself, so you contact as many people as you can. You exhaust every avenue and you research every possibility." (18: 56–75 years old, Stage 1 head and neck)
Experience navigating health/social systems	"My background is in insurance…so I know the system somewhat and I can kind of talk the language at times. And I'm not afraid to do that." (20: 56–75 years old, blood)
Resources (money, time)	"I did nothing but, every single day and night, I did nothing but research on the computer" (18: 56–75 years old, Stage 1 head and neck)
Modifying	
Cognitive coping mechanisms: Problem-focused	"When I get depressed or sad, I say, [name], take an hour and be depressed. Just take a whole hour. Who a is me, cry. Whatever you need to do, holler, scream. After that hour, go into action." (20: 56–75 years old, blood)
Cognitive coping mechanisms: Avoidance, resignation	"Just the weight of it all made me want to sleep. Just sleep. I wanted it to all go away." (02: 36–55 years old, Stage 4 breast)
Familiarity with financial difficulty	"So I had to learn to play with my money in ways that I never before had to." (17: 36–55 years old, Stage 4 breast)
Hindering	
Impact of financial strain on mental health	"Mental health and financial health, they go together. You gotta have the funds in order to relax, not to be stressed. All the stress over the years… And I'm sure that not only with my disease but with other diseases, it leads to other diseases when you are financially stressed." (20: 56–75 years old, blood)
Treatment side effects	"At that point, from the brain fog, I wasn't in a position to really think clearly or to navigate the system all by myself." (01: 56–75 years old, Stage 2 lung)

3.5. Emotional, physical, and financial health decline

Though the primary focus of our interviews was to understand patient experiences leading up to, or preventing, cost-related delayed and forgone medical care, it was clear that the process of coping with financial barriers to care, whether resulting in changes to healthcare utilization or not, had deleterious impacts on interviewees' financial health (e.g., depleted savings, consolidation of debt, giving up on buying a house), as well as their physical and emotional health. Even among interviewees who prioritized medical care above all else, cutting back on grocery spending or relying on food banks had the potential to lead to a less nutritious diet, inability to afford a gym membership limited opportunities to exercise, and the emotional stress of seeking resources and the prioritization process described above resulted in physical consequences. For example, one participant reported a new hypertension diagnosis, stating, *"I was diagnosed with high blood pressure…all the stress over the years…it leads to other diseases when you are financially stressed"* (20: 56–75 years old, blood).

3.6. Social positions and structural inequities

Social positions – related to an individual's socioeconomic status, age, race, ethnicity, and sexual and gender identity (among other factors) – influenced interviewees' experiences of each of the multi-level factors described above. Interviewees' positions, including intersecting positions along multiple dimensions of identity, had the potential to be associated with marginalization, advantage, and opportunities for strength and resilience (Fredriksen-Goldsen et al., 2014). Additionally, and related to social positionality, structural inequities – such as racism, discrimination, and social exclusion – create an inequitable distribution of power and resources, which shaped interviewees' experiences with financial challenges and the ability to overcome them (Alcaraz et al., 2020). Examples described by interviewees included shame associated with using social services [*"I never thought I would come to a day where I would have to apply for the food stamp program…to me that's somewhat embarrassing"* (20: 56–75 years old, blood)]; health system prioritization of patients with higher paying insurance [*"I was concerned, because of the fact that I did not have insurance, that I would not receive the proper care"* (08: 36–55 years old, blood)]; and discrimination from healthcare providers [*"I'm overweight, and I felt a little prejudiced… she [surgeon] made me feel like I did not deserve to get the procedure"* (02: 36–55 years old, Stage 4 breast)]. Social positions and structural inequities are included as underlying each of the other model components, as they influence each, with the potential to influence the extent to which financial barriers translate to deleterious physical, mental, and emotional health outcomes.

4. Discussion

Our findings describe the experiences of adults with a history of cancer coping with financial barriers to medical care, including their perspectives on the multi-level protective, hindering, and modifying factors influencing those experiences. Additionally, they demonstrate how the process of facing financial barriers to care influences patient physical and emotional health, both through cost-related delayed and forgone care, as well as independent of it. The adapted conceptual framework presented in Figure 1 is intended to inform multi-level intervention to lessen the financial barriers experienced and support patients in navigating health and social care systems to overcome them.

4.1. Qualitative findings

A key finding from our analysis was the influence of attempting to overcome financial barriers on individual emotional well-being. In particular, we describe the systemic frustration resulting from bureaucratic complexity of health and social care systems and resulting administrative burden. A qualitative study conducted among cancer survivors in Germany also identified the substantial influence of navigating a bureaucratic system, having insufficient resources and needing to ask for help on patient distress (Lueckmann et al., 2022). Frustration toward insurance companies dictating care decisions has also been documented among adults with cancer (Thomson and Siminoff, 2015), as well as the "logistic toxicity" of constantly searching for the lowest cost pharmacies for supportive medications (Etteldorf et al., 2022). Furthermore, several studies have highlighted the role of health insurance literacy – defined as the ability to obtain, understand and use health plan information (Paez et al., 2014) – in influencing overall patient financial hardship (Zhao et al., 2019; Khera et al., 2022) and delayed care in the absence of clear cost expectations (Waters et al., 2022).

In addition to the negative impact of coping with financial barriers to care on mental and emotional well-being, we found that the consequences of financial barriers – whether forgone care or other lifestyle changes – also had the potential to negatively impact mental and emotional well-being. This is in line with qualitative work conducted among cancer survivors in rural Australia, which described the potential negative impact of cost-saving strategies on individual enjoyment, access to social support, and well-being (Skrabal Ross et al., 2021). In turn, our findings also illustrate the role of mental health and emotional well-being in either supporting or hindering individuals in attempting to overcome financial barriers experienced, creating a feedback loop. This relationship is supported by an analysis of cancer survivors surveyed in the Cancer Survivorship Supplement of the Medical Expenditure Panel Survey, which found that patient-reported financial worry attenuated the association between financial difficulty and positive coping behaviors, suggesting that participants with high financial worry were less likely to use positive coping strategies to mitigate financial difficulties (Jones et al., 2018).

4.2. Adapted conceptual framework

Though our study was influenced by a conceptual framework of financial barriers to healthcare developed among adults with chronic cardiovascular conditions, our adapted framework diverges in several key ways based on our qualitative findings. First, we delineate multi-level influences in line with a socio-ecological framework. This allows us to frame individual outlook and resiliency – important components of both models – as being influenced by systemic factors rather than operating solely at the level of the individual. We also introduce the concept of prioritization, which involves determining how to allocate limited resources between different types of medical care and medical versus non-medical needs (e.g., mortgage, car payments). As a result, our model also includes non-clinical consequences of facing financial barriers to care. This is in line with prior work documenting high willingness to sacrifice both personally and financially for cancer care, especially among patients with metastatic disease (Chino et al., 2018).

In contrast to the model developed by Campbell and colleagues, which included mental illness and physical limitations as "predisposing" factors, we found that mental health challenges and physical limitations described by interviewees in our study were largely consequences of the cancer diagnosis, treatment, and associated financial hardship. As such we renamed these as hindering factors to include both factors caused by a cancer diagnosis and associated costs, as well as underlying mental and physical comorbidities that may exacerbate financial hardship experienced. This is in line with the broader psycho-oncology literature, which has documented both the consequences of cancer-related financial hardship on mental health (Inguva et al., 2022; Pangestu and Rencz, 2023), as well as the influence of underlying mental health comorbidities on cancer care access and outcomes (Baillargeon et al., 2011; Giese-Davis et al., 2011; Rieke et al., 2017). We also found that familiarity with financial difficulties, categorized as protective by Campbell and colleagues, could be either protective or hindering, depending on whether the interviewee was experiencing financial difficulty at the time of diagnosis.

Our interpretation of findings was also informed by existing conceptual frameworks of financial burden developed in the cancer context, with a particular focus on Jones and colleagues' theoretical model of financial burden after cancer diagnosis (Jones et al., 2020). As conceptualized by this model, our analysis studied the pathway between causes of financial burden and healthcare-specific financial coping behaviors (i.e., cost-related care interference). Based on patient experiences facing financial barriers to care analyzed in our study, we broadened the conceptualization of cost-related care interference to include prioritization, in addition to coping. This highlights the interrelated nature of approaches to reduce medical and non-medical costs and the inherent tradeoffs patients must face.

4.3. Implications

Our findings and the adapted conceptual framework present opportunities for intervention to both reduce the costs incurred, and thus financial barriers faced, as well as to support patients in navigating financial barriers experienced. The further upstream, or more systemic, the intervention, the more likely it will be to reduce current barriers preventing equitable access to cancer care. Examples of policy and regulatory changes that could substantially reduce the financial barriers to care experienced by adults with cancer in the United States include Medicaid expansion in states that have not yet, policies promoting containment of medical and pharmaceutical costs [e.g., Inflation Reduction Act (Shih et al., 2023)], and enforcement of community benefit obligations of not-for-profit hospitals (Patient Protection and Affordable Care Act, 2010; Doherty et al., 2022). Additionally, upholding and building upon patient protections passed with the 2010 Affordable Care Act is critical, particularly for cancer survivors, 190,000 of whom lost health insurance due to the erosion of such protections following the 2016 United States elections (Moss et al., 2020). Though we focus on United States policy implications, as our study was conducted among patients navigating the United States healthcare system, it is important to note that financial barriers to healthcare, particularly those related to the non-medical costs associated with a cancer diagnosis and associated care, are experienced by adults with cancer across the world, even in countries with universal healthcare coverage (Barbaret et al., 2017; Garaszczuk et al., 2022). Policies related to employment protections and social income support may be particularly important to reducing financial hardship experienced in these contexts (Sayani et al., 2021).

At the organizational level, health systems must make hospital-based financial assistance more accessible and eligibility criteria more transparent to promote equitable access to available resources. A recent qualitative brief described patient barriers to accessing financial assistance, including "lack of awareness, perceptions of ineligibility, fear of negative consequences, and being overwhelmed" (Doherty et al., 2022). Interviewees in our analysis described similar sentiments. Additionally, implementation of robust oncology financial navigation programs, proactively offered to all patients receiving cancer care, has the potential to systematically lift administrative burden and advocacy responsibilities off of patients and caregivers. Preliminary evidence has shown that financial navigation reduces patient financial hardship, (Wheeler et al., 2020; Doherty et al., 2021) improves patient satisfaction (Doherty et al., 2021), and may also improve health system revenue (Yezefski et al., 2018).

4.4. Strengths and limitations

This study must be viewed in the context of several strengths and limitations. First, we employed a template analysis within a pragmatic paradigm, involving several stages of analysis. Given that template analysis is a flexible approach that does not have an inherent philosophical position, it is possible that it could lead to superficial findings if used by inexperienced qualitative researchers with little knowledge of cancer-related financial hardship. However, our multi-disciplinary team included several experienced qualitative researchers and substantial expertise in various aspects of financial hardship. In turn, the flexibility of template analysis allowed us to employ a variety of qualitative paradigms to both align findings with participant lived experiences while also situating them in the context of existing literature. Another limitation of the methodology employed is that we did not engage in member checking or reflections (i.e., providing qualitative findings back to participants for feedback and corrections; Tracy, 2010) which limits our certainty in the interpretation of participant experiences. However the rigor and reliability of the multi-stage qualitative analysis, involving discussing findings and interpretation with patient advocates, lends credibility to our findings. Finally, our presentation of qualitative findings and an adapted conceptual framework together allows for readers to gain a better understanding of how the framework was conceptualized and examples of constructs via participants quotations.

Interviewees identified through PAF may not be representative of cancer survivors as a whole, given that they had already accessed at least one external resource, whether on their own or through a care team member. Furthermore, individuals willing and able to participate in an interview about their experiences may be mentally and physically healthier than the broader population of adults with a history of cancer. As a result, our findings may not reflect the full extent of the relationship between cancer-related financial hardship, financial barriers to healthcare, and mental illness. Future research should focus on this association specifically, particularly in light of concerning data showing an association between financial strain and suicide attempts (Elbogen et al., 2020).

Additionally, reaching participants by email may also bias the sample toward those that are technologically literate. However, given that the purpose of our study was to understand the experience of facing, and in some cases overcoming, financial barriers to care, this sample was well-suited to our research question. It is possible that recall bias influenced interviewee responses, given that the median time since diagnosis was 4.5 years, but a substantial portion of the interviews focused on interviewee's current experiences and those in the prior year, as the screener questions assessing financial hardship were based on the prior year. Lastly, our study focused on the patient perspective, but this is not meant to ignore the role of caregivers in navigating financial barriers to care with, or on behalf of, patients. Future research should apply and adapt this conceptual framework in the caregiver context, particularly given recent findings documenting spillover cost-related delayed and forgone care among family members of patients with cancer (Kazzi et al., 2022).

5. Conclusion

Despite individual motivation, knowledge, and support to access resources, interviewees facing financial barriers were limited by a constrained resource context characterized by impermanence, delays, administrative hurdles, and strict eligibility criteria. This study adapts the only existing conceptual framework of financial barriers to care to adult cancer survivors. Though our conceptual framework is not meant to be exhaustive or final, it presents an important opportunity for future research building on our understanding and conceptualization of patient experiences as they cope with cancer care costs and attempt to overcome financial barriers to needed medical care. It also serves as a useful framework for mapping multi-level interventions designed to reduce patient financial hardship and, ultimately, deleterious, inequitable health outcomes. Specifically, the framework points to the importance of upstream (policy and organizational) interventions, such as cost containment policies and systematic financial navigation programs, to reduce the administrative and financial burden experienced by patients and their caregivers.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by University of North Carolina at Chapel Hill Institutional Review Board (UNC-CH IRB#22-0467). Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

CB, RA, KG, EK, LS, DR, AP, and SW contributed to the conception and design of the study. CB, RA, and KG collected the data. CB and AW conducted the qualitative analysis. CB wrote the first draft of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

SW and DR have received research grants from Pfizer paid to their institution for unrelated work. LS and SW have received salary support from AstraZeneca paid to their institution for unrelated work.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1178517/full#supplementary-material

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Guaranteed Income and Financial Treatment (G.I.F.T.): a 12-month, randomized controlled trial to compare the effectiveness of monthly unconditional cash transfers to treatment as usual in reducing financial toxicity in people with cancer who have low incomes

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Cancer-related financial hardship (i.e., financial toxicity) has been associated with anxiety and depression, greater pain and symptom burden, treatment nonadherence, and mortality. Out-of-pocket healthcare costs and lost income are primary drivers of financial toxicity, however, income loss is a pronounced risk factor for cancer patients with low incomes. There has been little progress in developing an income intervention to alleviate financial toxicity cancer patients with low incomes. Unconditional cash transfers (UCT), or guaranteed income, have produced positive health effects in experiments with general low-income populations, but have not yet been evaluated in people with cancer. The Guaranteed Income and Financial Treatment (GIFT) Trial will use a two-arm randomized controlled trial to compare the efficacy of a 12-month UCT intervention providing $1000/month to treatment as usual on financial toxicity, health-related quality of life and treatment adherence in people with cancer who have low-incomes. The study will recruit 250 Medicaid beneficiaries with advanced cancer from two comprehensive cancer centers in Philadelphia, obtain informed consent, and randomize patients to one of two conditions: (1) $1,000/month UCT or (2) treatment as usual. Both arms will receive information on financial toxicity and the contact information for their hospital social worker or financial advocate upon enrollment. Participants will complete online surveys at baseline, 3, 6, 9, and 12 months from enrollment to collect patient-reported data on primary (i.e., financial toxicity, health-related quality of life, and treatment adherence) and secondary outcomes (i.e., anxiety, depression, food insecurity, housing stability). Social security records will be used to explore the effect on mortality at 2, 3, and 5 years post-enrollment. Linear mixed-models will be used to analyze all primary and secondary continuous outcomes over time and general estimating equations with a logit link and binary distribution for all binary outcomes over time.

Differences between treatment and control groups and treatment effects will be determined using models that control for age, gender, race, baseline food security, baseline housing stability, and baseline ECOG. Findings from this study will have significant implications for the development and implementation of programs and policies that address the financial burden of cancer and other serious illnesses.

KEYWORDS

cancer, oncology, financial toxicity, income, unconditional cash transfers, randomized controlled trial, social determinants of health

Introduction

Background and rationale

At least one-in-three cancer patients experience cancer-related financial hardship during the course of their treatment (Yabroff et al., 2018). Cancer-related financial hardship has been associated with anxiety and depression, greater pain and symptom burden, and treatment nonadherence (Zullig et al., 2013; Delgado-Guay et al., 2015; Arastu et al., 2018). Cancer patients are at a high risk for bankruptcy, an event that has been linked to a threefold increase in the likelihood of early mortality (Ramsey et al., 2013, 2016). The adverse health effects associated with cancer-related financial hardship are called *financial* toxicity. Financial toxicity has been identified across the socioeconomic spectrum of cancer patients, but women, people of color, and low-income families experience financial hardship more often and with greater severity (Altice et al., 2016; Tucker-Seeley and Yabroff, 2016). High out-of-pocket healthcare costs and lost income are the primary drivers of financial hardship in the general cancer-affected population (Yabroff et al., 2018). However, income loss is a pronounced risk factor for low-wage workers who tend to work in sectors that lack adequate employment and income protection programs during periods of disability (Blinder et al., 2017; Blinder and Gany, 2020). As a result, cancer patients with low incomes are at greater risk of food and housing insecurity (Gany et al., 2021). Conditions of material deprivation, one domain of the social determinants of health, are robustly associated with a host of adverse health outcomes and are a critical driver of cancer health disparities (Coughlin, 2021).

The impact of financial toxicity has been well documented, however there has been little progress in developing an intervention robust enough to alleviate financial toxicity patients with cancer (Doherty et al., 2021; Offodile et al., 2022). Studies suggest that, by improving access to copayment assistance programs and optimizing insurance, financial navigation can reduce out-of-pocket costs, but treatment effects are small to moderate and programs are underutilized due to patient- and system-level factors (Shankaran et al., 2018; Yezefski et al., 2018; Monak et al., 2019; Watabayashi et al., 2020; Wheeler et al., 2020; de Moor et al., 2021; McLouth et al., 2021; Biddell et al., 2022; Smith et al., 2022). In addition to individual-level support interventions like financial navigation, experts suggest that structural, policy-level solutions are needed to mitigate the economic burden of illness in the U.S (Yabroff et al., 2020). Unconditional cash transfers (UCT), sometimes described as *guaranteed income,* have produced positive health effects in experiments with general low-income populations, but have not yet been evaluated in people with cancer who have low incomes (Gibson et al., 2018). The Guaranteed Income and Financial Treatment (GIFT) Trial will use a two-arm randomized controlled trial design to compare the effectiveness of a monthly $1,000 UCT to treatment as usual on financial toxicity, health-related quality of life and treatment adherence in people with cancer who have low incomes.

The study was funded by the One Family Foundation and the Independence Blue Cross Foundation as the Institute for Health Equity's inaugural project. Our UCT intervention stands out for its unique feature of including a waiver that allows Supplemental Security Income (SSI) recipients to receive cash assistance without jeopardizing their existing benefits. We collaborated with the Social Security Administration (SSA) to develop this waiver through SSA's Interventional Cooperative Agreement Program (ICAP) which provides support to competitive projects conducting interventional research on disability insurance (Social Security Administration, 2023). This waiver is necessary because cash payments count as income under the SSA rules, which can affect a recipient's eligibility for SSI benefits. The SSA defines income as anything a person receives during a calendar month that can be used to fulfill their needs, whether in cash or in-kind, such as food or shelter (Social Security Administration, 2023). This waiver is a crucial component of our program as it enables SSI recipients to participate in the program without fear of losing their existing benefits. Without the waiver, our program would not be accessible to the individuals it aims to support, and its impact would be significantly limited. SSA will notify local Social Security offices that the individual is participating in an ICAP study that allows them to receive an additional $1,000 per month for 12 months.

Choice of comparator

In spite of growing awareness of the health effects of financial toxicity, clinical practice is widely dependent on a passive intervention model that requires patients to self-report financial and social needs (McLouth et al., 2021). Social workers and financial advocates who can help patients access copayment assistance, community grant programs, and public benefits are the standard of care. Participants in both arms of the study will receive information on financial toxicity and the contact information for their hospital social work and financial advocacy departments.

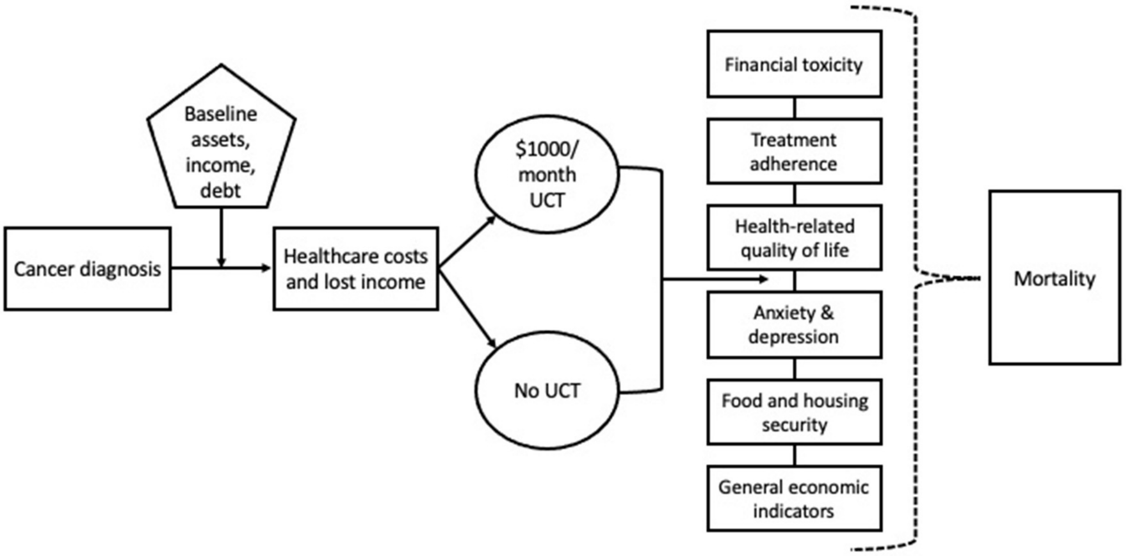

FIGURE 1
GIFT Trial causal model depicts the causal model underlying the GIFT Trial in which UCT impacts financial toxicity, health-related quality of life, treatment adherence, anxiety, depression, food, and housing instability and mortality.

Research hypothesis

A monthly UCT of $1,000 for 12 months is more effective than treatment as usual in the prevention of financial toxicity, diminished quality of life, and treatment nonadherence in people with cancer who have low incomes. See Figure 1 for the GIFT Trial causal model.

Study objectives

Primary objective

To determine if a monthly UCT of $1,000 for 12 months is more effective than treatment as usual on financial toxicity, health-related quality of life, and treatment nonadherence in people with advanced cancer (as determined by cancer stage and ECOG status) who have low income (as determined by Medicaid status).

Secondary objectives

To determine if monthly UCT is more effective than treatment as usual in reducing anxiety, depression, and poverty exposures (i.e., food and housing insecurity).

Exploratory objective

To compare the monthly UCT to treatment as usual with regard to mortality in people with cancer who have low incomes.

Trial design

The GIFT Trial is designed as a randomized, controlled, unblinded, multicenter superiority trial with two parallel groups and a combined primary endpoint of financial toxicity, quality of life, and treatment adherence. Randomization will be performed as block randomization with a 1:1.5 allocation stratified by age and treatment center.

Methods

Study setting

We selected two large, minority-serving, urban cancer centers to conduct the trial. Abramson Cancer Center at Penn Medicine and Sidney Kimmel Cancer Center at Jefferson Health.

Eligibility criteria

Patients must provide signed (paper or electronic) informed consent before any study procedures occur. In order to verify patients' low-income status, we use Pennsylvania Medicaid beneficiary status as a proxy variable for eligibility. To be eligible for Pennsylvania Medicaid (i.e., Medical Assistance) individuals must earn <133% of the federal poverty line (FPL) or 250% FPL if considered a "disabled worker" (i.e., less than $39,900 or $75,000/year for a family of four respectively) (Pennsylvania Department of Human Services, 2023; US Centers for Medicare Medicaid Services, 2023). All participants will have household incomes under 250% FPL.

Inclusion criteria

Patients eligible for the trial must comply with all the following at randomization:

1. Age $\geq$ 18
2. Newly diagnosed or recurrent advanced cancer (Stage 3–4)
3. Receiving chemotherapy or immunotherapy (with or without radiation) at one of the recruitment sites
4. Within 12 months of receiving systemic therapy and on surveillance at one of the recruitment sites

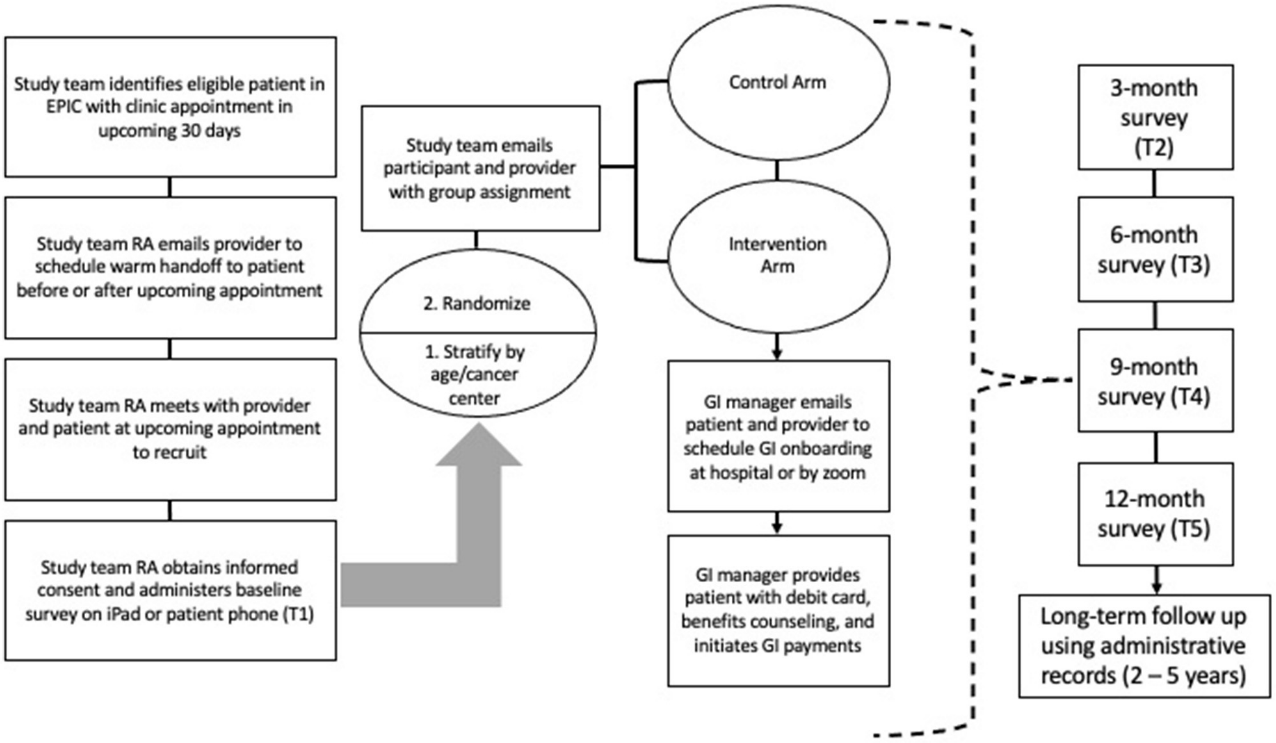

FIGURE 2
Participant flow diagram provides an overview of the study flow from recruitment through data collection. RA, Research assistant; GI, Guaranteed income.

5. ECOG performance status of 1–2
6. A Pennsylvania Medicaid beneficiary
7. A Pennsylvania resident

Exclusion criteria

1. Eligible for hospice (i.e., determined by provider to have a prognosis of 6 months or less) at time of randomization
2. Unable to communicate in English, Spanish, or Mandarin

Description of study conditions

Intervention arm

The intervention in this trial is a philanthropically funded UCT of $1,000 per month for 12 months. Upon randomization to the intervention arm, people in the intervention arm will be contacted by the guaranteed income (GI) manager who will schedule to meet the participant either in-person at an upcoming cancer center appointment or by Zoom videoconferencing software. At the meeting, the GI manager will explain the UCT intervention in detail, explain how participation may impact public benefits, how specific public benefits will be protected during participation in the trial (i.e., Medicaid, SSI, SSDI, SNAP), and answer questions about public benefit concerns. The GI manager will then provide the participant with a USIO Inc (2023) debit card, in-person or by mail, with instructions on how to use it and the dates that they can expect to receive payment. Each month the debit card will be refilled with $1,000 and participant will receive a confirmation text message or email. Participants will be asked to provide the name and contact information of a household member or caregiver who will serve as a beneficiary for their remaining monthly UCT in the event that they enter a nursing home facility or pass away before the end of 12 months.

Control arm

Participants randomized to the control arm will receive an email informing them of their assignment to the control arm. We reviewed the treatment as usual practices we believe to be related to the outcomes of interest in this trial and found that all sites have at least one social worker or financial advocate that is able to help patients access routinely available financial assistance programs in the hospital and wider community, including American Cancer Society support for transportation to and from appointments and temporary lodging as needed for treatment. Participants in the treatment and control arms will be provided with information on financial toxicity and contact information for their social worker or financial advocate. They can make use of any and all financial, material, and psychosocial support programs they encounter in the course of the trial. Participants are free to engage in other clinical trials during the course of this trial.

Modifications

Participants in the intervention arm may discontinue UCT payments at any time. Although we have taken every step to protect public benefits eligibility during the course of the trial there may be some interactions that we are not yet aware of, and each participant can work with the GI manager to weigh the costs and benefits of participation relative to currently unforeseen public benefits interactions. If a participant in the intervention arm dies during the 12-month intervention period, their debit card will be transferred to their designated beneficiary which is required to be next of kin or a caregiver. Having a caregiver or next of kin, however, is not required to participate in the study. In that case payments will not be redirected. If participants change cancer clinics or receive additional cancer care from another clinic, they will be able to remain in the trial. See Figure 2 for the GIFT Trial participant flow diagram.

Outcomes

Primary outcome measures

The primary outcomes of interest are financial toxicity, quality of life, and treatment adherence. Primary outcomes will be measured at baseline, 3, 6, 9, and 12 months.

Financial toxicity

Financial toxicity will be measured using the Comprehensive Score for Financial Toxicity (COST), a validated, 11-item patient-reported outcome measure of cancer-related financial hardship that captures three domains of financial hardship (also described as *financial toxicity*): resources, affect, and financial. Scores range from 0 to 44 and lower scores indicate greater financial hardship. COST scores have been associated with quality of life, anxiety and depression (de Souza et al., 2014, 2017).

Health-related quality of life

Quality of life will be measured using the Rand 36–Item Short Form Health Survey (SF-36) (RAND Corp, 2022). The SF-36 is scored to produce eight subscales: physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional wellbeing, social functioning, pain, and general health. Each subscale has a score ranging from 0 to 100, produced by coding and averaging the survey responses.

Treatment adherence

Treatment adherence questions were developed by Gany et al. Costas-Muniz et al. (2016) to identify barriers to cancer treatment among low-income and immigrant cancer patients. The first question asks if the respondent has missed any of the following appointments in the last three months: chemotherapy/infusion, radiation, general oncology, follow-up, or any other cancer-related appointment. If the respondents indicates yes, they are asked to identify a reason for missing each of the identified appointments: did not have childcare, could not afford transportation to appointment, could not afford copayment, could not afford insurance deductible, was not covered by insurance, prior approval was not obtained, I forgot about my appointment, I was scared/anxious, or other, please describe: (free text). The second question asks if the respondent has missed a dose of cancer-related medication in the last three months and if so, select a reason why: forgot to take it, forgot to buy/pick it up, not covered by insurance, no insurance, could not afford copayment, no time to buy/pick up, do not think they will work/help, do not like the side effects, could not afford transportation to the pharmacy, other, please describe (free text). The outcome variable is binary (yes/no to having missed any appointment or medication dose in the past 12 months).

Secondary outcome measures

The secondary outcomes of interest are anxiety and depression, food insecurity, housing stability, and general economic indicators. Secondary outcomes will be measured at baseline, 3, 6, 9, and 12 months.

Anxiety and depression

Anxiety and depression will be measured with the Hospital Anxiety and Depression Scale (HADS), a 14-item scale that is considered the gold standard for measuring anxiety and depression in cancer patients. Scores range from 0 to 21 on each subscale (anxiety and depression) and higher scores indicate greater likelihood of anxiety or depression (Zigmond and Snaith, 1983; Vodermaier and Millman, 2011; The Hospital Anxiety Depression Scale, 2021).

Food insecurity

To measure food insecurity we will use the USDA 6-item Short Form Food Security Survey (United States Department of Agriculture, 2021).

Housing stability

We derived a 7-Item tool from the American Housing Survey to assess housing instability (Bureau, 2023).

Economic and employment variables

We will collect data on weekly hours of employment, interruptions in employment and work reductions, income sources, employment protections, essential expenses (housing, transportation, utilities, food), general impact of cancer on finances, estimated amount of personal savings and estimated amount of total credit card debt.

Exploratory outcome

Mortality is long-term exploratory outcome that will be measured at 2, 3, and 5 years from baseline.

Mortality

The intervention’s potential impact on mortality will be explored using the Social Security records of all participants in the study. Mortality data from the Social Security records will be reviewed at 2, 3, and 5 years post-enrollment. The proportion of deceased participants from the intervention and control groups will be determined and compared. See Table 1 for GIFT Trial outcomes, data sources and measurement timepoints.

TABLE 1 GIFT Trial measures.

Outcome (measure)	Data source	Baseline (T1)	3m (T2)	6m (T3)	9m (T4)	12m (T5)	2–5 years
Demographic	Survey	X					
Employment, income, savings, debts, public benefits utilization		X	X	X	X	X	
Cancer type/stage		X					
Treatment nonadherence		X	X	X	X	X	
Financial toxicity (COST)		X	X	X	X	X	
Quality of life (FACT-G)		X	X	X	X	X	
Anxiety and Depression (HADS)		X	X	X	X	X	
Food insecurity (USDA)		X	X	X	X	X	
Housing instability (AHS)		X	X	X	X	X	
Mortality	Social security records						X

Sample size

The sample size was determined by the amount of philanthropic funding we secured for the Trial which was sufficient to provide $12,000/year to 100 participants. After accounting for anticipated attrition we determined that a 250 person sample was needed – 100 in the intervention group and 150 in the control group (overrecruited for differential attrition). We conducted power analyses based on the literature and pilot study findings to determine detectable treatment effects in the primary outcomes of interest. Power analyses methods and results for each primary outcome are described below. Recruitments sites were selected for serving racially diverse, low-income patient populations. Our pilot study sample was 50% Black, 35% white, 4% Asian, 4% mixed, and 7% other. 52% of the sample identified as Hispanic or Latino.

Recruitment

Each week the study team will use the electronic health record to view upcoming clinic appointments (in the next 2–3 weeks) and determine the study eligibility of the patients with upcoming appointments. A research assistant (RA) will contact each eligible patient's physician/nurse practitioner/physician assistant to let them know that the patient has been selected for recruitment to the study and the RA would like to meet with them prior to or after the upcoming appointment. The RA will also contact scheduling department to let them know that the patient is eligible for the study and will be approached at the upcoming appointment—both the receptionist and provider will be asked to tell the patient about the study and prepare them to be approached by the RA. The RAs will keep a participant tracking sheet and will record each step of approach and engagement. On the day of the appointment, the RA will approach the patient and use a designated quiet space to complete the informed consent (on paper) and Qualtrics baseline survey (on their phone, the RA's tablet, or with the assistance of the RA reading questions to them). The RA will provide the participant with information on financial toxicity and the contact information for their social worker or financial advocate at this time.

Allocation

Each week participants with completed baseline surveys in Qualtrics will be randomly assigned to one of the study conditions using a computer generated 1:1.5 randomization schedule stratified by age and recruitment site. We will over recruit for the control arm to compensate for an expected 30% differential attrition rate (an estimate derived from yet unpublished U.S. guaranteed income RCTs). Randomization schedule will be stored in a password protected excel spreadsheet that can only be accessed by the principal investigator and senior research coordinator who are not involved in the day-to-day recruitment of participants.

Data collection methods

All primary and secondary outcomes are patient-reported and will be collected using an online survey administered at baseline, 3, 6, 9, and 12 months post-enrollment. At baseline, the participants will also answer questions about their age, gender, race, education, cancer type, cancer stage, new or recurrent cancer diagnosis, household income, public benefits utilization, employment status and hours worked per week. At each data collection time point, participants will receive an email or text message with a survey link and directions for completing it. A RA will also call the participant to ask if they would like to complete the survey with them over the phone. Greenphire Clincards will be mailed to the participant's address at the 3-month data collection point and filled with $30 for each survey they complete. For the exploratory outcome of mortality, we have partnered with Social Security Administration who will provide aggregate data on participant mortality, earnings, and disability benefits at 2, 3, and 5 years from study enrollment.

Retention

A $30 incentive will be provided for each survey completed. Starting at each data collection time point, the study team will continue to contact the participant by email, text, and phone twice per week for 6 weeks until the survey is completed. We will call next of kin/caregiver if the survey is not completed within three weeks. If the survey is not completed within eight weeks of the data collection time point, the survey items will be treated as missing data. If response rate drops to 75% in any arm, the incentive will be increased to $50 per survey for participants in that arm of the trial.

Data management

Completed consent forms will be stored in a private institutional server maintained by the PIs University. Survey data will be entered and stored in Qualtrics, an online data collection and storage platform. The Qualtrics platform provides a high level of data safety and security that is HIPAA compliant for the collection and storage of personally identifiable information (Qualtrics, 2023). During periods of data analysis, data will be exported from Qualtrics to Stata SE17 as a .data file. The data will be stored in and accessed using Box, a secure cloud based platform that conforms to global compliance requirements for data privacy (Box, 2023). To protect confidentiality, we will only collect information from the participants that is essential to the study's aim of understanding the impact of UCTs on cancer patients' health and treatment outcomes. Participant's names, dates of birth, and treatment status will be collected from the electronic medical record for the purposes of outreach prior to the study. The research team will keep this information in a single, password protected excel spreadsheet stored on and accessible through a secure online document sharing platform. This information will be used to contact potential participants over the phone or at their next clinic appointment. We will maintain the contact information of all potential participants even if they decline to participate or are found ineligible in order to conduct feasibility analyses. Participants who enroll will provide identifiable personal information that will be linked to the survey data until data collection and analysis are complete. When the study is complete the data will be de-identified and stored in a secure online database with unique identifiers. The unique identifiers will be linked to the participant's personal information (name, date of birth, contact information) on a single, password protected excel spreadsheet stored on the principal investigator's password protected personal computer. Social Security Numbers (SSN) will be collected at study enrollment and entered directly into a separate, high security server maintained by the PI's University. To protect participants' eligibility for public benefits, each month the PI or Senior Research Coordinator will transfer participant SSNs and trial group allocation directly to the Social Security Administration (SSA) using an encrypted email platform developed and maintained by SSA.

Statistical methods

All survey data will be entered into and stored in Qualtrics, then analyzed using StataSE 17 or later, SAS v. 9.4 or later, and/or R v. 4.2.2 or later. The following descriptive statistics will be reported side-by-side for the treatment and control group at baseline: age (mean/SD and % over 64); gender (% per category); race (% per category); cancer type and stage (% per category); new or recurrent cancer diagnosis (% per category); baseline food security (mean/SD); baseline housing stability (% experience homelessness); income (mean/SD in U.S. dollars per year); employment (mean/SD in hours per week); ECOG score (% per category), COST score (mean/SD), treatment nonadherence in last 90 days (% yes). To determine if randomization was balanced Chi-square (or, if necessary due to sample size restrictions, Fisher's Exact Tests) will be used for categorical variables and independent *t*-tests (or, if non-normal, Kruskil-Wallis Tests) will be used at baseline, and between drop-outs and completers in each condition.

Linear mixed models will be used for all primary and secondary continuous outcomes over time. We will assess differences between treatment and control group after controlling for possible confounding variables. General estimating equations (GEE) with a logit link and binary distribution will be used for all binary primary and secondary outcomes over time. We will assess the odds ratio between treatment and control groups after controlling for possible confounding variables. GEEs with a log link and poisson distribution will be used for all non-binary, categorical primary and secondary outcomes over time. We will assess the risk ratio between treatment and control groups after controlling for possibly confounding variables.

Linear mixed-models and GEEs were selected because of the longitudinal nature of the study in which repeated measures will be collected across five timepoints. This approach will allow us to integrate observations from all five data collection time points into the statistical models. We plan to adjust these models by accounting for age, gender, race, new or recurrent cancer diagnosis, baseline food security, baseline housing stability, and baseline ECOG. These likely covariates were selected because they represent factors that have been associated with financial toxicity, quality of life and nonadherence in past studies (Altice et al., 2016; Yabroff et al., 2018). We suspect these variables will be correlated with the outcome variables, however, correlation structure will be determined at time of analysis.

Mortality as a long-term exploratory outcome will be analyzed at each time point separately. Chi-square (or, if necessary due to sample size restrictions, Fisher's Exact Tests) will be used to test for differences between the treatment and control groups. Logistic regressions will be used at each time point and will control for age, gender, race, new or recurrent cancer diagnosis, baseline food security, baseline housing stability, and baseline ECOG.

Power analysis for primary outcomes

All power calculations were conducted in Power Analysis and Sample Size (PASS) 2023. Power was calculated at alpha=0.05 with 200 patients at five timepoints. For all power estimates, we assumed an 8% mortality rate between primary timepoints; therefore, 28% of patients will be deceased by the 12 month time point (American Cancer Society, 2019). Power calculations were conducted with missing timepoints rather than on imputed data since we plan to compare imputed to non-imputed models. We further assumed an exchangeable correlation structure with a moderately strong intraclass correlation ($r = 0.6$).

Many estimates were obtained through the pilot analysis. We conducted an observational, pre-test/post-test pilot study in which we recruited 150 financially burdened cancer patients and provided them with a one-time grant of $1,000. We measured primary and secondary outcomes of interest prior to the intervention delivery and two months after to examine changes over time. We expect that the full trial, which will provide participants with 12 times the amount of cash that was provided in pilot, will yield higher treatment effects. We believe the estimates from the pilot are conservative estimates for the full trial, and any estimates not obtained from the pilot were overly conservative to ensure full power.

Financial toxicity

The pilot analysis saw a mean COST difference of 2.4 units (Treatment = 12.9, control = 10.5) and an overall standard deviation of 7.1 units. We expect the covariates we control for in the linear mixed model to have a moderate to moderately strong correlation (between 0.5 and 0.8). Although we expect to observe a larger mean COST difference in the full trial, we calculate the power of our full trial to be between 0.867 and 0.993.

Quality of life

The pilot analysis saw a mean SF-36 aggregate score difference of 3.4 units (Treatment = 39.8, control = 36.4) and an overall standard deviation of 29.4 units. We expect the covariates we control for in the linear mixed model to have a moderate to moderately strong correlation (between 0.5 and 0.8). Although we expect to observe a larger mean SF-36 aggregate score difference in the full trial, we calculate the power of our full trial to be between 0.1831 and 0.3294. In order to be fully powered, we will need to observe a mean SF-36 aggregate score difference of at least 6.5 assuming similar standard deviations. Although this is 2.9 units larger than observed in the pilot, we expect to see a larger difference between the treatment and control groups because of the compounding effect of monthly UCT relative to treatment as usual.

Treatment nonadherence

The pilot analysis saw a mean 30-day nonadherence rate of 11.5% for the control group and a mean nonadherence of 14.7% for the treatment group. We did not expect to observe an increase in nonadherence from pre to post intervention and do not have sound evidence to explain it. However, we can infer that because we only provided the pilot group with a one-time payment of $1,000, that this amount was insufficient to produce changes in 30-day nonadherence. Although we do not have sufficient evidence to corroborate nonadherence rates for our treatment group, we found the nonadherence rate for our control group to be somewhat lower than previous research on nonadherence in financially burdened cancer patients (Zullig et al., 2013; Costas-Muniz et al., 2016; Lee and Khan, 2016; Lee and Salloum, 2016; Nipp et al., 2016; Knight et al., 2018; Zhao et al., 2019). Two past studies that focused on reducing nonadherence to chemotherapy using a behavioral intervention to improve quality of life found significantly lower nonadherence to chemotherapy rates in the intervention group (19%) than in the control group (62.5%) (Cheville et al., 2015). We expect the covariates we control for in the GEE model to have a moderate to moderately strong correlation (between 0.5 and 0.8). Thus, we calculate the power to detect any difference between the treatment and control group to be between 0.065 and 0.095. If the nonadherence rate for our the trial treatment group is similar to the pilot, we will need to observe a nonadherence for the control group to be at least 32% which is possible given the nonadherence rates observed in past studies.

Missing data

Patterns of missing data (due to mortality and otherwise) will be analyzed. If the missing appears relatively random, multiple imputation will be used; otherwise, missingness will be addressed through last observation carried forward (LOCF). Imputed results will be compared to non-imputed results. A secondary analysis for all primary and secondary outcomes will be to test for dependence (through interactions) between treatment and time.

Data monitoring

The PI will conduct monthly quality assurance and data integrity checks which will include checking a random set of cases in the database to ensure that key data points are available.

Discussion

Over the last 50 years UCT demonstration projects conducted across the globe have generated a compelling body of evidence that demonstrates positive impacts on a range of health-related outcomes. UCT recipients in the US and Canada experienced improvements in birth outcomes, (Kehrer and Wolin, 1979; Chung et al., 2016) education attainment, (Maynard and Murnane, 1979; Forget, 2011) psychiatric conditions and substance abuse disorders (Costello, 2010). Globally, UCT has produced large, clinically significant reductions illness, injury, psychiatric emergencies, and related healthcare utilization (Forget, 2011, 2013; Baird et al., 2014). While other studies have demonstrated the positive health effects of UCT in other low-income populations, this trial will examine the benefit of providing ongoing income support to people with serious illnesses like cancer. Financial anxiety among cancer patients is high, but appropriate, given that 42.4 percent of U.S. cancer patients deplete their entire life's assets within two years of diagnosis (Gilligan et al., 2018). In low-income populations, income loss is a significant driver of financial toxicity, which is associated with an array of adverse health and treatment outcomes (Yabroff et al., 2018). Paid sick leave, medical leave under the Family Medical Leave Act (FMLA), and reasonable accommodations under the Americans with Disabilities Act (ADA) improve job retention in cancer patients (Blinder and Gany, 2020). However, these employment protections are either not accessible to all workers or are structured in a way that disadvantages low-wage workers (Vohra-Gupta et al., 2021). For example, just 33 percent of low-wage workers in the U.S. have any paid sick leave, compared to 95 percent of the highest paid workers (United States Bureau of Labor Statistics, 2022).

The absence of a strong social safety net in the US, relative to those of similarly developed nations, leaves many people at risk of health-related poverty (Liao et al., 2022). The consequences of poverty for individuals and society are well known, however, there are many barriers to the implementation of robust anti-poverty interventions in the U.S (Skidmore, 2018), Scientific evidence for the feasibility and effectiveness of UCT is growing, and so is bipartisan interest in guaranteed income as a cost-effective anti-poverty program (Ito, 2018). The appeal of our model is that it sidesteps one of the foremost ideological barriers to UCT: labor market participation. Although the labor market effects of UCT have been found to be negligible to positive, some are concerned that a guaranteed income would dissuade people from seeking employment (Hasdell, 2020). This study targets a population of people with serious illness, whom most people would agree should not have to work, and their family caregivers, who are engaging in the demanding work of providing care to a loved one. The US already has one federal program designed to protect income during illness and disability: Social Security Disability Insurance and Supplemental Security Income. It is well recognized that the current benefit from these programs is too low and that many recipients remain trapped in a cycle of poverty (Stapleton et al., 2006). Findings from GIFT may be directly applied to ongoing efforts to modernize disability income protections in the US. GIFT findings may have implications for non-governmental or market-based intervention as well. Health insurers and managed care organizations are interested in investing in the social needs of their beneficiaries, especially if they can demonstrate a return on investment relative to healthcare utilization and spending (Shrank et al., 2018).

The proposed study is an early effectiveness trial of UCT for cancer patients who have low incomes. Despite its many strengths there are some limitations that should be acknowledged. First, in order to verify patients' low-income status, we use Medicaid beneficiary status as a proxy variable for eligibility. As a result, this sample will not include low- to moderately low-income patients who may be experiencing financial hardship but do not have Pennsylvania Medicaid. Future studies of UCT for cancer may focus on recruiting participants with incomes slightly above the threshold for Medicaid. Second, this study relies predominantly on participants' self-reported survey data which may be limited by participant bias. In a supplemental mixed methods study, we plan to enhance GIFT trial findings by using participants' Medicaid claims data to analyze the impact of UCTs on healthcare utilization and spending and explore underlying mechanisms with qualitative interviews. Similarly, the GIFT trial will not examine the effect of UCT on caregivers, caregiver-patient dyads, or families. We may add a supplement to study these effects but have not yet developed these aims. Lastly, we are aware that what constitutes a clinically meaningful change in COST score has not been determined and that the measure has not been validated in low-income, racially diverse cancer patients. The principal investigator is currently conducting a study that aims to adapt, validate, and determine the predictive power of COST on clinical outcomes in a sample of low-income patients receiving care in a minority serving institution. These findings will aid in interpreting financial toxicity findings from the GIFT trial.

Ethics statement

This protocol and the template informed consent forms have been approved by the University of Pennsylvania. Research assistants trained in human subjects research and the responsible conduct of research will receive additional training from the PI on the process for obtaining informed consent from participants. Informed consent forms have been audited for readability at the 6th grade level. Participants will receive an information sheet and paper copy of the informed consent document for their records.

Author contributions

MD, AC, and SW conceived of the study and are the grant holders. MD initiated and implemented the study design. YB-S, DW, AL, and JJ guide the implementation. JH provided statistical expertise in the trial design and will conduct preliminary statistical analysis. All authors contributed to the refinement of the study protocol and approved the final manuscript.

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Conflict of interest

DW and YB-S were employed by company Mathematica, Princeton.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Corrigendum: Guaranteed Income and Financial Treatment (G.I.F.T.): a 12-month, randomized controlled trial to compare the effectiveness of monthly unconditional cash transfers to treatment as usual in reducing financial toxicity in people with cancer who have low incomes

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In the published article, an author name was incorrectly written as David Wittenberg. The correct spelling is David Wittenburg.

The authors apologize for this error and state that this does not change the scientific conclusions of the article in any way. The original article has been updated.

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Frailty and medical financial hardship among older adults with cancer in the United States

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Background: Little is known about the association between frailty level and medical financial hardship among older adults with cancer. This study aims to describe the prevalence of frailty and to identify its association with medical financial hardship among older cancer survivors in the United States.

Methods: The National Health Interview Survey (NHIS; 2019–2020) was used to identify older cancer survivors (n = 3,919). Both the five-item (Fatigue, Resistance, Ambulation, Illnesses, and Low weight-for-height) FRAIL and the three-domain (Material, Psychological, and Behavioral) medical financial hardship questions were constructed based on the NHIS questionnaire. Multivariable logistic models were used to identify the frailty level associated with financial hardship and its intensity.

Results: A total of 1,583 (40.3%) older individuals with cancer were robust, 1,421 (35.9%) were pre-frail, and 915 (23.8%) were frail. Compared with robust cancer survivors in adjusted analyses, frail cancer survivors were more likely to report issues with material domain (odds ratio (OR) = 3.19, 95%CI: 2.16–4.69; $p < 0.001$), psychological domain (OR = 1.47, 95%CI: 1.15–1.88; $p < 0.001$), or behavioral domain (ORs ranged from 2.19 to 2.90, all with $p < 0.050$), and greater intensities of financial hardship.

Conclusion: Both pre-frail and frailty statuses are common in the elderly cancer survivor population, and frail cancer survivors are vulnerable to three-domain financial hardships as compared with robust cancer survivors. Ongoing attention to frailty highlights the healthy aging of older survivors, and efforts to targeted interventions should address geriatric vulnerabilities during cancer survivorship.

KEYWORDS

frailty, medical financial hardship, cancer survivor, older adults, national sample

1 Introduction

Cancer is a chronic disease of aging; approximately 70% of all cancers occur in people aged ≥65 years, and the number of people with rapid growth will increase in the future (1–3). Despite more than 90% of the senior population having Medicare coverage, the high medical costs of treatment after a cancer diagnosis impose substantial financial hardship on older cancer survivors (4, 5). There is growing interest in understanding cancer-related financial hardships, needs, and sacrifices and identification of the detrimental characteristics among older individuals with cancer (5–11). Although much of this knowledge has been identified from previous studies in older cancer survivorship research areas, there is less evidence to assess the relationship between age-associated conditions and the financial hardships of medical care for this growing population. Therefore, understanding financial hardship among this population is challenging.

Age alone does not properly characterize physiological heterogeneity (12, 13). For older cancer survivors, the “stage of aging” is as important as the “stage of cancer”. Previous studies showed that the frailty status, which is emerging as one of the most important determinants of health and health outcomes, could be an ideal tool to stage aging rather than age groups among older adults (14, 15). Frailty, an age-related clinical syndrome characterized by vulnerability to stressors, has been suggested as a framework for understanding the highly individualized process of aging (16). In addition, frailty status had proven to be changeable and reversible (17). Frailty among cancer survivors is associated with increased risk for adverse events, including hospitalization, new onset of chronic disease, and mortality (18). A cohort of older community-dwelling individuals with frailty was associated with higher subsequent total direct healthcare costs after accounting for demographics, multimorbidity, cognition, and functional limitations (19). Previous studies have shown that frailty was associated with a high risk of healthcare utilization, long-term functional outcomes, and prolonged hospital stays in older adults with cancer (20–22). Additional research is warranted to determine if frailty assessment in a large population is feasible and will alleviate financial hardship regarding healthcare utilization aimed at reducing subsequent healthcare burdens. Understudied frail older adults in cancer survivorship research, especially about medical financial hardship, may hinder progress in aging-tailored interventions and strategies to effectively mitigate the financial burdens of cancer care. As a potentially modifiable age-related characteristic, frailty status could be an important intervention lever for addressing medical financial issues among older cancer survivors. To date, the study on the associations between complex frailty status and medical financial hardship of older cancer survivors is still limited.

This study used a large nationally representative sample to calculate frailty score, then quantified the prevalence of frailty in older cancer survivors, and finally compared medical financial hardship across the material, psychological, and behavioral domains stratified by frailty level. Furthermore, researchers comprehensively evaluated the association of the frailty of older cancer survivors with medical financial hardship and its intensity. Findings from this study will provide critical information needed for an understanding of health disparities and medical financial hardship in older adults with cancer, as well as key information for policymakers to have an insight into the rapidly aging population and cancer demographic of the country. Highlighting frailty status will also close the knowledge gap on aging-related consequences of cancer to enhance healthy aging among older adults with cancer.

2 Materials and methods

2.1 Data sources

The National Health Interview Survey (NHIS) data were used to identify older adults with cancer (aged ≥65 years). The NHIS is an annual, nationally representative household survey of the United States civilian non-institutionalized population. In the NHIS, cancer survivors were defined as those who reported that they had ever been told by a physician or other health professional that they had cancer or a malignancy of any kind. Due to the availability of measures on the FRAIL questionnaire, this study sample was restricted to the years 2019 and 2020. The COVID-19 pandemic impacted NHIS interviewing procedures beginning in late March 2020, so NHIS shifted from in-person interviews to all-telephone interviews starting in late March and continuing through June. Approximately one-third of the sample adult interviews in 2020 (n = 10,415) are composed of sample adults previously interviewed for the 2019 NHIS. Researchers combined the 2019 and 2020 data (excluding the 2019–2020 longitudinal sample from 2020), and the household response rate was 56.5% (23). Supplementary Figure S1 shows the flowchart for the inclusion and exclusion of NHIS participants, and the final analysis included a sample of 3,919 cancer survivors.

2.2 Individual-level characteristics

Demographic characteristics included age at the time of the survey, sex, race/ethnicity, education, marital status, health insurance, family income level as a percentage of the federal poverty level (FPL), and geographic region. Cancer-related variables included the number of cancer diagnoses to define single and multiple cancers (1 cancer *vs.* ≥ 2 cancers) and time since diagnosis, which was calculated using age at most recent diagnosis and age at the survey (<2 *vs.* ≥2 years).

2.3 Frailty status

The FRAIL Scale, developed by the Geriatric Advisory Panel of the International Society for Nutrition and Aging, is a validated screening tool (24, 25). For this study, NHIS 2019 and 2020 data were used to construct the modified FRAIL Scale, and the FRAIL questionnaire consisted of five components: Fatigue, Resistance, Ambulation, Illness, and Low body mass index (BMI) (26). Fatigue in the 2019 NHIS was measured by asking respondents, “Over the last two weeks, how often have you been bothered by feeling tired or having little energy?" with responses of "nearly every day" or "more than half the days" scoring 1 and "not at all" or "several days" scoring as 0. Fatigue in the 2020 NHIS was measured by asking respondents, "Thinking about the last time you felt very tired or exhausted, how long did it last?" with responses of "all of the day" or "most of the day" scoring 1 and "some of the day" scoring as 0. Resistance was assessed by asking respondents, "Do you have difficulty walking up or down 12 steps without any equipment or receiving help?", and Ambulation by asking, "Do you have difficulty walking 100 yards on level ground, that would be about the length of one football field or one city block, without any equipment or receiving help?"; "no difficulty" responses were each scored 0, and all other responses were scored 1. Illness was scored 1 for respondents who reported five or more illnesses out of 14 total illnesses (angina, anxiety disorder, arthritis, asthma, cancer, chronic obstructive pulmonary disease, coronary heart disease, dementia, depression, diabetes, heart attack, high cholesterol, hypertension, and stroke), and respondents with zero to four reported illnesses were scored 0. Low BMI was scored 1 for respondents with BMI < 18.5 kg/m^2; otherwise, it was scored 0. Frail Scale scores ranged from 0 to 5 and represented frailty status (3–5), pre-frailty status (1, 2), and robust status (0) (25).

2.4 Medical financial hardship

Material financial hardship was defined as "participants or their family members having reported problems paying for medical bills in the past 12 months, or reporting any current medical bills they are unable to pay at all (only participants who had reported problems paying for medications were asked these questions)" (27, 28). Psychological medical hardship was defined as "participants having reported sickness or an accident, and are worried about being unable to pay your medical bills at the time of the survey"; this was then dichotomized into hardship ("very worried" or "somewhat worried") or no hardship ("not worried at all") (27, 28). Behavioral hardship was defined as "reporting delaying medical care due to cost in the past 12 months (dental, medical, mental health, filling prescription), needing but did not get because of the cost in the past 12 months (dental, medical, mental health, filling prescription), or skipping medication doses and taking less medication to save money (only participants who had been prescribed medications in the past 12 months were asked these questions)" (9, 27). The measure for any medical financial hardship was based on whether a respondent reported any hardship in each domain. Medical financial hardship intensity was counted based on the number of co-occurring domains. The exact wording of questions or description of recoded variables in NHIS is shown in Supplementary Table S1.

2.5 Statistical analyses

First, the prevalence of each item on the FRAIL questionnaire and the frailty level were described. The distributions of sample individual-level characteristics were also stratified by frailty level (robust *vs.* pre-frail *vs.* frail) using chi-square statistics. Then, weighted percentages were calculated for medical financial hardship domains and intensity by frailty level. Finally, multivariable logistic regression models were developed to generate odds ratios (ORs) of reporting material, psychological, and behavioral domains or any medical financial hardship by frailty level. In all multivariable regression models, the confounding effects of age, sex, race/ethnicity, education, marital status, health insurance coverage, family income level, geographic region, survey years, number of cancer diagnoses, and time since diagnosis were adjusted. Further ordinal logistic regression analyses examined the associations between hardship intensity and frailty level. Sensitivity analyses were also conducted to stratify cancer survivors by age at the time of the survey (aged <75 ≥75 years) and also by sex. The data were analyzed between 16 April and 10 May 2022. All statistical analyses used sample weights to account for the complex survey design and survey non-response of NHIS and were performed using R software (version 3.4.4). All statistical comparisons were two-sided ($\alpha = 0.05$).

3 Results

As shown in Figure 1, 1,583 (40.3%) older individuals with cancer were robust, 1,421 (35.9%) were pre-frail, and 915 (23.8%) were frail. Individual-level characteristics are displayed in Table 1. Compared with robust cancer survivors, pre-frail and frail cancer survivors were more likely to be older, female, less educated, and unmarried. They were also more likely to have a family income match 200% or less of the federal poverty level and multiple cancers.

As presented in Table 2, approximately 4.6% of robust cancer survivors, 8.4% of pre-frail cancer survivors, and 18.4% of frail cancer survivors reported having problems paying medical bills. Approximately 26.0% of robust, 27.3% of pre-frail, and 38.0% of frail cancer survivors reported worrying about paying medical bills due to sickness or accidents. Cancer survivors with pre-frailty or frailty status report high rates of at least one measure of hardship in behavior compared to those with robust status (19.9% *vs.* 30.8% *vs.* 13.9%). Frail and pre-frail cancer survivors were less likely to have no hardship (46.5% *vs.* 60.2% *vs.* 66.2%, $p < 0.001$) and more likely to report hardship in all three domains (8.8% *vs.* 3.1% *vs.* 1.7%, $p < 0.001$) when compared with robust older adults with cancer (Figure 2).

As shown in Table 2, compared with robust cancer survivors in adjusted analyses, pre-frail cancer survivors were more likely to report material domain (OR = 1.70, 95%CI: 1.13–2.58) and behavioral domain of financial hardship (OR = 1.50, 95%CI: 1.15–1.94). However, the difference in rates of psychological domain hardship was not significant between robust and pre-frail cancer survivors (26.0% *vs.* 27.3%, p = 0.976). Among the sample, frail cancer survivors were more likely than those with robust status to report issues in the material domain (OR = 3.19, 95%CI: 2.16–4.69), psychological domain (OR = 1.47, 95%CI: 1.15–1.88), and behavioral domain (ORs ranged from 2.19 to 2.90, all with $p < 0.050$). We also found that frail groups were similar with regard to

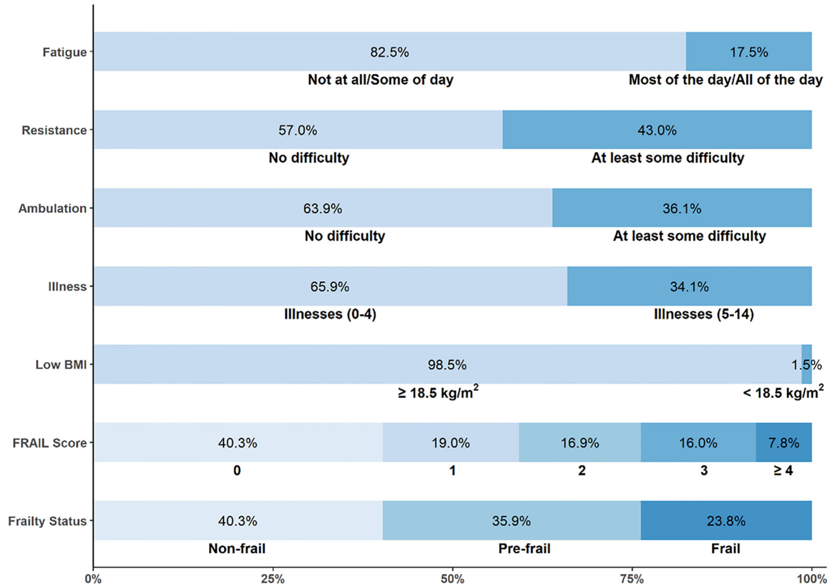

FIGURE 1
Prevalence of each FRAIL item and frailty level.

TABLE 1 Distribution of individual-level characteristics of older adults with cancer.

Individual-level characteristics	Older adults with cancer			p
	Robust	Pre-frail	Frail	
	N = 1,583	N = 1,421	N = 915	
	%	%	%	
Age, years				<0.001
65–74	60.1	47.0	39.3	
75+	39.9	53.0	60.7	
Sex				<0.001
Male	52.7	49.2	41.5	
Female	47.3	50.8	58.5	
Race/ethnicity				0.053
Non-Hispanic white	86.4	86.8	81.7	
Non-Hispanic black	5.8	6.6	6.8	
Hispanic	4.4	4.8	6.6	
Other	3.4	1.8	4.9	
Education				<0.001
<High school	9.5	13.4	26.5	
High school graduate	22.4	29.1	27.3	
≥Some college	68.1	57.5	46.2	
Marital status				<0.001
Married	69.3	60.3	50.9	
Not married or missing[a]	30.7	39.7	49.1	

(Continued)

TABLE 1 Continued

Individual-level characteristics	Older adults with cancer			p
	Robust	Pre-frail	Frail	
	N = 1,583	N = 1,421	N = 915	
	%	%	%	
Health insurance				<0.001
Medicare and private	48.6	45.6	35.0	
Medicare and other public	11.3	15.5	21.7	
Medicare only	30.9	28.9	31.0	
Other, uninsured, or missing	9.2	10.0	12.3	
Family income level as a % of FPL				<0.001
<200%	16.9	25.0	43.9	
200%–399%	29.9	35.0	32.6	
≥400%	53.2	40.0	23.5	
Region				0.414
Northeast	17.7	18.6	17.6	
Midwest	24.3	22.8	20.2	
South	36.4	38.9	41.1	
West	21.6	19.6	21.1	
Time since cancer diagnosis				<0.001
<2 years	12.8	11.8	13.9	
≥2 years	85.0	83.9	77.4	
Missing	2.2	4.3	8.7	
Number of cancer diagnoses				<0.001
1	81.5	77.7	73.2	
≥2	18.5	22.3	26.8	

FPL, federal poverty level.

[a] Not married includes widowed, divorced, separated, or never married.

TABLE 2 Associations of frailty level and medical financial hardship among older adults with cancer.

Financial hardship measures	Robust (Ref)	Pre-frail			Frail		
	%	%	OR (95%CI)[a]	p	%	OR (95%CI)[a]	p
Material	4.6	8.4	1.70 (1.13, 2.58)	0.012	18.4	3.19 (2.16, 4.69)	<0.001
Psychological	26.0	27.3	1.00 (0.81, 1.25)	0.976	38.0	1.47 (1.15, 1.88)	0.002
Behavioral	13.9	19.9	1.50 (1.15, 1.94)	0.003	30.8	2.45 (1.85, 3.24)	<0.001
Needed but didn't get care	7.9	12.5	1.61 (1.17, 2.22)	0.004	22.7	2.90 (2.06, 4.06)	<0.001
Delayed medical care	11.9	16.8	1.43 (1.08, 1.90)	0.013	26.2	2.26 (1.68, 3.03)	<0.001
Other changes	2.0	3.5	1.67 (0.97, 2.87)	0.065	5.1	2.19 (1.23, 3.92)	0.008

[a] ORs were conducted by multivariable logistic regressions. All regressions were controlled for age group, sex, race/ethnicity, education, marital status, health insurance coverage, family income, geographic region, survey years, number of cancer diagnoses, and time since diagnosis.

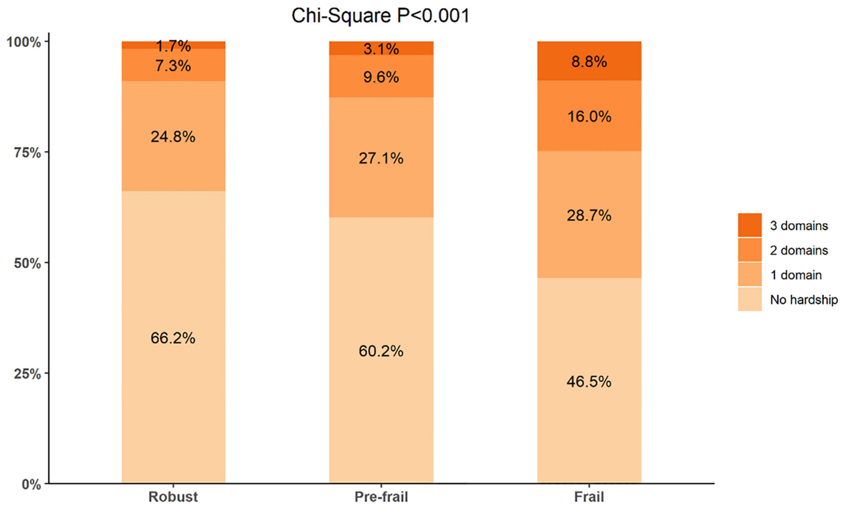

FIGURE 2
Medical financial hardship intensity and frailty level.

reporting both in three domains and most measures of a behavioral domain when compared with the robust group when stratifying survivors by the COVID-19 pandemic (before *vs.* during the COVID-19 pandemic), by age (<75 *vs.* ≥75 years), and by sex (male *vs.* female) (Supplementary Tables S2–S4).

When comparing frailty levels (robust as the referent), we found that frailty cancer survivors had higher intensities of financial hardship (zero *vs.* at least one domain, frail: OR = 1.92, 95%CI: 1.52–2.42; zero or one domain *vs.* at least two domains, frail: OR = 2.02, 95%CI: 1.41–2.90; zero or one/two domain(s) *vs.* all three domains, frail: OR = 2.56, 95%CI: 1.40–4.67) (Table 3).

TABLE 3 The association of frailty and intensities of medical financial hardship among older cancer survivors.

Intensity measure level	OR[a]	95%CI	p
0 *vs.* 1, 2, 3			
Robust	Ref		
Pre-frail	1.22	(0.99, 1.49)	0.057
Frail	1.92	(1.52, 2.42)	<0.001
0, 1 *vs.* 2, 3			
Robust	Ref		
Pre-frail	1.28	(0.90, 1.82)	0.177
Frail	2.02	(1.41, 2.90)	<0.001
0, 1, 2 *vs.* 3			
Robust	Ref		
Pre-frail	1.48	(0.76, 2.87)	0.253
Frail	2.56	(1.40, 4.67)	0.002

[a] ORs were conducted by logistic regressions. All regressions were controlled for age group, sex, race/ethnicity, education, marital status, health insurance coverage, family income, geographic region, survey years, number of cancer diagnoses, and time since diagnosis.

4 Discussion

4.1 Main findings

To our knowledge, this is the first study that focused on older adults with varying frailty levels in the nationally representative population-based database and examined its relationship with medical financial hardship in the United States. In this study, both pre-frailty and frailty statuses were associated with medical financial hardship among older cancer survivors. We found that more than one in three participants were categorized as pre-frail, and approximately one in four participants was categorized as frail. The prevalence of frailty in this study was higher (23.8% *vs.* 9.1%) than in a similar study (N = 416, aged ≥60 years) based on the Third National Health and Nutrition Examination Survey (29). Our findings that older cancer survivors with frailty status are vulnerable to the three-domain financial hardship when compared with those with robust status added knowledge on medical financial hardship during cancer survivorship. This information can also help to identify frailty conditions (previously overlooked in financial hardship research) that are very important in targeted interventions to improve older cancer survivors' financial and health outcomes (14, 26). With the rapid growth and diversification of the older population in cancer care, these findings are novel and useful to older cancer survivorship programs given the increasing attention paid to the impact of financial status and emphasis on age-associated conditions to reduce cancer-related health disparities.

Mohile et al. demonstrated that geriatric syndromes are more common in cancer patients than in those without cancer (30, 31). Other studies also showed that older cancer survivors may be at higher risk for financial toxicity than those with other chronic conditions (4, 32). There may be significant heterogeneity in the health status of older individuals at the same chronologic age, and this study demonstrated that age alone is insufficient to inform on medical financial hardship. Moving forward, using the five items of frailty, healthcare policymakers and healthcare professionals can know more characteristics and quickly identify vulnerable, high-risk, older individuals with cancer. Preliminary data have shown that incorporating a modified FRAIL questionnaire, a simple and useful instrument for identifying geriatric risk in older cancer survivors, into understanding the financial burdens of their cancer survivorship is feasible. These findings suggest that assessment of the frailty or selected components may improve the identification of older adults at risk of medical financial hardship to better facilitate the targeting of interventions aimed at reducing the future healthcare burden. This study is considered the first step in highlighting the importance of staging the aging in patient-reported financial outcome-related studies among older adults with cancer using a FRAIL questionnaire in the United States.

There is a scarcity of nationally representative survey studies that both contain frailty and financial hardship measures and methods appropriate for older adults with cancer to build an evidence base reflecting this typical population. In this study, frailty status correlated directly with the three domains of medical financial hardship and adds important age-related concerns that are not presented by previous research. This study's findings also provided a snapshot of the prevalence of frailty and pre-frailty among older adults with cancer survivors in the United States in the 2020s. Frailty groups deserve special attention, and if this problem is not addressed, growing medical financial hardship may also be associated with widening cancer disparities and worsened outcomes. Older cancer patients are often given complex information about the risks and benefits of cancer treatment, but their age-related problems and outcomes are not usually mentioned (33, 34). Incorporating frailty screening into the medical decision-making process for older cancer patients may help to find aging conditions that are often overlooked in routine oncology care but are important for these populations (35).

Given greater aging and rapid development of frailty, the experience of medical financial hardship is likely to increase and may exacerbate cancer-related health disparities. Older cancer survivors are more likely to have reduced resources to pay for medical care, thereby increasing the financial impact of cancer. Cancer survivors with frailty status have been shown to have more material, psychological, and behavioral financial hardships. Poorer quality of life and overall wellbeing, increased stress, restricted choices associated with limited resources, and decreased healthcare adherence are among the potential hypothesized mechanisms for the association between frailty and financial hardship (27). The mechanism for this increased psychological financial hardship is not entirely clear. Psychological domains were usually measured as any psychological, emotional, and social impact experienced by cancer survivors because of financial hardship. Although specific pathways are unknown, previous research (10, 27) showed that the feeling of distress because of costs of healthcare and concern about wages/income meeting expenses related to costs of healthcare may cause a shift in the attention of older cancer survivors away from material conditions to focus on psychological effects. It is likely that cancer survivors who are frail or pre-frail may have more financial distress and worry about medical costs.

4.2 Clinical implications

Given that cancer is often a long-term and age-related illness, staging the aging in cancer survivors should be considered as important as staging the cancer stage. As a large proportion of older cancer patients experience frailty status, which negatively impacts their experience of medical financial hardship, early frailty screening and preventive strategies are necessary to reduce financial hardship through decision-making and pretreatment optimization in the growing geriatric oncology population. Therefore, frailty assessments could be useful for stratifying aging status and identifying older adults with cancer who experienced more medical financial hardship, as well as for reducing medical costs by improving frailty status. In this observational study, the summarized evidence supports the integration of FRAIL metrics from NHIS items to understand the complex frailty level among older cancer survivors. A previous study showed that because this tool can be self-administered and does not require a face-to-face physical examination, it can be an efficient and cost-effective way to screen large numbers of people for frailty (26). Early frailty screening can allow oncologists to discriminate robust individuals from frailty individuals from the heterogeneous elderly patient population. If medical resources are available, the management of frailty survivors should be multidisciplinary. If not, they should be offered at least cautious medical attention to reduce medical financial hardship and improve their quality of life.

This study's findings warrant future research to create frailty interventions that may need to be implemented to help those with robust or pre-frailty status avoid frailty from ever developing. A previous study showed that successful exercise, physical activity, pharmaceutical trials, and dietary interventions can prevent or remediate frailty in older adults with cancer (18). In addition, non-oncologic aging interventions to better understand the value of frailty may improve survivors' health-related quality of life and satisfaction with medical experience, as well as mitigate their medical financial hardship; psychological, mobility, comorbidity, medication management, and nutritional interventions are recommended for individualized management strategies to optimize care for the individual with pre-frailty or frailty status (36). Recently, a nationwide trial study found that a geriatric assessment intervention can improve patient–oncologist communication about aging-related problems in robust, pre-frail, and frail older adults with advanced cancer (37).

4.3 Strengths and limitations

This study's strengths include the latest nationally representative older cancer sample and well-designed measures to quantify frailty and medical financial hardship. We provide a novel approach to measuring FRAIL to localize older individuals at high risk. Although these five questions of frailty are not validated, it is believed that the quantified results can elucidate frailty. These strengths facilitate the ability to provide national estimates of frailty prevalence among older cancer survivorship and identify frailty level as a risk factor for medical financial hardship for the first time.

Consistent with other national survey studies (28, 38), this study also has several limitations, such as cross-sectional study design, the possibility of reporting errors due to self-reporting, and relatively low response rates. Due to the rotating questions of availability from NHIS data, the item Fatigue from the NIHS questions was measured differently in 2019 and 2020, so the extrapolation of the FRAIL instrument may be limited. This study also lacks data on the stage of cancer and the details of cancer treatment, as well as the differences with regard to the drivers of financial hardship among older patients with different cancer trajectories, which should be examined because these drivers may vary by the stage of disease or by treatment modalities. In addition, because the age and age of cancer diagnosis answers were both top-coded 85 by the NHIS, researchers were unable to calculate more details of time since cancer diagnosis for some of the oldest (≥85 years) samples. Therefore, this study was unable to conclude that those samples would provide similar results.

5 Conclusions

In summary, this study found that both pre-frailty and frailty statuses are common in older adults with cancer and that frailty status is associated with multiple domains of financial hardship. This knowledge will help ongoing research about important age-related concerns among older cancer survivorship care. Efforts to target interventions should address geriatric vulnerabilities during the medical decision-making process and cancer survivorship.

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: http://www.cdc.gov/nchs/nhis.htm.

Ethics statement

The National Center for Health Statistics ethics review board approved all the NHIS protocols, and all survey participants provided informed consent to participate in NHIS. Therefore, no informed consent was required.

Author contributions

Conceptualization: JL and MS. Methodology: JL and MS. Formal analysis: JL. Data curation: JL. Writing—original draft preparation: MS. Writing—review and editing: JL, LL, JZ, SZ, and NY. Visualization: JL and MS. Supervision: NY. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fonc.2023.1202575/full#supplementary-material

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Financial burden of men with localized prostate cancer: a process paper

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Background: Many individuals undergoing cancer treatment experience substantial financial hardship, often referred to as financial toxicity (FT). Those undergoing prostate cancer treatment may experience FT and its impact can exacerbate disparate health outcomes. Localized prostate cancer treatment options include: radiation, surgery, and/or active surveillance. Quality of life tradeoffs and costs differ between treatment options. In this project, our aim was to quantify direct healthcare costs to support patients and clinicians as they discuss prostate cancer treatment options. We provide the transparent steps to estimate healthcare costs associated with treatment for localized prostate cancer among the privately insured population using a large claims dataset.

Methods: To quantify the costs associated with their prostate cancer treatment, we used data from the Truven Health Analytics MarketScan Commercial Claims and Encounters, including MarketScan Medicaid, and peer reviewed literature. Strategies to estimate costs included: (1) identifying the problem, (2) engaging a multidisciplinary team, (3) reviewing the literature and identifying the database, (4) identifying outcomes, (5) defining the cohort, and (6) designing the analytic plan. The costs consist of patient, clinician, and system/facility costs, at 1-year, 3-years, and 5-years following diagnosis.

Results: We outline our specific strategies to estimate costs, including: defining complex research questions, defining the study population, defining initial prostate cancer treatment, linking facility and provider level related costs, and developing a shared understanding of definitions on our research team.

Discussion and next steps: Analyses are underway. We plan to include these costs in a prostate cancer patient decision aid alongside other clinical tradeoffs.

KEYWORDS

prostate cancer, financial toxicity, cost estimates, multidisciplinary collaboration, shared decision making (SDM), quality of life

Introduction

"Financial toxicity" (FT) is the personal financial burden faced by those undergoing cancer treatment, specifically the harms associated with this burden (Yousuf, 2016). Any individual with cancer may experience FT, including those with prostate cancer. In the US, prostate cancer is the most commonly diagnosed cancer in men and the second leading cause of cancer-specific mortality (Siegel et al., 2022). For patients with localized prostate cancer, the type of treatment they choose contributes to their susceptibility to FT, with radiation and surgery often having greater direct costs, financial burden, and variability over time (Imber et al., 2020; Stone et al., 2021). Patients experiencing FT are more likely to report nonadherence to medication, inability to afford prescription drugs, and forgoing mental health services, doctor's visits, and medical tests (Knight et al., 2018). FT is associated with disparate health outcomes and lower quality of life (Yousuf, 2016).

Survival is similar for non-metastatic, localized prostate cancer across treatment options (i.e., radiation, surgery, active surveillance), but patients must weigh quality of life tradeoffs (e.g., distress, urinary incontinence, erectile dysfunction) during this preference-sensitive decision (Bill-Axelson et al., 2014; Lamers et al., 2017; Sanda et al., 2018). Providing cost estimates of the cost burden associated with different prostate cancer treatment pathways alongside clinical tradeoffs can support this decision; cost can be a substantial quality-of-life tradeoff that is often not discussed or not precisely known to patients during decision-making (Politi et al., 2021). There is a growing call regarding the importance of including direct and indirect cost information in shared-decision making conversations for prostate cancer as nonmetastatic treatment outcomes are generally similar and costs can help inform patients as they weigh their options (Ubel et al., 2013; Politi et al., 2023). Direct costs include insurance related fees (e.g., co-pays, co-insurance) and indirect costs include the often unforeseen costs (e.g., loss of work, absenteeism, presenteeism). Even with interest from patients and clinicians, cost conversations can be difficult to navigate(Kelly et al., 2015) due to the multidimensional nature of costs, impacting material, behavioral, and psychosocial domains (Tucker-Seeley and Thorpe, 2019). Discussing cost burden with patients upfront can enable patients to consider potential tradeoffs, seek financial assistance early on in their care, and thus potentially reduce future costs and the burden of care (Ubel et al., 2013; George et al., 2021).

In this paper, we aimed to quantify direct care costs and the associated financial burden for patients aged 18–63 years diagnosed with localized prostate cancer as the first step. We plan to incorporate this data into shared decision making materials and support patients as they consider which treatment option is right for them. Cost information will help patients consider both side effects and financial burden when they make decisions about their treatment among different treatment options. In this paper, we outline the steps involved in estimating direct costs following a prostate cancer diagnosis using insurance claims data. This report outlines lessons learned and recommendations for other researchers conducting similar analyses.

Methods

Step 1: identifying the problem

This research question arose from an existing project, evaluating a prostate cancer treatment decision aid that includes relative cost information led by a member of the research team (Politi et al., 2021). Formative interviews identified a gap in cost information for those making decisions about prostate cancer treatment options and their clinicians. Clinicians wanted to know more about these costs and patients and caregivers wanted to share more about the impact of immediate and downstream direct and indirect costs on their life (Politi et al., n.d.). Consequently, our research question was informed by the clinical, research, community and patient partners engaged in this formative work. Our research team prioritized engaging with these partners throughout the duration of this project. We knew this complex problem would also require the expertise of a multidisciplinary team as it spans patient care, clinical decision making, patient-centered communication, and economic evaluation.

Step 2: engaging a multidisciplinary team

To develop a multidisciplinary collaborative team, the team met to discuss the research question and identify a potential funding source prior to approaching other team members. We invited a community collaborator and leader of a prostate cancer community-based organization to join our core research team and engage with local and regional community partners to incorporate their perspectives on costs and their impact on patients. We also engaged an urologist with clinical expertise on prostate cancer treatment, a health economist with expertise in cost analyses using administrative claims data, and a community-engaged researcher and leader of a local cancer center. We identified the need for expertise in these specific disciplines because of the complexities of calculating costs incorporating the clinical, economic, and community perspectives. To ensure our questions were clinically relevant and our operational definitions were accurate, a practicing urologic surgeon scientist helped generate and review the treatment definitions, billing and procedure codes, and define the clinical context. The health economist with expertise in estimating patient direct costs and large claims databases has worked extensively with data scientists on the institutional informatics team to oversee the analyses. The community-engaged researchers with expertise in health disparities provided important perspectives on the disproportionate experiences of FT by those from socially, economically, and racially marginalized groups. A postdoctoral trainee with expertise in cancer survivorship to support focusing on the impact of cost upfront and through survivorship over time. With this team of content and research experts, we also identified a research coordinator with extensive experience in clinical decision support informed by billing and procedure codes to oversee the administrative aspects of this project.

Step 3: reviewing the literature and identifying the database

Through engaging our multidisciplinary team, we identified, reviewed, and selected the codes to extract, with this process occurring over multiple phases. First, the research team reviewed existing literature to identify procedure and billing codes. This involved reviewing peer reviewed literature and guidelines. Second, we reviewed the procedure codes included in the Fair Health Consumer[1] prostate cancer shared decision making cost tool. Third, we reviewed the National Library of Medicine's Value Set Authority

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[1] https://www.fairhealthconsumer.org/

Center (VSAC; https://vsac.nlm.nih.gov/) and the Unified Medical Language System (UMLS; https://www.nlm.nih.gov/research/umls/index.html). The research team compiled these resources, reviewed them together, and confirmed the procedure set we would use in this project. Our clinical team member, a practicing urologic surgeon, led iterative review and selection of procedure codes and discussed with clinical partners, including a radiation oncologist with experience working in claims data, when there were uncertainties about which to include. Our final code set is included in Table 1.

Based on this review, our research team decided to use data from the Truven Health Analytics MarketScan Commercial Claims and Encounters, including MarketScan Medicaid, (MarketScan). We selected MarketScan because of the inclusion of variables needed for our research question and to conduct analyses, national representativeness of a privately insured population, extant literature using MarketScan for similar analyses on financial burden in cancer survivors, and the availability and expertise within our institution. While the median age for prostate cancer is 66 years, over 170 million people under 65 years are covered by private health insurance (National Health Statistics Reports, 2021). Specifically, there were 224,733 new prostate cancer cases diagnosed in the US in 2019, and 37% of those cases were among men aged 45–64 years (Prostate Cancer Incidence by Stage at Diagnosis, 2023). These cost estimates will be relevant to this large group of people. Individuals with private insurance often spend more on care, have more medical debt, and report that costs impact care access (Wray et al., 2021). Those under 65 years are often exposed to more variable costs and cost estimates may be particularly relevant to this population.

Step 4: identifying outcomes

Based on the findings from our initial work and literature review, the research team identified that treatment-related costs can occur over time, and a single time point would be unable to capture the costs across a trajectory of prostate cancer care. Thus, we quantified these costs cumulatively at 1 year, 3 years, and 5 years. Estimating costs at multiple time points would provide a better estimate of patient costs over time (Eldefrawy et al., 2013; Gustavsen et al., 2020). Using the MarketScan database for data extraction, we created an analyzable dataset to estimate the patient, clinician, and system/facility costs. Initially, our goal was to estimate these costs for patients with localized prostate cancer. Ideally, localized prostate cancer would be defined by Gleason, PSA, or tumor staging data, but these variables are not available in the MarketScan, despite the many strengths that prompted us to choose to use this database. Considering this limitation, we chose to use the metastatic vs. non-metastatic variable to define our cohort of interest.

TABLE 1 Summarized list of treatment options, procedures, and CPT codes for the 3 treatment types.*

Treatment option	Procedure	CPT codes
Active surveillance	Biopsies	55700–55706
	Pelvic MRI	72195–72197
Prostatectomy	Open	55840
	Laparoscopic	55866
Radiation	Temporary hormones	J9218, J9202, J3315, J3489, J0897
	External beam	77401–77416 and G6003-G6014
	Seeds/internal/brachytherapy	77263
	Fiducial marker placement	55876
	Biodegradable injections	55874

* Please see the supplementary information for the complete list of CPT codes used in this analysis.

Step 5: defining the cohort

We defined localized prostate cancer as being diagnosed with prostate cancer and the absence of metastatic diseases using International Classification of Diseases, Ninth/Tenth Revision, Clinical Modification (ICD-9/10-CM). We first included patients with at least 2 outpatient codes at least 30-days apart or one inpatient prostate cancer diagnosis (ICD-9185, ICD-10 C61) between 2006 and 2019 (the most updated data at the time of study). Among these patients, the date of diagnosis (index date hereafter) was defined as the date of the first biopsy within +/− 30 days of a prostate cancer diagnosis, as biopsy is needed to determine a diagnosis and the dates of biopsy and diagnosis may lag administratively. Patients without a date of diagnosis were excluded. Additional exclusion criterion included patients: (1) with a secondary cancer diagnosis other than prostate cancer, (2) with a metastatic cancer diagnosis in the 12-months prior to or post the index date, (3) with a prostate cancer diagnosis in the 11-months prior to the index date, (4) with medical coverage <12-months prior to index date or < X-year after index date since this indicates incomplete cost data, where X = 1, 3, or 5 (i.e., the duration of the target cumulative cost of interest), (5) age < 18 years or age > 63 years at index (for the concern of incomplete data due to Medicare eligibility), (6) female sex, and (7) missing or negative costs within the duration of the target cost due to administrative data entry errors (see Figure 1).

Defining the treatment groups

We defined a patient's initial treatment decision as the first treatment codes present within the 12-months following their index biopsy code. We categorized patients into 3 groups based on their initial treatment choice following diagnosis: active surveillance, surgery, and/or radiation using the Current Procedural Terminology (CPT) codes (see Table 1). Surgery included laparoscopic and open prostatectomy. Radiation included external beam and seeds/internal/brachytherapy. Active surveillance was defined as having no surgery or radiation codes within 12-months of the index date. Specifically, within 12-months following diagnosis, if a patient did not have treatment codes for either surgery or radiation, the patient was considered to have selected active surveillance. We estimated the cost associated with this treatment and all follow-up costs within the 5-year period, including other potential treatments (i.e., surgery, radiation). This approach captures all treatment related costs associated with their initial treatment decision.

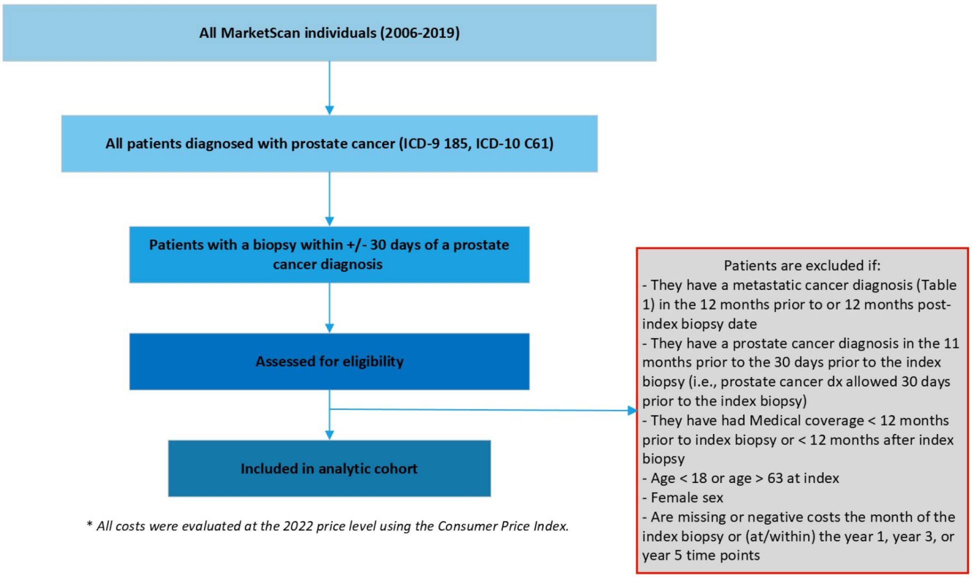

FIGURE 1
Defining the analytic cohort.

Step 6: designing the analytic plan

The analytic plan was finalized as the research team refined our research question and defined our variables. The analytic plan was an iterative process and refined as the team identified the data available in the database, the variables of interest, and our overall research objectives. Our team decided we would quantify total costs at 1, 3, 5 years following diagnosis and aggregate these costs across those time points. Total costs were evaluated from the healthcare sector's perspective, including patients' out-of-pocket cost and cost paid by third party payers. Costs pooling from different years were evaluated at the 2022 price level using the Consumer Price Index Medical Care Component (Consumer Price Index (CPI), 2023). For unadjusted analysis, we plan to average costs across patients receiving each treatment option to calculate mean costs for each treatment pathway. For adjusted analyses, the distribution of the total costs at different years will be visually examined. Appropriate statistical analyses will be determined and performed using these total costs as the outcome variables with covariates including patient characteristics (e.g., age, comorbidities), insurance types, geographical region where they received treatments, and treatments that they received. Total costs by initial treatment decision will be predicted based on the estimated regression at the three time periods based on patient characteristics, insurance type, geographical region, and a combination of treatment options.

Results

Lessons learned and strategies

A summary of lessons learned, strategies, and examples is described below in detail and summarized in Table 2.

Complex research questions across multiple disciplines

Our team met frequently and worked together to translate our research questions across discipline specific language, including across oncology, urology, public health, economics, data science, decision science, psychology, occupational therapy, and community engaged research. Initially our meetings were 60-min every other week, but we increased the frequency to meeting for 30-min twice a week. While this increased frequency can be demanding to the research team members, we found as the momentum of our project started to increase, we needed rapid feedback and to update the team on progress. We did cancel meetings if they were not needed and corresponded over email to update the team. We also shared detailed meeting minutes to keep all team members apprised of updates. Through our frequent, brief meetings, we refined our analytic plan, and we were able to ask questions in real time to address and translate discipline specific jargon and assumptions, and ultimately agree on our analytic process. We then created a draft analysis plan to circulate with the research team to elicit additional input from our team members. Through this process, we incorporated scientific, medical, and community perspectives to refine our questions and define a clinically meaningful cohort within the larger dataset. This is an ongoing process as new information emerges or challenges arise, yet our goal is to identify these issues early and often so we can address them in a way that aligns with the research question, data, science, clinical relevance, and patient experiences.

Defining the cohort

Due to the aforementioned limitations of unavailable data to define localized prostate cancer in the MarketScan database, we worked with our team to identify which metrics/measures exist

TABLE 2 Challenges and recommendations.

Challenge	Recommendation	Example solution
Identifying the research expertise needed and ensuring shared understanding across multiple disciplines and progress updates.	Leverage the range of expertise by engaging a multiple disciplinary team from clinical, scientific, and community-based perspectives. At the beginning of the project, prioritize dedicating time to selecting team members that represent expertise in the priority areas for your project. Their perspectives and knowledge are essential for identifying the relevant treatment codes, reviewing the codes to ensure they make sense clinically, and confirming the data are available within the dataset, conducting the analysis, and interpreting the results.	Our team is made up of experts in oncology, urology, public health, economics, data science, decision science, psychology, occupational therapy, and community engaged research. We conducted twice weekly, 30-min meetings and circulated detailed meeting minutes to clarify disciplinary jargon and ensure mutual understand of our approach and plan.
Defining the cohort for non-metastatic PCa without Gleason, PSA, or tumor staging data (limitations to the data set).	Review the variables available in the dataset and their clinical meaning to identify a strategy for how to address the research question. Determine how to use the available variables to define your cohort, relevant costs, and treatment pathways as accurately as possible. This can include using specific billing codes, procedure codes, time intervals, absence or presence of codes, among other strategies.	In the absence of available variables for Gleason, PSA, and tumor staging data, we used metastatic vs. non-metastatic cancer diagnosis to help define a patient cohort with localized prostate cancer. This distinction comes with additional considerations, including how to identify the non-metastatic cohort and when to exclude metastatic cases (e.g., upfront, at a certain period of time). Our team defined non-metastatic as: (1) a diagnosis with prostate cancer and no metastatic cancer codes present at any point prior to and/or 30 days after the index date and (2) patients who progress to metastatic prostate cancer within 12-months after the index date will be excluded; however patients progressed after 12-months will be included.
Identifying procedure and billing codes.	Review existing literature, cross-reference resources for ICD-9/10 and CPT code identification including the National Library of Medicine's Value Set Authority Center (VSAC) and the Unified Medical Language System (UMLS). This is an iterative process that requires repeated review and confirmation from key team members (i.e., clinical expert).	We compiled a list of ICD-9/10 and CPT through: (1) peer reviewed literature and guidelines, (2) reviewed procedure codes from existing patient facing resources (i.e., Fair Health Consumer), and (3) national repositories (VSAC; UMLS). The research team, including a clinical expert, complied these resources, reviewed them together, and confirmed the final procedure set.
Identifying when a patient chooses active surveillance	Active surveillance is not a specific CPT code and therefore requires applying a definition for how active surveillance will be operationalized. This can be done by reviewing extant literature, discussing with a multidisciplinary team, reviewing medical system processes and procedures, and defining treatment option.	Since the absence of surgery or radiation codes does not necessarily indicate an active surveillance treatment choice, the team worked together through multiple iterations of our operational definition for active surveillance. Based on a literature review, the team's knowledge of medical system processes, and consultation with a urologist routinely involved in patient care and billing, active surveillance was defined as: patients diagnosed with prostate cancer who, within 12-months of diagnosis, have billing codes for biopsy or biopsy and pelvic MRI an no other treatment codes.
Linking facility and provider level related costs using treatment variables.	By using inpatient facility claims, only CPT codes will be used to identify the procedures and there is a discrepancy between the number of people with facility costs vs. the number with provider costs.	Link facility claims +/− 1 day to provider surgery claims. We are doing this for inpatient facility claims as well as outpatient facility claims to capture any procedures that were done on an ambulatory basis.
Shared understanding of definitions and documentation of research questions	On our team of experts, we needed to closely manage and document our operational definitions and current status of the project. At each key decision point, find a way to confirm the approach with team members and receive individual and group approval. This will eliminate confusion and facilitate effective collaboration.	Brief, frequent team meetings; shared box folder; sub-group working meetings and circulating minutes with the full team; project dictionary for key terminology to document operational definitions; regular email updates outlining most-recent updates and key decisions.

and how to feasibly extract them from the database. Through this process, our team elected to use metastatic vs. non-metastatic cancer diagnosis to help define localized prostate cancer. This distinction comes with additional considerations, including how to identify the non-metastatic cohort and when to exclude metastatic cases (e.g., upfront, at a certain period of time). We selected the time parameters to provide the framework needed to verify the confirmed prostate cancer records. Primarily, we determined that the date of a patient's initial biopsy would serve as the index date. 12-months before the prostate cancer index date no ICD codes for prostate cancer beyond 30-days from the index date and if both biopsy and diagnostic codes are present within 1-month, we will consider this patient to be diagnosed with prostate cancer. Limitations to this approach include those patients who may have had a biopsy outside of what was captured in the MarketScan database, but the research team evaluated the tradeoffs between a smaller sample size and a well-defined patient cohort (patients diagnosed with non-metastatic prostate cancer) and erred on the side of caution to include confirmed prostate cancer records in our analysis.

Identifying procedure, billing codes, and patient treatment decision making

Our team reviewed existing databases to cross-reference resources for ICD-9/10 and CPT code identification. This included FairHealth, and the National Library of Medicine's Value Set Authority Center (VSAC) and the Unified Medical Language System (UMLS). Specifically, we needed to define what the operational definition would be for active surveillance as it is the absence of a discrete treatment event, rather a cluster of treatment events over time. At what time point can we determine the patient has chosen active surveillance? Our research team defined selecting active surveillance as a prostate cancer diagnosis and the absence of surgery or radiation related codes within the 12-months post index diagnosis (i.e., first biopsy). Our team decided this timeframe was a clinically meaningful timeframe in which you would expect a patient to initiate and commence their initial treatment plan.

Defining treatment decisions

For those categorized as selecting active surveillance, if the patient transitioned to another treatment type as defined by the presence of treatment-related codes (i.e., surgery, radiation; Table 1) after 12-months, we included these patient records since we are interested in capturing all treatment related costs associated with their initial treatment decision. This approach allowed us to estimate the overall costs (initial costs and follow-up costs) associated with following treatment paths: (1) first electing active surveillance treatment (at 1-year, 3-years, and 5-years), (2) first electing surgery treatment (at 1-year, 3-years, and 5-years), and (3) first electing radiation treatment (at 1-year, 3-years, and 5-years).

Linking facility and provider level related costs using treatment variables

Using CPT codes to identify the procedures lead to a discrepancy between the number of people with facility costs versus the number with provider costs. To avoid a systematic missing of facility costs, our research team considered: (1) either providing the ICD-9/10 procedure codes for treatments that would logically be done during an inpatient admission (especially the surgical procedures) or (2) linking facility claims to provider surgery claims based on dates (+/− 1 day). We decided to use approach 2 because each case would likely vary and approach 2 would be more inclusive of all associated costs.

Shared understanding of definitions and documentation of research questions

One of our team's main challenges has been reaching a shared understanding of the definitions and criteria for our analytic plan. We have adopted several strategies to help enhance communication and achieve consensus among our multi-disciplinary team. Primarily, we have conducted frequent, short meetings to ensure that all team members are updated and to create space to troubleshoot issues and misconceptions. In addition, we have created a centralized location for all files and realized the importance of regularly updating documents and operational definitions that are iteratively adjusted. We have also identified the importance of sending team-wide email updates after any modification is made to the analytic plan, cohort definitions, or inclusion and exclusion criteria. Not all team members are able to be present at each meeting, so regular email updates have also been a critical method for communicating changes and maintaining consensus.

Discussion and next steps

Cost analyses are currently underway. We will be estimating total costs at 1-year, 3-years, and 5-years following diagnosis. In parallel, we are conducting semi-structured interviews among Black prostate cancer survivors and their caregivers to characterize the role of direct and indirect costs during their prostate cancer treatment through lived experiences. We are planning to include these direct and indirect costs in a prostate cancer patient decision aid and test this decision aid among patients with localized prostate cancer.

Limitations

This research approach is not without limitations. First, active surveillance and watchful waiting are very different treatment types philosophically and in practice, but it is challenging to differentiate these approaches using claims data as the billing records may appear to be the same. Therefore, our multidisciplinary research team agreed upon using 12-months as the timeframe to suggest a patients' selection of active surveillance. However, this could include some watchful waiting patients, which has the potential to artificially lower cost estimates. Additionally, MarketScan data does not include data on PSA, Gleason score, or tumor staging data. While this limited our ability to define low risk prostate cancer, the overall goal of the analysis is to better understand treatment-specific costs. Selecting a prostate cancer treatment pathway is a preference-sensitive decision, and therefore it is still important to include this information. MarketScan only includes claims data for those who are insured (including those eligible for Medicaid and Medicare), precluding those who are uninsured from our analysis. Together with a lack of race or ethnicity data, our analysis is not able to consider health equity. To address this, our larger research project includes a second aim where we will conduct qualitative interviews with Black men with prostate cancer to identify and further explore the direct and indirect costs associated with their treatment. We are also continually learning new information about our approach and analysis and identifying challenges. With new information and challenges, we will make informed decisions for how to proceed with the input of our team. Thus, our final analytic plan will be reported at the end of this research project. Our goal for this paper is to rapidly translate our methods and strategies to other researchers grappling with similar questions in an effort to facilitate academic discourse and increase transparency.

Conclusions

Leveraging the expertise of a multidisciplinary team can help to identify the essential factors needed to estimate patient-related costs. These are complex research questions that evolve iteratively as additional information is uncovered through identifying the variables and clarifying the analytic plan. As we finalize our decision aid with cost information from this work, we will engage with clinical, patient, caregiver, community and decision science partners to review the presentation of information and identify supports needed to implement in routine care. We will prioritize recruiting from socially and economically marginalized populations to evaluate how the inclusion of costs may support decision making because of the disproportionate financial burden experiences by these populations.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

AH: conceptualization, methodology, investigation, writing (original draft, review, editing), resources, supervision, and funding acquisition. HR: investigation, writing (original draft, review, editing), and visualization. S-HC: conceptualization, methodology, investigation, writing (review, editing), supervision, and funding acquisition. AL'H: investigation, writing (review, editing). EK and MP: conceptualization, methodology, writing (review, editing), and funding acquisition. BD and RW-J: conceptualization, writing (review, editing), and funding acquisition. All authors contributed to the article and approved the submitted version.

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Conflict of interest

RW-J was employed by The Empowerment Network Inc., United States. MP was a consultant for UCB Biopharma in 2022 on a topic unrelated to this manuscript.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

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Pilot study of a Spanish language measure of financial toxicity in underserved Hispanic cancer patients with low English proficiency

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Background: Financial toxicity (FT) reflects multi-dimensional personal economic hardships borne by cancer patients. It is unknown whether measures of FT—to date derived largely from English-speakers—adequately capture economic experiences and financial hardships of medically underserved low English proficiency US Hispanic cancer patients. We piloted a Spanish language FT instrument in this population.

Methods: We piloted a Spanish version of the Economic Strain and Resilience in Cancer (ENRICh) FT measure using qualitative cognitive interviews and surveys in un-/under-insured or medically underserved, low English proficiency, Spanish-speaking Hispanics (UN-Spanish, $n=23$) receiving ambulatory oncology care at a public healthcare safety net hospital in the Houston metropolitan area. Exploratory analyses compared ENRICh FT scores amongst the UN-Spanish group to: (1) un-/under-insured English-speaking Hispanics (UN-English, $n=23$) from the same public facility and (2) insured English-speaking Hispanics (INS-English, $n=31$) from an academic comprehensive cancer center. Multivariable logistic models compared the outcome of severe FT (score>6).

Results: UN-Spanish Hispanic participants reported high acceptability of the instrument (only 0% responded that the instrument was "very difficult to answer" and 4% that it was "very difficult to understand the questions"; 8% responded that it was "very difficult to remember resources used" and 8% that it was "very difficult to remember the burdens experienced"; and 4% responded that it was "very uncomfortable to respond"). Internal consistency of the FT measure was high (Cronbach's $\alpha=0.906$). In qualitative responses, UN-Spanish Hispanics frequently identified a total lack of credit, savings, or income and food insecurity as aspects contributing to FT. UN-Spanish and UN-English Hispanic patients were younger, had lower education and income, resided in socioeconomically deprived neighborhoods and had more advanced cancer vs. INS-English Hispanics. There was a higher likelihood of severe FT in UN-Spanish (OR=2.73, 95% CI 0.77–9.70; *p*=0.12) and UN-English (OR=4.13, 95% CI 1.13–15.12; *p*=0.03) vs. INS-English Hispanics. A higher likelihood of severely depleted FT coping resources occurred in UN-Spanish (OR=4.00, 95% CI 1.07–14.92; *p*=0.04) and UN-English (OR=5.73, 95% CI 1.49–22.1; *p*=0.01) vs. INS-English. The likelihood of FT did not differ between UN-Spanish and UN-English in both models (*p*=0.59 and *p*=0.62 respectively).

Conclusion: In medically underserved, uninsured Hispanic patients with cancer, comprehensive Spanish-language FT assessment in low English proficiency participants was feasible, acceptable, and internally consistent. Future studies employing tailored FT assessment and intervention should encompass the key privations and hardships in this population.

KEYWORDS

Spanish, financial toxicity, English proficiency, Hispanic, underserved, ENRICh, cancer, health insurance

1. Introduction

Financial toxicity (FT) reflects the personal economic burden borne by individuals with cancer (Zafar et al., 2013). FT results from the direct and indirect costs of treatment and disease, and it manifests in a variety of ways such as the accrual of medical debt, non-adherence to treatment due to cost, and development of psychological distress related to financial concerns. In prior studies, as many as half of individuals with cancer in the US were found to experience FT during treatment or survivorship (Altice et al., 2017). Prior studies have also suggested that racial and ethnic minorities have especially high prevalence of FT, attributed to greater socioeconomic vulnerability from lower income and higher rates of un- or under-insurance (Bernard et al., 2011; Kent et al., 2013; Nipp et al., 2016; Kaul et al., 2017; Zheng et al., 2017). In the US, evidence suggests that the Hispanic population overall has lower population-level educational attainment, household income, and English language proficiency as well as the highest uninsured rate of any racial or ethnic group (Office of Minority Health, 2022). These elements have been shown to place Hispanic populations at especially high risk for decreased healthcare access and more advanced cancer at diagnosis (Chebli et al., 2020). Non-citizen status is an additional factor that can potentiate these challenges (Ashing-Giwa et al., 2006; Buki et al., 2008; Simon et al., 2013; Azzani et al., 2015; Lentz et al., 2019). As a result, Hispanic patients with cancer have substantial risks for developing FT.

However, conflicting evidence exists on the severity and spectrum of FT in US Hispanics. For example, 42% of Hispanics with a cancer history in the 2010 National Health Interview Survey reported a negative financial impact compared with 33% of non-Hispanic whites (Ashing-Giwa et al., 2006). In contrast, a recent analysis of the 2012, 2014, and 2017 Health Information National Trends Surveys (HINTS) did not find a significant difference between Hispanics and non-Hispanic white respondents reporting that they were hurt financially due to cancer (Panzone et al., 2021). Comprehensive measurement and assessment of FT in Hispanic cancer patients and survivors are therefore still needed to improve nuanced understanding of severity, sources, dimensions, and mitigators of FT in this population.

In addition, given the large population of US Hispanics with low English proficiency and the relationship between low English proficiency and quality of care, there is a need for Spanish language tools to measure FT that adequately encompass and represent the aspects of financial hardship that this population experiences. Advancing assessment of FT in US Hispanic patients and survivors with cancer will promote early identification, inform tailored interventions, and enhance delivery of community-partnered health resources for high-risk individuals in this population.

To advance the assessment and understanding of FT in low English proficiency Hispanic cancer patients, we developed and piloted a Spanish language version of the previously validated Economic Strain and Resilience in Cancer (ENRICh) FT measure (Smith et al., 2021; Xu et al., 2022). The English version of the ENRICh measure has been psychometrically validated and has been used in prior studies to identify risk factors and outcomes in cancer patients with FT. In addition, the English version of the instrument has been useful for measuring the severity of subdomains of FT, including material burdens, coping resource depletion, and the psychological burden of FT (Maldonado et al., 2021; Corrigan et al., 2022).

The primary objective of this pilot study was to evaluate the acceptability and appropriateness of the Spanish language instrument for assessing FT in a pilot sample of un-/under-insured or medically underserved low English proficiency Hispanic individuals receiving ambulatory oncology care from a public medical safety net hospital. This hospital is in the Houston metropolitan area, Texas, where persons of Hispanic ethnicity comprise approximately 45% of the population. The study's secondary objective was to conduct exploratory analyses of the impact of insurance status and English language proficiency on FT outcomes. To address this objective, we conducted exploratory comparisons of FT outcomes reported in the pilot sample of un-/under-insured and underserved low English proficiency Hispanics (UN-Spanish) with the FT outcomes of two other groups with a historical comparison with: (1) un-/under-insured and medically underserved English-speaking Hispanics (UN-English) and (2) insured English-speaking (INS-English) Hispanics drawn from the parent study of the English version ENRICh FT instrument psychometric validation analysis (Smith et al., 2021).

2. Materials and methods

This study was approved by the University of Texas M. D. Anderson Cancer Center Institutional Review Board. All participants provided informed consent or waiver of signed consent per protocol.

2.1. Study population

2.1.1. Spanish language sample (UN-Spanish)

Individuals were eligible for survey and cognitive qualitative interviews if they were aged ≥18 years, had confirmed diagnosis of cancer, indicated in their medical record that they required Spanish language interpretation for care, and were receiving ambulatory oncology care (active cancer treatment or follow-up/surveillance care) at the Lyndon B Johnson Hospital Oncology Clinic (LBJ) in Houston, Texas. LBJ is a facility in the county public health system which provides care for medically underserved and un- or under-insured patients with a household income of <150% of the Federal Poverty Level in partnership with the county-based healthcare safety net. This facility provides financial assistance through sliding scale out-of-pocket medical charges based on income level (Patient Eligibility, 2022).

Participants in this study were selected as a purposive sample of patients who presented for care at the clinic during 12 select clinic dates (based on research staff availability) between November 2020 and May of 2021 who were approached for study participation. The individual's need for Spanish language interpretation indicated in the medical record was confirmed in person by the research staff prior to study enrollment. Of the 27 patients who were approached for participation, four refused, making a total of $n = 23$ in the UN-Spanish Hispanic sample. As described, use of the "Spanish-speaking" category label (UN-Spanish) reflects low English language proficiency.

2.1.2. Comparison sample (UN-English and INS-English)

The comparison English-speaking Hispanic samples were derived from the parent survey cohort assembled for the psychometric validation analysis in the Economic Strain and Resilience in Cancer study (ENRICh) and the short form validation (Smith et al., 2018, 2021; Xu et al., 2022). Eligibility criteria for the parent cohort were identical, except all participants were required to be able to read and complete the survey in English. English language preference in these participants was also confirmed at the time of study enrollment. Eligible patients received ambulatory oncology care between March and September 2019 at LBJ or the University of Texas M.D. Anderson Cancer Center (MDA), an academic National Cancer Institute (NCI) designated comprehensive cancer hospital. Among enrollees from the parent ENRICh survey ($N = 312$, a response rate of 63.5% from 491 invited), all Hispanic respondents ($n = 31$ from MDA and $n = 23$ from LBJ) were included in the present analysis.

2.1.3. Definition of patient comparison groups

A total of three comparison groups were defined for this analysis: (1) un-/under-insured and underserved low English proficiency Hispanics (UN-Spanish) enrolled from the public clinic ($n = 23$); (2) un-/under-insured and underserved English-speaking Hispanics (UN-English) from the public clinic ($n = 23$); and (3) insured English-speaking Hispanics (INS-English) from the academic comprehensive care center ($n = 31$).

2.2. Development of the Spanish-language version of ENRICh

The Economic Strain and Resilience in Cancer (ENRICh) instrument is a 15-item measure of patient-reported financial toxicity (FT) that is psychometrically validated among English-speaking survey respondents (Smith et al., 2021). The instrument scores overall FT. In addition, it scores FT in three subdomains: (1) material hardship such as out-of-pocket medical costs, spent savings, accumulated credit card or other debt, and lost income; (2) depletion of coping resources such as employment benefits, professional assistance from formal resources (e.g., professional organizations, charities), and informal support (e.g., from family and friends); and (3) related psychological burdens such as stress related costs or financial hardship. Respondents rate each item and the final scores, including overall score and each subdomain score, range from 0 to 10 (with higher scores indicating more severe burden).

2.2.1. Spanish instrument translation and assessment

For this pilot, the ENRICh instrument was translated into Spanish through iterative forward translation followed by backward translation harmonized for Latin American Spanish (Supplementary Table S1). To assess acceptability of the Spanish-language instrument, respondents participated in a cognitive debriefing and qualitative interviews as guided by the COnsolidated criteria for REporting Qualitative research (CORE-Q) criteria. Interviews and instrument administration were conducted in Spanish by bilingual members of the study team. Sessions were audio-recorded and transcribed verbatim and analyzed in English using a deductive approach based on the existing conceptual model of FT delineating major subdomains of FT: material, psychological, and behavioral (Altice et al., 2017; Tucker-Seeley and Thorpe, 2019). Two independent coders (GM and GS) analyzed the data.

Participants first completed the Spanish version ENRICh instrument and then were asked to rate items on a 6-item questionnaire regarding aspects of usability, relevance, comprehension, and ease of response to instrument items (with a score of 0 representing very usable, relevant, easy to understand etc. and score of 8–10 categorized to represent very difficult to use, not relevant, very difficult to understand etc. Therefore, lower scores on these scales represent higher acceptability).

Finally, participants were also asked to reflect on their qualitative understanding of the constructs and concepts in each item using their own words. Each item was followed by open-ended qualitative interview probes by the interviewer to determine whether there were additional aspects of economic burden and financial hardship. If literacy was a barrier or the participant expressed such a preference, the interviewer read aloud both the questions and answer options for the participant. Quantitative score responses were summarized, and qualitative responses were coded for representative quotes on themes and subdimensions of FT.

2.3. Financial toxicity instrument scoring

An overall FT score and material FT, coping FT, and psychological FT domain subscores were calculated as an arithmetic average of item scores (re-weighted for missing items based on the total number of items completed) as previously reported in the original English psychometric validation analysis (Smith et al., 2021). In the original scoring, surveys with more than half of the items with missing responses were considered invalid. In this study, no respondent had more than half of survey items as missing responses, so scores for all respondents were included in analysis.

FT scores were further analyzed as continuous or dichotomous outcomes in multivariate models. The dichotomous cut point was defined as severe FT, indicated by a score >6. This approach for dichotomization was adapted based on prior findings demonstrating that a cut point score at 5 defining severe FT predicted the adverse outcomes of accumulation of medical debt and non-adherence to medical care (Maldonado et al., 2021). Because of the shift in distribution of scores toward higher scores with more severe FT in the present study sample (attributable to the high percentage of underserved, uninsured individuals), the cut point was defined at 6 for this analysis.

2.4. Ethnicity and other covariates

Hispanic ethnicity and patient race. Data on self-identified ethnicity and race were abstracted from each respondent's medical record. These fields are pre-determined menu options which patients select as a component of routine registration for care at both facilities. In the MDA medical record, respondents may select "Hispanic or Latino/a" or "Not Hispanic or Latino/a" for ethnicity. In the LBJ medical record, respondents may select the same options, with another submenu option if "Hispanic or Latino/a" was selected to further categorize ethnicity as "Mexican, Mexican American, or Chicano/a" vs. "Other Hispanic, Latino/a, or Spanish origin." At LBJ, "Hispanic/Latino/a" is also offered as an option for race, but it is not available as an option for race at MDA. Other race categories of respondents in this sample were "Black or African-American" and "American Indian," based on respondents' category selection for race in the medical record.

2.4.1. Sociodemographic and clinical covariates

Age at survey, home address, gender, education, work status, marital status, race, ethnicity, primary cancer disease site (e.g., breast, lung, prostate, etc.), and cancer stage at diagnosis (categorized as local vs. regional or advanced or metastatic, adopted from the Surveillance Epidemiology and End Results summary stage framework) were also collected. Respondents were surveyed for total household income, health insurance status [including public (e.g., Medicaid, Medicare, other state programs), private (employer-purchased, self-purchased), or uninsured], highest attained level of education, and current work status. Home address zip codes were linked to Federal Information Processing System (FIPs) codes to calculate Area Deprivation Index (ADI) scores. The ADI scores the individual's neighborhood-based socioeconomic deprivation level and has been previously found to be associated with healthcare outcomes (Ludwig et al., 2011; Hu et al., 2018; Neighborhood Atlas – Home, 2022). ADI scores range from 1 to 100 (least to greatest severity of neighborhood deprivation, respectively) normalized based on national percentile ranking across neighborhoods in the US. Categories used in univariate and multivariable analyses were based on variables' distributions.

2.5. Statistical analyses

Internal consistency of item scoring for the overall FT measure was tested for each patient group (UN-Spanish, UN-English, INS-English) using Cronbach's α. Univariate associations between covariates and patient groups, and overall FT score were tested using the Wilcoxon Rank Sum Test and Fisher's Exact Test. Multivariable logistic models were tested to identify the adjusted associations for patient groups and odds of severe overall FT and subdomain FT (scores ≥ 6). Covariates were considered for retention in the models if they demonstrated univariate associations with $p \leq 0.05$. Final parsimonious models were derived based on retaining important covariates identified in prior studies of FT (age and sex) (Smith et al., 2021). Insurance status, ADI, chemotherapy, and advanced/metastatic cancer were tested but excluded as final covariates due to non-significance, collinearity with the main independent variable of interest (patient group), or the models based on Akaike information criterion (AIC) lacking goodness of fit. Models were performed on the entire cohort with the INS-English group as the referent category compared with UN-English and with UN-Spanish groups. Secondarily, models were performed on the subset only of un- or underinsured patients to directly compare the UN-English vs. UN-Spanish groups to explore the effect of English language proficiency on FT outcomes. Analyses were conducted using SAS Enterprise Guide version 7.11 (Cary, NC). Statistical tests were two-sided with a p value ≤ 0.05 considered statistically significant.

3. Results

Among all participants ($N = 77$), the mean age was 50.2 (SD 14.4) years with a variety of cancer types: breast 39.0% ($n = 30$), gastrointestinal 20.8% ($n = 16$), hematologic 9.1% ($n = 7$), lung 9.1% ($n = 7$), genitourinary 7.8% ($n = 6$), soft tissue 6.5% ($n = 5$), and other 7.8% ($n = 6$). Among the patients who specified the subcategory of Hispanic ethnicity, 39% (18 of 46) specified "Mexican, Mexican American, or Chicano/a." One patient specified American Indian race and two patients specified Black or African-American race.

UN-Spanish and UN-English Hispanics tended to be younger and have lower education and lower income than INS-English Hispanics. Home neighborhood deprivation indicated by mean ADI score differed between groups, with Hispanic patients from the UN-Spanish [75.1, standard deviation (SD) 16.6] and UN-English (65.0, SD 23.8) groups living in more deprived neighborhoods vs. INS-English Hispanics (54.9, SD 25.8) ($p = 0.03$). All INS-English Hispanics had health insurance. Other detailed characteristics compared between groups are shown in Table 1.

3.1. Spanish language FT measure cognitive debriefing and acceptability

Among the UN-Spanish Hispanic group, there was high acceptability of the instrument. Most respondents found it easy to answer the questions (median 0, IQR 0–1 with a lower score

TABLE 1 Participant characteristics and comparisons between insured English-speaking (INS-English), un- and under-insured English-speaking, and un- and under-insured low English proficiency Hispanic individuals with cancer.

Patient characteristics	INS-English	UN-English	UN-Spanish	*p*-value
	(*n* of 31, %)	(*n* of 23, %)	(*n* of 23, %)	
Age, Mean, standard deviation (SD)	55.6, 14.0	44.1, 13.4	49.1, 13.8	**0.023**
Gender % (*n*)				0.37
Male	9 (29.0%)	11 (47.8%)	7 (30.4%)	
Female	22 (71.0%)	12 (52.2%)	16 (69.6%)	
Neighborhood Area Deprivation Index Score, Mean, SD	54.9, 25.8	65.0, 23.8	75.1, 16.6	**0.03**
Currently Working for Pay				**0.001**
Yes	15 (48.39%)	3 (13.04%)	2 (8.70%)	
No	15 (48.39%)	20 (86.96%)	21 (91.30%)	
Income				**<0.001**
<$10,000	2 (6.45%)	10 (43.48%)	6 (26.09%)	
$10,000–$34,999	4 (12.90%)	12 (52.17%)	6 (26.09%)	
$35,000–$49,999	3 (9.68%)	1 (4.35%)	0 (0%)	
$50,000–$99,999	13 (41.94%)	0 (0%)	0 (0%)	
>$100,000	8 (25.81%)	0 (0%)	0 (0%)	
No Response	1 (3.3%)	0 (0%)	11 (47.8%)	
Education				**<0.001**
Less than High School, High School, or GED	10 (32.26%)	15 (65.22%)	14 (60.87%)	
Some College, Associate Degree, or Trade Certification	14 (45.16%)	8 (34.78%)	0 (0%)	
College, Graduate, or Advanced Degree	7 (22.58%)	0 (0%)	1 (4.35%)	
No Response	0 (0%)	0 (0%)	8 (34.78%)	
Marital Status				0.41
Married or Living as Married	18 (58.06%)	9 (39.13%)	11 (47.83%)	
Other	13 (41.94%)	14 (60.87%)	12 (52.17%)	
Insurance				**<0.001**
Private (Employer or Purchased)	28 (90.32%)	1 (4.35%)	0 (0%)	
Medicaid or Other State	0 (0%)	6 (26.09%)	2 (8.70%)	
Medicare	3 (9.68%)	1 (4.35%)	1 (4.35%)	
No Insurance	0 (0%)	15 (65.22%)	20 (86.96%)	
Received Chemotherapy				0.10
Yes	23 (74.2%)	20 (87.0%)	22 (95.7%)	
No	8 (25.8%)	3 (13.0%)	1 (4.4%)	
Advanced or Metastatic Cancer				**0.001**
Yes	16 (51.6%)	14 (60.9%)	22 (95.7%)	
No	15 (48.4%)	9 (39.1%)	1 (4.4%)	
Disease Site				
Breast	16 (51.6%)	8 (34.8%)	6 (26.1%)	0.34
Gastrointestinal	4 (12.9%)	5 (21.7%)	7 (30.4%)	
Other*	11 (35.5%)	10 (43.5%)	10 (43.5%)	
Median Interval from Diagnosis in days (interquartile range)	297 (82, 575)	270 (99, 546)	860 (173, 1,687)	**0.006**

*Other disease sites include: central nervous system, head and neck, hematologic (leukemia, lymphoma, myeloma), lung, genitourinary, gynecologic, sarcoma and other soft tissue, and thymic malignancies. Bold values indicate $p < 0.05$.

representing greater ease in responding; 0% very difficult), easy to understand the questions (median 0, IQR 0–3 with a lower score representing greater ease in understanding; 4% score of very difficult), felt comfortable responding to the questions (median 0, IQR 0–1 with a lower score representing greater comfort in responding; 4% very uncomfortable), felt it was easy to remember the resources that were offered in the last month (median 0, IQR 0–1 with a lower score representing greater ease in recall; 8% very difficult), and felt it was easy to remember the financial burdens of the last month (median 0, IQR 0–2; 8% very difficult). Some respondents found questions repetitive (median 0, IQR 0–3 with a lower score representing greater comfort with the level of repetition; 17% very repetitive). Only two respondents found the 0 to 10 scale difficult to understand and expressed that they would prefer binary options only (yes or no) for items.

Regarding the cognitive interviews, UN-Spanish Hispanic respondents still identified frequent material hardships attributed to a lack of savings, medical bills, insurance coverage difficulties, and income losses (Table 2). These respondents identified that a complete lack of savings, credit, or income was an underlying rationale for choosing a score of "0" in material FT items, but there was a conflict in scoring, with "0" being a response that represented a complete lack of the resource vs. "10" being a response that represented the severe hardship from lacking that resource. Individual item scoring for material FT items demonstrated that respondents frequently scored "0" (Table 3). For example, the frequency of a "0" score for the following items were: cancer or cancer treatment impacted "money in savings" (33.3%), "spending from savings" (36.4%), and "credit card use" (75.0%). Therefore, qualitatively, respondents expressed that an option of "I do not have savings/credit cards/income" could be added for these items to better tailor to their circumstances.

In qualitative interviews, respondents also identified additional specific dimensions of cancer-related FT, including the impact of undocumented immigration status and lack of basic resources such as food, housing, and transportation. Respondents further identified potential factors that mitigated FT, including support resources through church and family. The financial assistance program offered through the public safety-net hospital was another key mitigating factor (Table 2).

3.2. Financial toxicity scores: exploratory comparison of severity and dimensions by patient groups

Cronbach's α values demonstrated high internal consistency for measuring the underlying construct of overall FT in each group: UN-Spanish = 0.906, UN-English = 0.904, and INS-English = 0.906. The median scores for overall FT were similar for UN-Spanish (5.4, IQR 1.5–7.1) vs. UN-English (6.0, IQR 3.4–8.3) groups ($p = 0.12$). However, the INS-English group had significantly less severe overall FT, with a median score of 3.2 (IQR 1.9–5.3) ($p = 0.01$) (Table 3).

The subdomain scores for material FT, coping FT, and psychological FT are found in Table 3. The coping FT domain demonstrated the most substantial differences in median scores for UN-Spanish (5.0, IQR 2.5–8.0) and UN-English (6.3, IQR 3.0–8.4) Hispanics vs. INS-English (2.4, IQR 0.6–6.4) ($p < 0.001$). Other covariate correlates of FT are shown in Supplementary Table S2.

In multivariable models, compared with INS-English Hispanics, the likelihood of severe overall FT (score > 6) was significantly increased for UN-English Hispanics [Odds Ratio (OR) = 4.13, 95% Confidence Interval (CI) 1.13–15.12; $p = 0.03$] and increased with borderline statistical significance for UN-Spanish Hispanics (OR = 2.73, 95% CI 0.77–9.70; $p = 0.12$). Compared with INS-English Hispanics, there was a significantly higher likelihood of severe coping FT for both UN-English (OR = 5.73, 95% CI 1.49–22.1; $p = 0.01$) and UN-Spanish Hispanics (OR = 4.00, 95% CI 1.07–14.92; $p = 0.04$) (Table 4). In the subset analysis including only the un-/under-insured groups, there were no significant differences detected for UN-Spanish Hispanics vs. UN-English Hispanics for overall FT ($p = 0.59$), material FT ($p = 0.32$), coping FT ($p = 0.62$), or psychological FT ($p = 0.44$). (Table 2).

4. Discussion

FT is a critical source of financial anxiety and disparities in care delivery and health outcomes in cancer patients and survivors. Though early available data support that, overall, minority populations in the US have especially high prevalence of FT, comprehensive measurement of FT among Hispanics with cancer in the US remains lacking. The need for measuring FT is especially true for Hispanics who face serious socioeconomic barriers in order to advance FT screening and intervention in high-risk individuals. Our pilot study demonstrated the initial feasibility, acceptability, and internal consistency of a Spanish-language ENRICh measure to assess FT in low English proficiency Hispanic cancer patients using a translated version of a multi-dimensional validated tool for scoring FT (Smith et al., 2021). Our pilot focused on assessing a medically underserved Hispanic population with low English proficiency, un- or under-insurance, and high poverty level receiving care from a public safety net clinic. The low English proficiency Hispanic respondents in our study lived in highly disadvantaged neighborhoods in the larger Houston metropolitan area, with a mean ADI score representing the highest quartile of socioeconomic deprivation relative to neighborhoods across the US. The low English proficiency respondents in our study demonstrated low access to economic and health resources when compared with a control group of insured English-speaking Hispanics drawn from the same large metropolitan area.

The socioeconomic barriers and healthcare burdens observed in this low English language proficiency group in our study align with prior findings in Hispanic cancer survivors (Blinder et al., 2012; Jagsi et al., 2014; Lee and Salloum, 2016). Bilingualism among Hispanics in prior studies is associated with higher income (Katz et al., 2017), while low English language proficiency is associated with more recent immigration and socioeconomic disadvantage (Schhneider et al., 2006). In our study sample of UN-Spanish Hispanics, lower education and income were accompanied by low access to health insurance. Un- or under-insurance was a significant predictor of FT, especially coping FT, in our analysis. Once accounting for un- and under-insurance, we explored for an independent effect of language acculturation on FT but did not identify statistically significant effects in comparisons of FT for high vs. low English proficiency Hispanics. Possibly the qualitatively reported mitigating support resources such as church or extended family may offer critical protective effects on FT in this population with language barriers, potentially consistent with the mitigating effect of social support on FT identified in a recent qualitative study of Hispanic

TABLE 2 Qualitative responses on aspects of material, coping, and psychological financial toxicity during cognitive interviewing and linguistic validation, translated from Spanish.

Hardships

Depletion/lack of pre-existing assets

"Without working, the finances are gone, and you depend on people's help."

"I cannot provide like—like what we need at home. Let's say, if we need to buy something additional for our home, or if I need emergency money, I do not have it. I cannot do that because I paying for everything else."

"I don't have any savings from the time I used to work."

Lack of credit and credit card access

"We do not use credit cards."

"I don't have credit cards."

"I don't have a credit card."

Food insecurity

"Once every fifteen days, thank God, a church provides us with food."

"As I have paid for gas, to come here—I have paid for gas, I have—well, I've been hungry and not wanting to buy any little thing, and that's where all the money is going."

Transportation difficulties

"Well, I don't drive. I don't have the—I drive, but I don't have a car. I have to depend on someone else to get me around."

"A lot of people do struggle, for instance, to find transportation to come to the hospital. Or many people do not have the ten dollars or the six—eight dollars that they charge you for parking."

"Sometimes I don't have anybody who can give me a ride to the hospital, and I have to spend my money to pay for taxis or transportation."

Immigration difficulties

"If you don't have a backup, an insurance, which you cannot have as Hispanic and immigrant here, undocumented, unfortunately—I mean, it gets very difficult."

Burdens

Medical bills

"When I was first diagnosed, I did not have insurance, as I told you, and what they needed was urgent because it was a stage four cancer with metastasis, and I needed to get the treatment immediately. And so just in order to start getting treatment, I needed an average of 5,000 dollars, which I didn't have."

"Yes, because before getting sick, I never had medical expenses, and now I have a pending bill of 4,000 dollars."

Lack of insurance

"At the beginning, it was a hard blow, and it affected me a lot because I didn't have medical insurance; I didn't have anywhere—nothing to help me cover the expenses of a disease like this one."

Income loss

"The cancer caused me to have bone problems, and I fractured my back. Imagine how hard it was to work. I fractured my back twice, three vertebrae, and the last time I fractured two vertebrae, and I cannot work. It is even harder because it is a construction job. And that affects me."

"When this began, I had to stop working, and therefore, I stopped having money, you know?"

"I went from earning, let's say, 5,000 dollars per month, to earning—to maybe earning 100 dollars per day, in the—when I started the treatment—the disease. So there were times when I could not do anything."

"When I got sick, I had to quit my job."

Impairment in caregiving responsibilities

"I can no longer take care of her. It did affect my ability to take care of my child."

"Always—all the time, since I started this treatment—this case—the responsibility has fallen more on her, on my wife, because when it was the two of us—that is, 100 percent—it was less of a burden on both of us."

"It is supposed to be me who should be taking care of the cousins when my aunt is not there, but I struggle a lot."

Mitigating factors

Social network support resources

"I borrowed money from relatives, friends in order to start with the treatment because I didn't have any type of insurance."

"Well, they helped me with my groceries, people from the church. They gave me food, thank God."

"Like churches—they help you with a percentage."

"Right now, I cannot work. Sometimes I have to pay for the rent or for the food to my aunt. My dad got in a very bad financial state when he had to pay for the chemo, so I'm nervous that they are going to—to lose my insurance or something like that."

Formal assistance resources

"Thank God my wife was able to find—well, she applied to get the gold card (public clinic financial assistance program), and I was lucky that they gave it to me, right?"

"The gold card (public clinic financial assistance program), yes. I get that help."

TABLE 3 Median scores and frequency of response of score "0" for individual items, subscores, and overall scores for financial toxicity (FT) compared between groups.

Item	UN-Spanish				UN-English					INS-English				*p* value 3 groups
	n of 23	Median	IQR	% "0"	*n* of 23	Median	IQR	% "0"	*p* value 2 groups	*n* of 31	Median	IQR	% "0"	
Material FT subdomain														
Money in savings	21	3.0	0.0–9.0	33.3%	23	10.0	7.0–10.0	8.7%	**0.01**	28	5.0	2.0–10.0	17.9%	**0.01**
Other money owed	23	0.0	0.0–7.0	52.2%	22	8.5	0.0–10.0	27.3%	**0.03**	31	5.0	0.0–8.0	35.5%	0.06
Medical spending	23	2.0	0.0–8.0	34.8%	21	7.0	2.0–9.0	14.3%	0.17	31	6.0	2.0–9.0	16.1%	0.25
Spending household income	23	5.0	2.0–9.0	13.0%	23	5.0	2.0–10.0	17.4%	0.59	31	6.0	2.0–9.0	16.1%	0.84
Spending from savings	22	2.0	0.0–8.0	36.4%	23	6.0	0.0–10.0	26.1%	0.21	31	3.0	0.0–6.0	29.0%	0.31
Credit card use	20	0.0	0.0–2.0	75.0%	23	0.0	0.0–8.0	60.9%	0.35	31	3.0	0.0–6.0	38.7%	0.14
Material FT subscore	23	3.3	0.8–6.7	13.0%	23	5.8	3.3–8.3	0.0%	**0.04**	31	4.3	2.4–7.3	6.5%	0.10
Coping FT subdomain														
Ability to pay all bills	23	5.0	0.0–8.0	26.1%	23	10.0	0.0–10.0	26.1%	0.11	31	2.0	0.0–7.0	38.7%	**0.01**
Ability to pay for food	22	4.0	0.0–9.0	27.3%	23	8.0	2.0–10.0	13.0%	0.22	30	0.0	0.0–1.0	66.7%	**<0.001**
Ability to work usual number of hours at job	22	10.0	9.0–10.0	18.2%	23	10.0	9.0–10.0	17.4%	0.92	31	0.0	0.0–8.0	58.1%	**<0.001**
Ability to contribute to typical household responsibilities	23	6.0	3.0–10.0	17.4%	23	9.0	6.0–10.0	8.7%	0.21	29	3.0	0.0–8.0	37.9%	**0.01**
Assistance with managing medical bills	22	3.0	0.0–10.0	45.5%	23	4.0	0.0–10.0	39.1%	0.81	30	0.0	0.0–4.0	73.3%	**0.04**
Assistance with typical responsibilities	23	8.0	1.0–10.0	21.7%	23	9.0	5.0–10.0	17.4%	0.6	30	2.5	0.0–8.0	40.0%	**0.04**
Assistance with care for dependents	23	5.0	0.0–10.0	39.1%	23	5.0	0.0–10.0	34.8%	0.87	31	0.0	0.0–5.0	54.8%	0.07
Assistance from community	23	0.0	0.0–6.0	60.9%	23	0.0	0.0–9.0	56.5%	0.73	30	0.0	0.0–0.0	76.7%	0.16
Coping FT sub score	23	5.0	2.5–8.0	4.3%	23	6.3	3.0–8.4	0.0%	0.31	31	2.4	0.6–4.6	9.7%	**<0.001**
Psychological FT subdomain														
Stress level about finances	23	7.0	1.0–10.0	21.7%	21	10.0	7.0–10.0	0.0%	0.05	30	7.0	2.0–10.0	10.0%	**0.05**
Psychologic FT subscore	23	7.0	1.0–10.0	21.7%	21	10.0	7.0–10.0	0.0%	0.05	30	7.0	2.0–10.0	10.0%	**0.05**
Overall FT score	23	5.4	1.5–7.1	4.3%	23	6.0	3.4–8.3	0.0%	0.12	31	3.2	1.9–5.3	6.5%	**0.01**

UN, un-/under-insured and underserved; INS, insured; IQR, interquartile range; FT, financial toxicity. Bold values indicate $p < 0.05$.

TABLE 4 Multivariable logistic models of severe (score>6) overall, material, coping, and psychological financial toxicity (FT), for all patients (*N*=77) and the subset of un-/under-insured and underserved patients (*N*=46).

All Patients (*N*=77)												
Covariate	Overall FT			Material FT			Coping FT			Psychological FT		
	OR	95% CI	*p*	OR	95% CI	*p*	OR	95% CI	*p*	OR	95% CI	*p*
Group												
INS-English	1.00	–	–	1.00	–	–	1.00	–	–	1.00	–	–
UN-English	4.13	1.13–15.12	**0.03**	2.13	0.6–7.5	0.24	5.73	1.49–22.1	**0.01**	1.75	0.52–5.91	0.37
UN-Spanish	2.73	0.77–9.70	0.12	1.06	0.3–3.82	0.92	4.00	1.07–14.92	**0.04**	1.08	0.35–3.31	0.89
Female	0.47	0.17–1.31	0.15	0.42	0.15–1.18	1	0.40	0.14–1.17	0.09	0.53	0.19–1.46	0.22
Age (years)	1.00	0.96–1.04	0.98	1.00	0.97–1.05	0.66	0.99	0.96–1.03	0.75	1.00	0.97–1.04	0.86

Un-/under-insured and underserved Patient Subset (*N*=46)												
Covariate	Overall FT			Material FT			Coping FT			Psychological FT		
	OR	95% CI	*p*	OR	95% CI	*p*	OR	95% CI	*p*	OR	95% CI	*p*
Group												
UN-English	1.00	–	–	1.00	–	–	1.00	–	–	1.00	–	–
UN-Spanish	0.71	0.21–2.44	0.59	0.52	0.14–1.91	0.32	0.74	0.22–2.52	0.62	0.60	0.17–2.18	0.44
Female	0.41	0.11–1.46	0.17	0.36	0.09–1.34	0.13	0.38	0.11–1.38	0.14	0.30	0.07–1.25	0.10
Age (years)	1.00	0.94–1.04	0.61	1.00	0.96–1.06	0.87	0.98	0.94–1.03	0.5	1.00	0.97–1.07	0.40

FT, financial toxicity; OR, odds ratio; CI, confidence interval; INS, insured; UN, un-/under-insured and underserved. Bold values indicate $p < 0.05$.

breast cancer patients (Chebli et al., 2020). Notably, while respondents in our study also qualitatively identified the financial assistance provided through the county public health program as another mitigating factor, respondents did not identify use of a wider spectrum of potential formal assistance resources outside the healthcare system, such as charity and other professional organizations. As the need for access to variety of formal assistance resources to help mitigate FT was identified in another qualitative study of diverse breast cancer patients with financial barriers (Gharzai et al., 2021), future studies underlying the barriers to knowledge and use of community assistance resources for cancer-related FT in low English proficiency Hispanics may elicit key intervenable factors (social determinants factors) and needs (the spectrum of social needs as well as needs specifically related to FT) in this population.

Notably, this pilot sample size was limited, and therefore the exploratory model in the present analysis is not sufficient to rule out independent effects of language acculturation on FT. Further, what is likely is that the language acculturation aspect interacts in complex ways with the socioeconomic, neighborhood, and healthcare environment factors before, during, and after diagnosis and treatment to influence FT outcomes. Our practical Spanish language FT measurement items are applicable to support additional investigations of this question.

This study identified distinct characteristics of FT among underserved, low English language proficiency Hispanic patients to guide and incorporate into future investigations. UN-Spanish Hispanic patients frequently identified a complete lack of resources such as income, savings, or credit cards and severe basic needs privations. Studies of FT with a focus on loss or decline of wealth (e.g., worsened credit score, defaulted mortgages, or loss of savings, retirement, or assets) (Katz et al., 2017), or measures such as the Comprehensive Score for Financial Toxicity (COST) (de Souza et al., 2017), that do not include specific basic needs privation could lead to gaps in representation of the severity and dimensions of FT in populations such as this. To continue adding to the available scientific evidence, these aspects of FT need to be represented in future studies of medically underserved Hispanic cancer patients (Ashing-Giwa et al., 2004; Blinder et al., 2012; Jagsi et al., 2014; Lee and Salloum, 2016; Jagsi et al., 2018; Shankaran et al., 2022). Providing options in responses to indicate that credit, savings, or income may not be relevant due to a complete lack of resources is important to avoid inaccurate floor effects in scoring. Multi-dimensional FT assessment, such as that provided by the ENRICh instrument, is needed to discern the aspects of material burden, coping, and psychological impact of FT. Prior large population studies of US Hispanics demonstrate the conflicting evidence on the severity and spectrum of FT (Ashing-Giwa et al., 2006; Panzone et al., 2021), potentially due to the heterogeneity of aspects of FT. Our results may help bridge the conflicting evidence, with our analysis demonstrating a wide variation in FT within this entirely Hispanic sample, for example, between the insured English-speaking vs. uninsured low English proficiency subgroups—variation that may be diluted in analyses of Hispanics as a single category.

This study has limitations to consider. There was a limited sample size and statistical power, and therefore the models analyzing the correlates of overall and subdomain FT are exploratory. The comparison groups were obtained as a convenience sample at only two institutions. In addition, the UN-English interviews were conducted at the onset of the COVID-19 pandemic whereas the INS-English surveys were conducted years prior to the pandemic, and therefore the potential economic factors that were impacting the participants enrolled before vs. after the pandemic may have differed. Furthermore, the comparisons between the groups in the analysis are still exploratory and require additional validation as well as examination of multi-level contributions to variation in outcome (i.e., organization-levels vs. patient-level effects). A strength of the study samples was the high density of Hispanics in the Houston metropolitan area from which they were drawn, which includes populations of mostly Mexican (76%), Salvadoran (8%), and Honduran (3%) origin (Demographic and Economic Profiles of Hispanics by State and County, 2011; Hispanic Population and Origin in Select U.S, 2016), reflecting the diversity of the US national Hispanic population (Key facts about U.S., 2019). However, future studies are still needed to fully understand the impact of neighborhood, geographic, ethnic, immigration status, and generational factors, given the heterogeneity of the US Hispanic population with even more broadened inclusion.

5. Conclusion

In this pilot study focused on un- and under-insured Hispanics with cancer, comprehensive FT measurement with the ENRICh FT measure in high-risk, low English proficiency individuals was feasible, acceptable, and internally consistent when administered in Spanish. While the results provide a tool for practical and useful Spanish language measurement items to assess multi-dimensional FT in additional research and practice, they also emphasize that future studies employing FT assessments focused on high-risk Hispanic populations need to encompass the types of privations and economic hardships this population uniquely faces, such as severe basic needs privations and deficient or lacking access to resources such as savings and credit. The results of this study identified that inadequate insurance was a potential predictor of FT among Spanish- and English-speaking Hispanics. While language acculturation was not found to be an independent risk for FT in exploratory analysis, further exploration of the differences among lower and higher English proficiency in additional diverse subpopulations continue to be warranted, especially to disentangle the potential effects of language proficiency, sociodemographic factors, and insurance factors. The initial findings from this pilot study provide practical insights and items for FT assessment in future practice and research as well as key understandings for tailoring ongoing efforts in financial toxicity measurement, assessment, and intervention to meet the specific needs of underserved Hispanic populations with low English language proficiency.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by University of Texas M. D. Anderson Cancer Center Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

Author contributions

SP, TM, SS, RV, SG, and GS: contributed significantly to the experimental design. GM, SP, Y-SC, KK, NT, HM, and D-KN: implementation. JS, GM, SP, RY, C-FW, SS, Y-CS, and GS: analysis and interpretation of the data. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1188783/full#supplementary-material

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Expanding research on the impact of financial hardship on emotional well-being: guidance of diverse stakeholders to the Emotional Well-Being and Economic Burden of Disease (EMOT-ECON) Research Network

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The Emotional Well-Being and Economic Burden (EMOT-ECON) Research Network is one of six research networks funded by the National Institutes of Health (NIH) to advance research about emotional well-being (EWB), and the only one that focuses on addressing how economic burden due to disease or illness affects EWB. The network convened researchers, patients, patient advocates, health care providers and other stakeholders from across the US to discuss the significance of addressing the impact of the economic burden of disease on EWB, the complexity of this prevalent problem for patients and families, and the research gaps that still need to be studied to ultimately develop strategies to reduce the impact of economic burden of disease on EWB and health. Participants identified some important future areas of research as those investigating: (i) prevalent and relevant emotions for patients experiencing economic burden of disease and financial hardship, and how their broader outlook on life is impacted; (ii) constructs and contexts that influence whether the economic burden is stressful; (iii) strategies to deal and cope and their positive or negative effects on EWB and health; and (iv) multi-level and multi-stakeholder interventions to address economic factors (e.g., costs, ability to pay), administrative burdens, education and training, and especially patients' emotional as well as financial status.

KEYWORDS

emotional well-being, medical financial hardship, economic burden of disease, financial toxicity, network

1. Introduction

Worry about affording medical care is highly prevalent among Americans (Weissman et al., 2020). About 60% of Americans stress about costs of health care and medications and/or medical bills including unexpected bills, and more than 50% worry they will not be able to pay for the health care services they may need in the future (American Psychological Association, 2018, 2019; Montero et al., 2022). It is also common to see media stories highlight exorbitant medical bills and medical debt that patients face. For example, a 2020 news article reported "on the verge of being intubated and put on a ventilator, the person [a COVID-19 patient] "gasped out" the question, "Who's going to pay for it?" to their medical team" (Mahbubani, 2020). All medical conditions have economic consequences that result from the costs of medical care and treatment, other expenses indirectly related to care such as traveling to access doctors and care facilities, and potential loss of income (Pisu et al., 2018). The scientific literature over the past 10 years has defined and reported on medical "financial hardship" which refers to distress and difficulty in paying medical bills and accessing or using recommended medical care due to cost (Altice et al., 2017). Now, there is increased awareness of "financial toxicity" as a side effect of medical treatment equivalent to other physical toxicities such as nausea, pain, or fatigue (Zafar and Abernethy, 2013). In the United States, it is estimated that 137 million adults experience some form of medical financial hardship, including 28% of adults 65 and older and almost 47% of younger adults (Yabroff et al., 2019), across a spectrum from relatively manageable related distress to catastrophic expenses with medical debt being the number one cause of bankruptcy (Hamel et al., 2016).

Medical financial hardship is associated with worse mental and physical health, and leads to behaviors such as forgoing medical treatment and delaying health care that can be detrimental to health (Altice et al., 2017; Yabroff et al., 2019). However, its full impact on well-being has not been fully investigated yet. In particular, there is a great need to understand how medical financial hardship across its spectrum affects individuals emotionally due to notable and common increases in stress, depression, worry and other negative emotions that may result from such hardship (American Psychological Association, 2018, 2019; Barbaret et al., 2019; Chan et al., 2022; Montero et al., 2022). Similarly, there is a need to understand how these emotions and stress impact health outcomes (Pressman and Cohen, 2005; Diefenbach et al., 2008; Ryff and Singer, 2008; Irwin and Cole, 2011; Boehm and Kubzansky, 2012; Cohen et al., 2012; Pressman et al., 2019). Moreover, while there is growing research on the negative effects of financial hardship, much less is known about what to do to help with this issue. In cancer and other illnesses, patients manage the financial and emotional aspects associated with the economic burden of disease using strategies that can be problem- and/or emotion-focused (even while insured) (Head et al., 2018). It is necessary to understand the broader impacts these strategies have on patients and families. Similarly, interventions may be needed at community, health system, and policy levels to prevent medical financial hardship and its impact on well-being.

To advance knowledge in this area, the Emotional Well-Being and Economic Burden (EMOT-ECON) Research Network was funded to spearhead research and develop new insights about the impact of economic burden of disease on emotional well-being, with the ultimate goal of developing the strategies needed to reduce such impact. It is one of six research networks funded by National Institutes of Health (NIH) agencies to advance research about emotional well-being. Recently, emotional well-being has been defined as "a multi-dimensional composite that encompasses how positive an individual feels generally and about life overall, including both *experiential* features (emotional quality of momentary and everyday experiences) and *reflective* features (judgments about life satisfaction, sense of meaning, and ability to pursue goals that can include and extend beyond the self)" (Park et al., 2022). The economic burden of disease leading to medical financial hardship has the potential to impact both of these features. To guide its work, a Strategic Planning Meeting was convened virtually in October 2021, and an in-person Scientific Meeting was convened in January 2023. The goal of these meetings was to bring together diverse stakeholder groups from academic and other institutions across the US including researchers studying medical financial hardship and/or emotional well-being, patients and patient advocates, and health care providers, to guide ongoing and future work in these intersecting domains. This paper summarizes key discussions and recommendations from these meetings to inform the directions and priorities in the study of the economic burden of diseases and emotional well-being and future work of the EMOT-ECON network.

2. Meeting activities

2.1. Strategic Planning Meeting

The four-hour virtual Strategic Planning Meeting included 13 invited participants from across the US including researchers, patient advocates, and health providers, plus EMOT-ECON investigators (MP, ML, MM) and staff. It started with a summary of existing literature and presentation of a conceptual framework to guide research of the network adapted from an established stress and coping theory (Lazarus and Folkman, 1984) (Figure 1). This framework acknowledges that the primary appraisal of the economic burden of disease as a stressor may be influenced by several health, demographic, social, economic, and psychological factors. Secondary appraisal may lead to different *strategies to deal or cope* with the stressor, selected based on the emotion-and problem-focused coping behaviors identified by Head et al. (2018) in a cancer population. Discussions on this framework were held along the three priority areas of EMOT-ECON, which include (i) Ontology and Measurement, i.e., identifying components of emotional well-being in the context of patients and

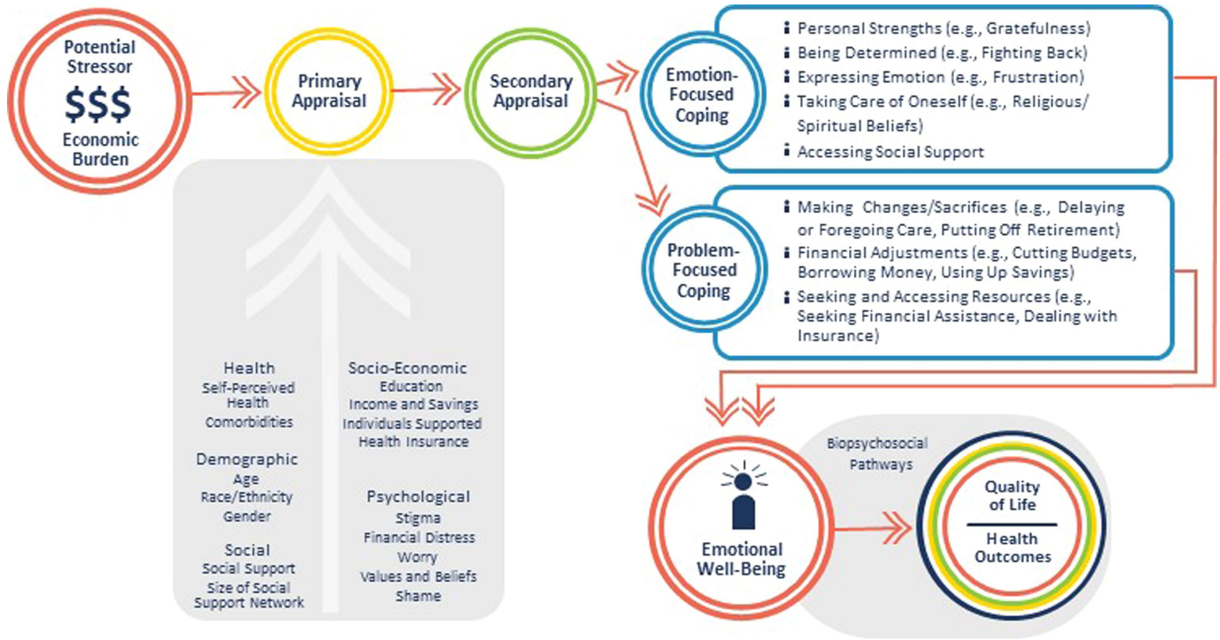

FIGURE 1
Conceptual framework showing the possible pathways in which the economic burden of disease impacts emotional well-being.

families facing economic burden of disease; (ii) Mechanisms, i.e., the processes by which the economic burden of disease affects patients' emotional well-being, and the processes by which emotional well-being affects health in this context; and (iii) Prevention and Intervention, i.e., potential interventions that may be relevant for minimizing the impact of economic burden of disease on emotional well-being. Discussions at this meeting were recorded and transcribed.

2.2. Scientific meeting

The in-person Scientific Meeting was a full day meeting with a total of 29 participants from academic and other institutions across the US including patients and patient advocates, health care providers, representatives from financial and media agencies, and researchers with expertise in psychology, sociology, economics, medicine, and health services research. The meeting included two sets of discussions with one moderator and 5–6 participants in each of 5 roundtables. Each set of discussions lasted about 40 min and the major themes from each roundtable were then shared with the larger group. Participants used sticky notes to write their answers to the posed discussion questions. These were collected by the moderators to guide the discussions and the summary reports to the larger group. All notes were subsequently transcribed. Summary reports were recorded.

For the first roundtable, participants were asked to discuss the different types of *strategies* used to deal or cope when facing different aspects of financial hardship, as well as their potential positive and negative effects on patients (direct effects), and caregivers, families, and others (indirect effects). For the second roundtable, attendees were asked to discuss *potential interventions* for primary, secondary and tertiary prevention. Primary prevention interventions were described as those that may be implemented to prevent the economic burden of disease from becoming a stressor. Secondary prevention interventions were described as those that may be implemented to identify and support patients who experience financial hardship to prevent an impact of financial hardship on emotional well-being. Finally, tertiary prevention interventions were described as those that may be implemented to manage poor emotional well-being resulting from economic burden of disease to avoid exacerbations and complications such as, for example, clinical depression.

3. Summary of Strategic Planning Meeting discussions

3.1. Ontology and measurement

Participants discussed limitations in the definition and measurement of both emotional well-being and financial hardship. For patients who experience medical financial hardship, unique and important elements that may not be appropriately assessed in existing measures of emotional well-being include the ability to get needed care and the ability to remain productive in day-to-day or work-related activities. With respect to economic burden, attendees proposed measuring a different construct. Acknowledging existing measures of overall financial well-being, they discussed measuring medical financial well-being rather than hardship, and then identifying protective factors that may preserve such financial well-being, which would benefit the field by shifting the focus on primary prevention. Similarly, participants noted that current measures of financial hardship relate to defined limited time points, e.g., over the past week or month, and miss the measurement of longer-term or chronic financial hardship, which may have different impacts on emotional well-being and health.

3.2. Mechanisms

Before discussing the mechanisms by which the economic burden of disease affects patients' emotional well-being, participants discussed at length what influences whether the economic burden of disease becomes a stressor. First, participants discussed a hallmark of this stressor, the extreme *uncertainty and unpredictability*, compared to other financial stressors that may be more predictable, such as regular bills and expenses. The following characterize the economic burden of diseases:

(a) Unknown amounts of out-of-pocket expenses for medical care, even when patients are insured;
(b) Unknown timing of medical bills, including when patients are billed and when they should pay the bill;
(c) Unknown consequences of being unable to pay medical bills and worry about being unable to access needed treatment.

It was recognized that patients and their families may have varying baseline financial skills or self-efficacy to problem-solve when faced by these kinds of uncertainty.

Second, attendees identified the *difficulty of dealing with financial issues* as a specific and related stressor. Patients may have difficult and stressful interactions with insurance companies and health care billing offices, and may face the threat of having medical debt turned to collection agencies. These interactions add stress even at low levels of economic burden.

Participants then discussed how research should investigate the extent to which the economic burden of disease is perceived as a stressor across life circumstances. For example, this may depend on when the disease occurs during the lifespan, levels of available family or other support, cultural belief systems, socioeconomic status, or other social determinants of health. Given these varying circumstances, there may be a differential impact on the experiential and reflective components of emotional well-being described above (Park et al., 2022). Similarly, the extent to which economic burden of disease is perceived as a stressor may depend on disease prognosis and curability, which affect how patients prioritize health care in relation to the costs of care, and impact amount and duration of medical expenses and ability to work. Moreover, the extent to which economic burden of disease is perceived as a stressor may differ depending on aspects of the economic burden of disease, e.g., whether patients face high out-of-pocket expenses for care but no job loss vs. low or no high out-of-pocket costs of care but job loss.

With respect to mechanisms by which the economic burden of disease affects emotional well-being, participants discussed the role of what people do to deal or cope with the burden. First, upon reviewing the strategies listed in the conceptual framework, it was recognized that some of them have positive or negative effects on emotional well-being and health. For example, a problem-focused strategy cancer patients commonly adopt is to forgo medical care or to skip prescribed medications to reduce costs (Head et al., 2018). This may have negative consequences for disease progression and health, but it may also impact emotional well-being directly as patients may be acutely aware that this strategy is detrimental to their health. Second, attendees recognized that experiencing emotions such as anger or sadness may be appropriate responses to this burden, and thus contribute positively to emotional well-being. Third, participants discussed the importance of investigating differences in coping strategies and their positive and negative effects for patients with different socioeconomic status or living in different contexts, for example patients living in poverty or rural areas.

Lastly, participants discussed valuable areas of research to understand factors that could moderate the impact of economic burden of disease on emotional well-being. In particular, those discussed were: (i) comfort with uncertainty, (ii) literacy (health literacy, numeracy, insurance literacy, etc.) and the ability to understand costs and manage other personal economic challenges; (iii) resilience; (iv) personal empowerment in interacting with different medical and non-medical professionals to navigate financial hardship; (v) available resources such as support or insurance; and (vi) living context that may be characterized by existing policies or type of health care system, i.e., for example a system of universal health care coverage.

3.3. Prevention and intervention

Considering the stress caused by uncertainty, unpredictability, and dealing with financial issues, participants discussed potential benefits of interventions to improve knowledge of costs, such as financial and/or insurance education interventions. For example, financial counseling/navigation interventions are designed to link patients to needed resources, but could be extended to include efforts to inform patients about monetary costs or time off work, and even guide patients to choose care based on cost information, if appropriate. Entities providing such services could be within health care system or outside: for example, financial and/or insurance education programs may pair insurance representatives with patients to help them choose the "right" insurance, guide them through open enrollment processes, evaluate if supplemental insurance is needed, or simply help them understand what their insurance covers. Participants discussed ongoing projects where patients are paired with a financial counselor from a non-profit consumer education and training service group who help guide patients manage expenses while on treatment (Henrikson et al., 2022; Smith et al., 2022; Wheeler et al., 2022).

Participants considered whether individual-level interventions alone would be effective in reducing the impact of economic burden of disease on emotional well-being. Specifically, there was some discussion on whether stress reduction, coping-based interventions, or family interventions would be effective. Overall, it was acknowledged that financial hardship cannot be addressed solely at the individual level. Attendees considered what kind of studies could be done to inform healthcare policies to prevent economic burden of disease. For example, studies could compare the level of economic burden or financial hardship across states or other geographic areas with different drug pricing policies or health care or insurance market dominance.

3.4. Framework updates and recommendations

Based on the discussions, the network's conceptual framework was updated as shown in Figure 2 to recognize the contexts in which financial hardship occurs and impacts emotional well-being, the

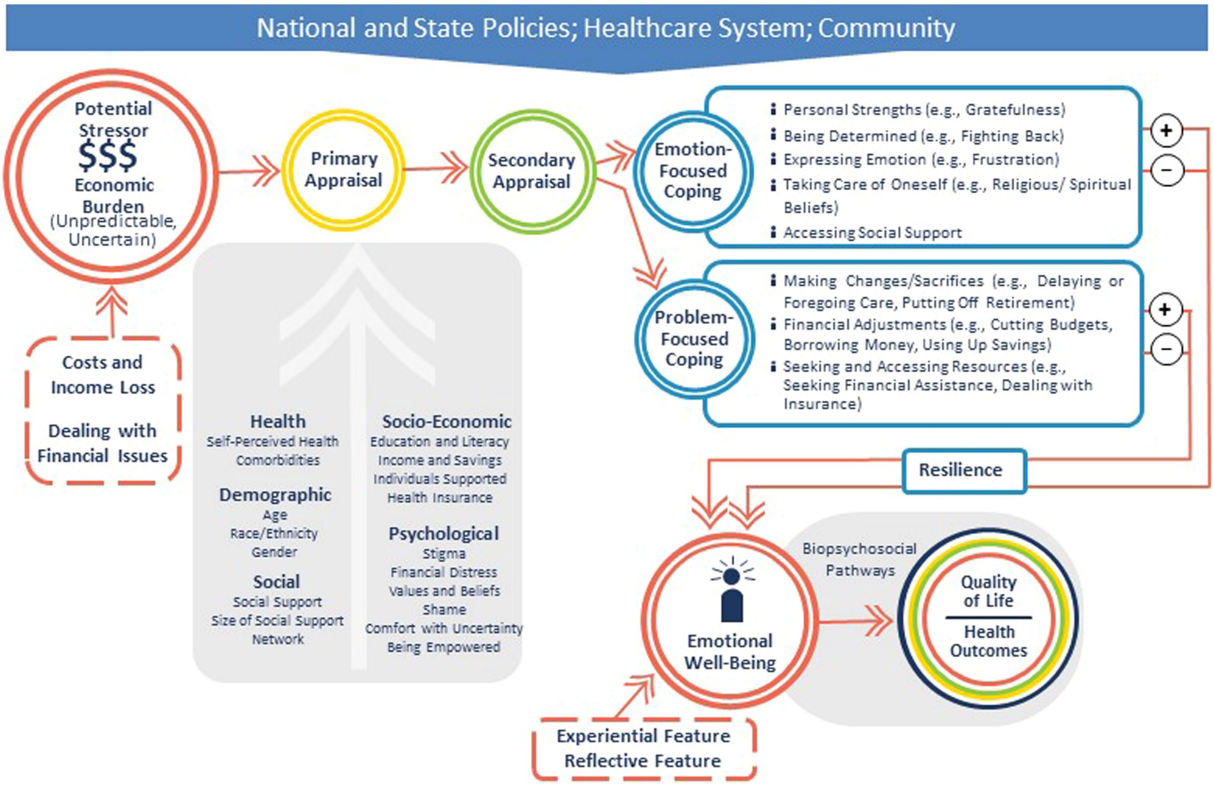

FIGURE 2
Updated conceptual framework after the EMOT-ECON Strategic Planning Meeting.

characteristics and components of the stressor and emotional well-being, and the potential positive and negative effects of the "coping" strategies. Attendees recommended that the research of the EMOT-ECON network should grow organically without preset definitions of either emotional well-being or economic burden and that explorations of all aspects of the framework were needed and valuable. Overall, research on overwhelming costs of healthcare and other economic consequences of disease, and how they impact the emotional well-being of those subjected to such burden, will be important to bring public awareness to these problems.

4. Summary of scientific meeting discussions

4.1. Roundtable discussion on types of strategies to deal or cope with economic burden of disease, and potential positive and negative direct and indirect effects

Table 1 summarizes themes emerging from discussions about strategies which aligned with the emotion-focused and problem-focused coping illustrated in Figure 2. Attendees identified direct positive and negative effects that may be common across several types of strategies (e.g., reduced stress may be a direct positive effect of Managing Stress or Seeking Resources and Information, fatigue and energy expenditure could be direct negative effects of Self-advocating or Seeking Resources and Information) or unique to a strategy (e.g., specific positive and negative effects of Seeking Support). With respect to indirect effects, attendees proposed positive effects such as promoting preventive care in the family, or a transcendent effect by which the patient learns from the experience to help others. For negative indirect effects, attendees discussed the impact on family choices, for example on children's college decisions, on caregivers' work and health, and on relationship strains. Participants also highlighted the feeling of helplessness that not only patients and caregivers, but also others, in particular health care team members, may experience when observing someone deal with medical financial problems. All of these topics constitute important topics for future research on the economic burden of disease and its impact on emotional well-being.

4.2. Roundtable discussion on potential primary, secondary, and tertiary prevention interventions

Participants discussed interventions at society or community, policy, and health care system levels across the three prevention approaches (i.e., primary, secondary, tertiary). Table 2 summarizes interventions for primary and secondary prevention. Discussions recognized that interventions need to reduce health care costs, increase the ability to pay, reduce administrative burden, and raise awareness, education, and training about financial hardship for patients, caregivers, and the workforce of health care, financial and other institutions. Attendees also recognized that these efforts need to

TABLE 1 Some strategies to deal or cope with the economic burden of disease and potential effects identified in roundtable discussions at the Scientific Meeting of the EMOT-ECON network (Memphis, TN, January 2023).

Strategies	Examples	Effects	
		Positive	Negative
Emotional responses	Gratitude, Positive attitude, Manage emotions that prevent active coping, Ignore problem, Feel inadequate, Anger, Guilt, Fear, Shame, Constant grieving, Social disengagement	Discover own strength, Become a role model/example/source of hope	Decrease in emotional regulation, Reduced sense of self-worth, Overwhelming stress that makes it hard to take behavior action
Seeking support	Support from family friends, church, Prayer, Spending time with family, Tangible support with family finding extra job or loan	Become more socially connected, Increased sense of belonging/ community, Renewed appreciation for the existing support, Increased sense of meaning, Winnow social networks to focus on people who are important	Worry about protecting family and friends from stress or from others' judgments or negative reactions, Feel shame or stigma in asking for help, embarrassment about finances in addition to disease, the burden of making others feel more comfortable with the diagnosis, Manage expectations from others, Compare self to others (social media), Relationship erosion
Self-advocating	Self-advocating when dealing with administrative burden	Increased sense of control, Increased resilience, Sharpened self-efficacy skills, Increased awareness of own resourcefulness	Fatigue/feeling overwhelmed from having to self-advocate
Managing stress	Manage stress through meditation, exercise, art therapy, humor and other stress relieving activities, Taking personal time, Substance use and abuse	Reduce stress/hormones (biological benefits), Positive lifestyle changes	Substance use dependency
Seeking resources and information	Seek/utilize financial assistance programs, information about anticipated costs and to navigate complexities of insurance, Track medical and other costs, Get treatments from other countries, Seek cheaper treatments, Find "donors" or use crowdfunding platforms	Decrease debt and burden, Increased sense of control and ability of maintaining normalcy, Reduce stress/ hormones, biological benefits	Fatigue, Extra energy expended, Stress of making the case for worthiness to donors, Donor fatigue based on erroneous belief that costs stop after treatment
Making economic adjustments	Borrow money from friends/relatives/ financial institutions, Seek payment plans and discounts, Deplete savings, Sacrifice leisure activities, Find extra jobs, Apply for disability	Gaining general financial skills, Obtain extra money, Reduced medical costs, Ability to pay medical and other bills	Increased debt, Guilt of spending family money, Disempowerment and lack of control, Feel inadequate (cannot provide for family), Credit rating and long-term impact lasting for years and impacting family members
Making medical care adjustments	Forgo or delay care, Go off treatment without consultation, Ration or stop medicine doses	Reduced treatment costs	Deterioration of health, Suboptimal care, Worry about effects on health
Changing life perspective/goals	Find other positive things in life, Change work/life goals	Become a role model/example/source of hope, Re-assess values and priorities	Not able to have life milestones; Not able to play usual role in family or social circle

go hand in hand with interventions to strengthen mental health, tailoring them to meet patients where they are mentally and financially, so as to provide the best chance of successfully reducing the impact of economic burden. Attendees supported screening for financial hardship, but also for anxiety and depression, recognizing that patients with mental health problems may be less able to deal with practical and financial problems. They also supported financial navigation and coaching in health care and other systems, as well as strengthening peer support to address economic burden.

Discussions for tertiary prevention to manage poor emotional well-being resulting from economic burden of disease and prevent exacerbations and complications reflected on the effects of economic burden and the strategies to deal and cope with this burden reported in Table 1. Participants proposed strengthening mental health workforce and support with interventions to address clinical depression, to target positive affect and also to promote a more holistic, eudaimonic well-being that incorporates meaning and purpose (Ryff, 2017). Moreover, participants

TABLE 2 Some potential prevention interventions identified in roundtable discussions at the Scientific Meeting of the EMOT-ECON network (Memphis, TN, January 2023).

Levels	*Primary Prevention Interventions* To prevent the economic burden of disease from becoming a stressor	*Secondary Prevention Interventions* To prevent an impact of financial hardship on emotional well-being
Society/Community	Early education through schools or media awareness campaigns on: - Costs of care and financial toxicity - Financial education and financial literacy - Health insurance - Emotion-based coping Employment of financial coaches in banks, insurance companies, and other institutions, with training in costs of care and medical debt	Education on insurance literacy and costs of care for patients and caregivers Personal financial coaches in hospitals/clinics Establishment of programs in financial institutions to train employees to help people with severe disease manage overall debt (medical and not).
Policy	*Insurance*: Universal healthcare; Revisiting health insurance benefit/policy to design coverage that minimizes patient burden; Health insurance reform including elimination of premium increases during illness, establishing disease specific out-of-pocket maximum, covering certain conditions fully, offering Medicaid supplements after reaching out-of-pocket maximum regardless of personal resources; Close coverage gap for Social Security Disability Insurance and Medicare. *Income-related*: Guaranteed income during severe illness and for clinical trial participation; Employment protections; Automatic eligibility for disability for specific diagnoses without burdensome eligibility process and automatic renewals. *Pharmaceutical companies*: Policies to lower costs of drugs; Drug price policy reform. *Research*: Funding for research to gain evidence for policy change.	*Insurance*: Ensure coverage for mental health.
Health care system	*System-level changes*: *Costs*: Reduced operation costs; Provision of transportation and more local services to decrease travel costs; Implementation of institutional simplification to reduce administrative burden. *Care*: Standardized provision of information on support systems and expected cost estimates early in treatment; *Mental health*: Establishment of screening for depression and anxiety as patients with mental health problems may be less able to deal with practical and financial problems *Workforce*: Establishment of financial navigation/counseling; Increased providers' awareness of economic burden of disease and of resources available to help patients; Creation of medical school curricula to raise awareness about costs of care *Patients*: Patient education on asking questions about resources, Removal of stigma	*System-level changes*: Establishment of universal screening for financial issues and risk of job loss; Systematic queries of social needs and screening patients based on available metrics at the institutions, i.e., prior use of financial assistance or payment plans, debt with institution, high utilization of ED; Establishment of a stratification system for people who need more or less intervention support; Establishment of workflow to deal with crisis, i.e., for patients with severe financial distress. Optimization of follow-ups and referral to available resources post financial hardship screening; Reducing administrative burden, and wait times while improving referral systems; Consideration of billing pauses and billing forgiveness tied to payment; Lower patient costs/fees; *Care*: Provision of consolidated care to reduce costs and address all patients' needs; Provision of treatment plans that include costs; Interventions based on patient's profile and/or previous history of mental and financial stress; Ensuring patients are comfortable accessing provider care team (doctors, navigators, etc). *Workforce*: Provision of training on cost conversations; Establishment and training of financial navigators or coaches. *Patients*: Establishment of support groups with patients with financial hardship experience or training existing support groups to talk about costs of care and financial hardship; Education on disability benefits; Informational support to stop avoidance behaviors like ignoring payments due; Financial and insurance literacy training; Education for caregivers.

discussed the need to support caregivers facing burnout and helplessness.

5. Conclusion

Researchers, patients, health care providers, patient advocates, and other stakeholders, bring unique perspectives to the task of understanding the impact the economic burden of disease on emotional well-being and ultimately on health. This cross-disciplinary lens made for unusually energizing and creative discussions at the Strategic Planning and Scientific meetings of the EMOT-ECON network, attesting to the unique value and power of this approach. Overall, although not an exhaustive list, participants identified some important future areas of research, which included: (i) aspects of emotional well-being relevant to patients experiencing economic burden of disease and financial hardship, both in terms of what are prevalent and relevant emotions, and how the broader outlook on life is impacted; (ii) constructs and contexts that may influence, or protect from, perceiving the economic burden as stressful; (iii) ways in which patients deal or cope with the medical financial hardship across different contexts and populations with positive or negative effects on emotional well-being and health; and (iv) interventions at multiple levels and from multiple stakeholders that address economic factors (e.g., costs, ability to pay), administrative burdens, education and training, and especially patient's emotional as well as financial status.

Discussions at these EMOT-ECON meetings and the updated framework align with current research on financial hardship. For example, recent research has started to recognize the complexity of such hardship which is not only due to high costs of care or reduced ability to work and earn an income, but to uncertainty and the difficulty of dealing with financial issues. Cancer patients in Gharzai et al. (2021) described the impact of having limited knowledge of the treatment course, of the costs and work limitations to be incurred, and the financial adjustments patients make through treatment. Lyman and Kuderer (2020) discuss the "abuse" and "torture" associated with dealing with the health care system when patients are not able to meet financial responsibilities, especially for the most vulnerable patients. In a German population with a different health care system from the US, Lueckmann et al. (2022) found that bureaucracy had a significant impact on whether patients experience financial distress, with patients feeling helpless due to time-consuming and complex processes, incomprehensible decisions by authorities and agencies, and lack of knowledge about rules and regulations when dealing with these entities. Thus, as emerging from the EMOT-ECON meetings, future areas of research may include the investigation of personal characteristics like comfort with uncertainty, empowerment in dealing with financial issues, or literacy (e.g., health literacy, health insurance literacy, numeracy), and their role in how patients deal with the characteristics and components of the economic burden of disease, how they cope, and what the effects of that coping are on emotional well-being. The need to maintain focus on structural problems (cost of healthcare, insurance bureaucracies) is also key going forward.

The strategies identified in our meetings to deal and cope with the economic burden of disease build on those identified in previous literature (Head et al., 2018; Banegas et al., 2019; Kayser et al., 2021). Several frameworks recognize the potential negative impact of creative but medically non-advisable problem-focused strategies like lower adherence to treatments, delayed or forgone care (Altice et al., 2017; Carrera et al., 2018; Lentz et al., 2019). However, the literature has not clearly delineated the pathways by which financial hardship, directly and through these strategies, affects emotional well-being, health, and quality of life. Some studies have examined the mediator effects of social support and limiting care due to costs on the relationship between financial toxicity and quality of life (Hastert et al., 2019; Hallgren et al., 2020). Santacroce and Kneipp (2019) explicitly includes the biological response to stress in the pathway from financial hardship to quality of life outcomes of parents of pediatric oncology patients, which is critical because this increased stress can change disease course and related outcomes (Cohen et al., 2007). The themes reported in Table 1, although not exhaustively, provide an initial roadmap to guide future research on understanding the occurrence and extent of proposed direct and indirect effects of strategies to deal with the economic burden of disease. Importantly, our discussions highlighted the impact these strategies may have in the present, but also on the long-term financial status and outlook on life and future well-being of patients and families. Further research on all these aspects and on mechanisms by which the economic burden of disease impacts emotional well-being, and then overall health, is required to evaluate the full impact of financial hardship due to disease. Previous literature on emotions and stress has shown how these may have important implications for health outcomes by significantly altering physiological processes, for example, impacting the immune system, increasing inflammation and susceptibility to infection or by leading to poor health behaviors, such as poor sleep quality, unhealthy eating habits, and reduced physical activity (Diefenbach et al., 2008; Irwin and Cole, 2011; Cohen et al., 2012). Positive emotions, however, can be protective by leading to improvements in health behaviors, undoing some of the health harms of stress and together with other types of psychological well-being (e.g., purpose, good relationships) leading to healthier physiological profiles (e.g., healthier blood pressure and immune function), better longevity and disease morbidity, and in some cases, higher disease survival (Pressman and Cohen, 2005; Ryff and Singer, 2008; Boehm and Kubzansky, 2012; Pressman et al., 2019). Thus, it is important to understand how emotions and stress deriving from the economic burden of disease impact physiology and health behaviors, and if intervening on these leads to better health outcomes in patients experiencing medical financial hardship.

Participants highlighted how interventions to prevent or mitigate financial hardship are not limited to providing financial support either by reducing costs or providing financial navigators or counseling. Some of these interventions have been or are currently being tested (Patel et al., 2021; Smith et al., 2022), and will be important tools to prevent the impact of economic burden of disease on emotional well-being. Discussions at the EMOT-ECON meeting highlighted the concurrent need for mental health interventions to prevent financial hardship in patients who may be too stressed to deal with financial issues, or to mitigate its impact for those already experiencing it. In fact, several strategies were proposed to systematically identify and intervene on individuals based on both their emotional and financial status. The effectiveness of this approach across a spectrum of financial hardship severity would be an important area of future research. Moreover, as previously advocated (Yabroff et al., 2020), participants recognized that, to make meaningful changes, addressing medical financial hardship requires a multilevel approach and multiple stakeholders' commitment starting with raising awareness and educating individuals before they become patients.

In summary, discussions at the EMOT-ECON network meetings highlighted the significance of addressing the impact of the economic burden of disease on emotional well-being and beyond, the complexity of this prevalent problem for patients and families, and the research gaps that still need to be studied. The EMOT-ECON network will support researchers who tackle these research gaps to advance understanding of both the economic burden of disease and emotional well-being, and help build the knowledge base to ultimately develop strategies to reduce the impact of economic burden of disease on the emotional well-being, and ultimately the health, of patients and their loved ones.

Author contributions

MPi and MM developed the concept and obtained funding for the EMOT-ECON network. MPi wrote the manuscript. MM and ML contributed critical revisions to the first draft of the manuscript. All authors contributed to organization, conduct of the EMOT-ECON meetings, manuscript revisions, read, and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Financial toxicity in cancer patients and subsequent risk of repeat acute care utilization

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Background: Acute care (AC) visits by cancer patients are costly sources of healthcare resources and can exert a financial burden of oncology care both for individuals with cancer and healthcare systems. We sought to identify whether cancer patients who reported more severe initial financial toxicity (FT) burdens shouldered excess risks for acute care utilization.

Methods: In 225 adult patients who participated in the Economic Strain and Resilience in Cancer (ENRICh) survey study of individuals receiving ambulatory cancer care between March and September 2019, we measured the baseline FT (a multidimensional score of 0–10 indicating the least to most severe global, material, and coping FT burdens). All AC visits, including emergency department (ED) and unplanned hospital admissions, within 1-year follow-up were identified. The association between the severity of FT and the total number of AC visits was tested using Poisson regression models.

Results: A total of 18.6% ($n = 42$) of patients had any AC visit, comprising 64.3% hospital admissions and 35.7% ED visits. Global FT burden was associated with the risk of repeat AC visits within 1-year follow-up (RR = 1.17, 95% CI 1.07–1.29, $P < 0.001$ for every unit increase), even after adjusting for sociodemographic and disease covariates. When examining subdimensions of FT, the burden of depleted FT coping resources (coping FT) was strongly associated with the risk of repeat AC visits (RR = 1.27, 95% CI 1.15–1.40, $P < 0.001$) while material FT burden showed a trend toward association (RR = 1.07, 95% CI 0.99–1.15, $P = 0.07$).

Conclusion: In this prospective study of acute oncology care utilization outcomes among adult cancer patients, FT was a predictor of a higher burden of acute care visits. Patients with severely depleted material and also practical and social coping resources were at particular risk for repeated visits. Future studies are needed to identify whether early FT screening and intervention efforts may help to mitigate urgent acute care utilization burdens.

KEYWORDS

financial toxicity, cancer, acute care, emergency department, screening

Introduction

Cancer patients and survivors experience significant personal economic burdens from direct out-of-pocket medical costs, productivity losses, and employment disability. These burdens can total up to thousands of dollars of financial burden to the patient annually, ultimately leading to financial toxicity (FT) after the diagnosis and treatment of the disease in up to half of individuals with cancer (Pisu et al., 2018; Smith et al., 2019; Mariotto et al., 2020). FT disproportionately impacts vulnerable cancer patients—those who are younger or socioeconomically disadvantaged (Pisu et al., 2018; Smith et al., 2019) and the financial burdens can be exacerbated when the patients require acute care through repeated emergency department (ED) visits and unplanned hospitalizations (Peery et al., 2015; Albright et al., 2019; Whitney et al., 2019).

In general populations of elderly patients, evidence suggests that individuals reporting more severe health-related social needs—such as financial, food, transportation, or housing insecurity as well as loneliness—subsequently require more frequent ED and acute hospital visits, including avoidable causes. Avoidable causes in these general patient populations include infection, exacerbation of chronic cardiopulmonary conditions, and falls or trauma. Such prior evidence has therefore prompted and supported the rationale for enhancing social needs screening and early intervention on health-related social needs in general medical settings to help mitigate costly acute care utilization burdens and associated poor health outcomes in the general population (Oh et al., 2018; Lash et al., 2022; Alishahi Tabriz et al., 2023).

In cancer patients, however, it remains unclear whether a similar association exists for health-related social needs predicting excess acute care utilization in this population. Such evidence would support FT interventions as a potential tool for mitigating costly and repeated acute care utilization specifically for this group (Traeger et al., 2015; Basch et al., 2017; Nipp et al., 2019). To address this knowledge gap, the evaluation of acute care utilization patterns associated with cancer-related FT is needed. Cancer-related FT is a construct that incorporates the needs that arise from both health-related material and psychosocial coping burdens. Furthermore, FT can be captured using validated measurement in individuals with cancer (Smith et al., 2019, 2021, 2022; Blinder et al., 2022). Thus, the excess risks for both avoidable and unavoidable acute care utilization associated with FT in the oncology care setting can be quantitatively elucidated. For cancer populations, avoidable causes of acute care utilization could include anemia, nausea, vomiting and dehydration, fever, and infection (Alishahi Tabriz et al., 2023). Such an analysis in cancer patients is important to inform current efforts to expand FT screening (Bradley et al., 2021; Shih et al., 2022), define relevant adverse outcomes associated with FT, and create intervention strategies to mitigate adverse outcomes in this population (Smith et al., 2022). Therefore, to advance this understanding, we conducted a survey-based study to quantify FT in a diverse sample of adult patients with cancer and prospectively characterized acute healthcare utilization patterns. The primary objective of this analysis was to quantify the association between the severity of patient-reported FT and subsequent acute care utilization within the following year. We hypothesized that patients experiencing more severe FT would experience a higher burden of acute care utilization.

Methods

This study was approved by the University of Texas M. D. Anderson Cancer Center Institutional Review Board.

Data sources and patient sample

Eligible participants were enrolled in the Economic Strain and Resilience in Cancer (ENRICh) study (the parent study was previously reported in prior publications Smith et al., 2021; Xu et al., 2022) between March 2019 and September 2019. All participants were at least 18 years old, receiving ambulatory cancer care for pathologically confirmed cancer in 1 of 14 different radiation, surgical, or medical oncology clinics at a comprehensive cancer center main campus or community-based satellite clinical sites. Of the 364 patients approached for study participation, 232 patients (64%) agreed to participate. Excluded from analysis were patients who did not answer at least half of the survey questions ($N = 1$), did not consent to medical record review ($N = 2$), or were lost to clinical follow-up after the survey date ($N = 4$), leaving a final analytic sample size of $N = 225$.

Outcome: acute care visits

We extracted from the electronic medical record encounters for any unplanned hospitalizations or emergency care visits in the oncology center, which were defined as care encounters requiring acute care utilization. The follow-up period spanned 1 year from the participant's survey date. The type of visit was confirmed in the electronic health record and medical claims as urgent, unplanned, or not elective. Each visit was further categorized as all-cause or potentially avoidable by a review of coded reasons for the visit/admission and a review of the medical chart notes, with the categorization guided by previously published criteria for categories of avoidable acute care visit types by the Centers for Medicare and Medicaid Services (CMS) quality indicators for patients with cancer (anemia, nausea, fever, dehydration, neutropenia, diarrhea, pain, pneumonia, sepsis, or emesis) (Alishahi Tabriz et al., 2023; Qualitynet, n.d.). For analyses, the outcome of acute care (AC) visits was categorized dichotomously (any AC visit vs. none during 1-year follow-up) or as the total number of AC visits during 1-year follow-up.

Financial toxicity and other covariates

To assess FT, patients completed a survey including the ENRICh FT instrument, a measure comprised of 15 items for patient-reported severity of cancer-related financial burden (Smith et al., 2021). The global FT score, representing the overall FT burden, was calculated along with the scores for material FT and coping FT subdimensions. The global and subdimension scores

TABLE 1 Univariable associations of patient characteristics with the outcome of any acute care (AC) Visits by 1-year follow-up.

	Any AC visit *n* (%)	No AC visit *n* (%)	*P*-value
Age, median (interquartile range)	60.6 (52.0–70.1)	63.1 (53.6–70.1)	0.44
Sex			0.14
Female	19 (45.2%)	106 (57.9%)	
Male	23 (54.8%)	77 (42.1%)	
Race and ethnicity			0.91
White non-Hispanic	30 (71.4%)	138 (75.4%)	
Any Hispanic or Latino	7 (16.7%)	25 (13.7%)	
Black or African American Non-Hispanic	4 (9.5%)	15 (8.2%)	
Asian Non-Hispanic	1 (2.4%)	5 (2.7%)	
Education			0.90
Less than high school	1 (2.4%)	4 (2.2%)	
High school or GED	6 (14.3%)	37 (20.2%)	
Some college, associate degree or trade certification	17 (40.5%)	72 (39.3%)	
College degree (BS, BA)	10 (23.8%)	43 (23.5%)	
Graduate degree (MS, MA)	5 (11.9%)	18 (9.8%)	
Advanced degree (PhD, MD, JD)	3 (7.1%)	8 (4.4%)	
No response	0 (0.0%)	1 (0.6%)	
Household income			0.50
$0–$19,999	3 (7.3%)	16 (8.8%)	
$20,000–$49,999	11 (26.8%)	30 (16.6%)	
$50,000–$74,999	6 (14.6%)	32 (17.7%)	
$75,000 or more	21 (51.2%)	103 (56.9%)	
Insurance			1.00
Employer or marketplace-based	23 (54.7%)	99 (54.1%)	
Medicaid	1 (2.4%)	5 (2.7%)	
Medicare	17 (40.5%)	74 (40.4%)	
Other	1 (2.4%)	5 (2.7%)	
Cancer type			**<0.001**
Breast	7 (16.7%)	75 (41.0%)	
Central nervous system	1 (2.4%)	3 (1.6%)	
Gastrointestinal	11 (26.2%)	13 (7.1%)	
Gynecological	3 (7.1%)	4 (2.2%)	
Head and neck	8 (19.1%)	18 (9.8%)	
Leukemia/lymphoma/myeloma	4 (9.5%)	11 (6.0%)	
Lung	6 (14.3%)	18 (9.8%)	
Prostate	0 (0.0%)	28 (15.3%)	
Other	2 (4.8%)	13 (7.1%)	
Disease extent			**0.001**
Local	7 (16.7%)	90 (49.2%)	
Regional	16 (38.1%)	50 (27.3%)	
Distant	15 (35.7%)	35 (19.1%)	

The bold values indicate $P < 0.05$.

range from 0 to 10, with 0 representing the least FT burden and 10 representing the most severe FT burden. The material FT subdimension score reflects financial depletion from aspects such as out-of-pocket medical costs, spent savings, accumulated debt, and lost income related to the respondent's cancer diagnosis, treatment, and survivorship. The coping FT subdimension score reflects the severity of depletion of resources to cope with FT burdens, such as savings or income, employment benefits, and formal organization-based resources (e.g., charities and professional organizations) and informal resources to financially cope (e.g., financial and resource help from family and friends) (Lentz et al., 2019) (Supplementary material). The ENRICh FT measure and the subdimensions it measures have been examined to be valid and reliable in previously published psychometric analyses (Smith et al., 2021; Xu et al., 2022) and predictive of adverse health outcomes (Maldonado et al., 2021; Corrigan et al., 2022). Prior published psychometric analyses were conducted for item reduction and evaluation of reliability with high internal consistency and demonstrated criterion validity and known-group validity. In descriptive statistics, FT scores were presented by quartiles, and in analytic models for this analysis, FT scores were tested as continuous variables, as per prior published analyses (Corrigan et al., 2022; Xu et al., 2022).

Sociodemographic and clinical covariates including patient age (at survey), sex, race, ethnicity, cancer histology type, cancer acuity, chemotherapy use, and extent of disease (local, regional, and distant guided by SEER overall staging approach) were abstracted from the electronic health record. For analyses, based on distributions, race and ethnicity were recategorized as a dichotomous variable as White non-Hispanic vs. others (combining non-White Hispanic or non-Hispanic plus another Hispanic ethnicity); the extent of cancer stage was dichotomized as distant vs. local or regional; and the cancer histology type was recategorized as higher acuity cancer disease site vs. lower acuity cancer disease site based on the empiric distribution of acute care visit counts by patients with that disease type above and below the median number of visits. Higher acuity utilization disease types included gastrointestinal, head and neck, and lung cancers. Lower acuity cancer sites included breast, prostate, leukemia, lymphoma, myeloma, gynecologic, central nervous system, skin, soft tissue, genitourinary, neuroendocrine, thymus, thyroid, and unknown primary cancers.

Statistical analysis

Univariable associations between patient sociodemographic and clinical characteristics with the dichotomous outcome of any

AC visits were tested using Pearson's chi-square test or Fisher's exact test for categorical variables and the Wilcoxon rank sum test for continuous variables. The likelihood ratio chi-square test in a logistic model was used to examine the unadjusted association between global FT and any AC visits.

The association between FT and repeated episodes of AC visits was then examined using Poisson regression models. We specified Poisson regression models with a log-link function to estimate the relative risk (RR) of acute care visits across the FT scoring scale (from 0 to 10), with the estimate reflecting the increase in risk per each 1-unit increase in the score. A parsimonious final model was selected to reduce collinearity and include *a priori* clinically relevant covariates (Corrigan et al., 2022). Analyses were conducted using SAS Enterprise Guide version 7.11 (Cary, NC). Statistical tests were two-sided with a P-value of <0.05 considered statistically significant.

Results

Patient characteristics

Among all participants ($N = 225$), 42 patients (18.6%) utilized any AC visit within 1 year of follow-up, for a total of 84 AC visits. Visits were comprised of 54 (64.3%) inpatient admissions and 30 ED visits (35.7%). The most frequent causes for AC visits were cellulitis ($n = 8$), pneumonia ($n = 5$), pleural effusion ($n = 5$), fever of unknown origin ($n = 4$), and dehydration ($n = 4$). The most frequent causes for visits requiring inpatient admission were cellulitis ($n = 7$), pleural effusion ($n = 3$), and abdominal abscess ($n = 3$). A total of 24 (28.5%) visits were categorized as potentially avoidable. Patients with regional and distant diseases were more likely to require any AC visits. The most common cancer types requiring AC visits included gastrointestinal (26.2%), head and neck (19.1%), breast (16.7%), and lung (14.3%) cancers (Table 1).

Severity of FT burden and subsequent risks of AC visits

The median time from survey respondents' diagnoses of cancer to their FT survey was 7.4 months (interquartile range 3.4–13.2). A total of 12.5% of patients with the lowest global FT burden (1st quartile of FT scores) required any AC visit within 1-year follow-up compared with 17.9% of patients in the second quartile, 21.1% of patients in the third quartile, and 25.0% of patients in the fourth quartile (most severe FT burden). The distribution of patients requiring multiple AC visits is also shown in Figure 1. A total of 7.0 and 7.1% of patients in the third and fourth quartile of FT burden had three or more AC visits, while 0.0 and 2.5% of patients in the first and second quartile had three or more visits. On unadjusted analysis, there was a trend toward significance in the association between global FT burden and the likelihood of any AC visit [Odds Ratio (OR) = 1.11; 95% Confidence Interval (CI) 0.99–1.24; $P = 0.087$ for every unit increase in the ENRICh FT score]. Global FT burden was associated with a lower likelihood of potentially avoidable (vs. all-cause) AC visit (OR = 0.74, 95% CI 0.85–0.96; $P =$ **0.02**).

Global FT burden was associated with the risk of repeat AC visits within 1-year follow-up (RR = 1.17, 95% CI 1.07–1.29, **$P < 0.001$** for every unit increase), even after adjusting for sociodemographic covariates, disease acuity type, and disease extent (Table 2). When examining subdimensions of FT, the burden of depleted FT coping resources (coping FT) was strongly associated with the risk of repeat AC visits (RR = 1.27, 95% CI 1.15–1.40, **$P < 0.001$**), while material FT burden showed a trend toward association (RR = 1.07, 95% CI 0.99–1.15, $P = 0.07$) (Table 3). When examining the outcome of repeated potentially avoidable AC visits vs. all-cause visits or no visits, there was not a significant adjusted association with FT measures (Global FT RR = 0.96, 95% CI 0.80–1.16, $P = 0.69$; Material FT RR = 0.94, 95% CI 0.81–1.09, $P = 0.43$; Coping FT RR = 1.02 RR = 0.83–1.25, $P = 0.84$). The

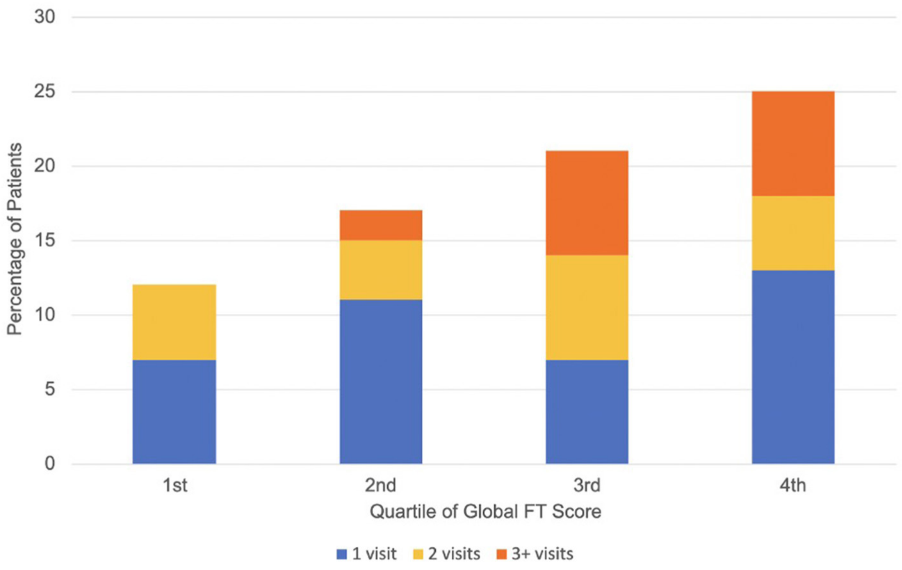

FIGURE 1
Distribution of acute care visit frequency by quartile of global financial toxicity score. Higher quartile represents worse financial toxicity.

acuity of the disease site was associated with the risk of repeated AC visits in these models, while age was not significantly associated including in sensitivity analyses that characterized age categorically (Supplementary material).

Discussion

In our study cohort of adult cancer patients with a spectrum of disease types undergoing comprehensive cancer care, individuals with the highest quartiles of severity of cancer-related FT at the study baseline showed significant, excess risks of subsequent acute oncology care utilization through 1-year follow-up. This included excess risk of all-cause and potentially avoidable clinical indications for care, with the vast majority of clinical encounters, more than 70%, not being potentially avoidable. More severe FT coping resource depletion—including the depletion of material, employment, professional, and social support resources—was especially predictive of subsequent repeat AC visits. Coping resource depletion was a stronger predictor of these repeat AC visits than direct material depletion. FT as a predictor of repeat AC visits remained significant even after accounting for disease type acuity and extent.

TABLE 2 Multivariable predictors of repeated acute care visits by global financial toxicity (FT) score.

	Global FT		
	Estimate	95% CI	*P*-value
FT score	1.17	1.07–1.29	**<0.001**
Age	1.01	0.99–1.03	0.39
Race/ethnicity			
White non-Hispanic	1		
Other	1.48	0.91–2.38	0.11
Cancer type			
Higher acuity cancer disease site	1		
Lower acuity cancer disease site	3.22	2.05–5.05	**<0.001**
Disease extent			
Local or regional	1		
Distant metastases	1.09	0.68–1.75	0.72

The bold values indicate $P < 0.05$.

While consistent with evidence that lower socioeconomic status is associated with more frequent acute care use in general medical populations (Hong et al., 2007; Lash et al., 2017), results from the present study provide additional insight to our previously reported data specific to cancer patients, which identified that patients with more severe cancer-related FT baseline were more likely to miss routine oncology care visits (Maldonado et al., 2021) but accumulate excess unpaid medical debt within 6-month follow-up. Collectively with results from the prior study, the present analysis suggests a possible explanatory mechanism, where patients experiencing severe resource privations have a paucity of financial, coping, and social resources that contribute to lower access or adherence to planned, non-urgent oncology care visits in the short term. However, missed routine or necessary visits subsequently lead to higher risks of acute clinical complications and unmet supportive care needs, resulting in a higher frequency of urgent care use on longer-term follow-up (Hong et al., 2007). What remains needed in the additional prospective study is to determine whether this association is causal. Furthermore, future investigation is needed to discern whether efforts for early identification of and financial navigation in high-risk cancer patients with FT will translate into a meaningful decrease in acute oncology care resource burdens for healthcare systems (Raghavan et al., 2021), especially given the finding in our data that the acute visits in patients with severe FT were more likely all-cause than potentially avoidable.

There are limitations to consider. Though the patient sample had a variety of tumor types and acuity, this study was based at one comprehensive cancer center in a single metropolitan area in the USA, and therefore, additional studies to validate findings in highest-risk populations for FT, such as patients who are uninsured

TABLE 3 Multivariable predictors of repeated acute care visits by coping and material financial toxicity (FT) subdimension scores.

	Material FT			Coping FT		
	Estimate	95% CI	*P*-value	Estimate	95% CI	*P*-value
FT score	1.07	0.99–1.15	0.07	1.27	1.15–1.40	**<0.001**
Age	1.00	0.99–1.02	0.66	1.01	0.99–1.03	0.22
Race/ethnicity						0.38
White non-Hispanic	1			1		
Others	1.55	0.95–2.51	0.08	1.44	0.90–2.33	0.13
Cancer type						
Higher acuity cancer disease site	1			1		
Lower acuity cancer disease site	3.11	1.99–4.88	**<0.0001**	3.54	2.24–5.60	**<0.001**
Disease extent						
Local or regional	1			1		
Distant metastases	1.15	0.71–1.85	0.57	1.06	0.66–1.70	0.80

or receiving care through healthcare safety net systems, are still needed. Because the sample of survey respondents selected from this population of academic comprehensive cancer care center patients was comprised of 74.7% non-Hispanic White, 38.8% with a college degree or higher, 55.1% with an annual household income of $75,000 or more, and 97.3% with an insurance other than Medicaid public insurance, the results may have limited generalizability, particularly to uninsured and underinsured lower-income US populations. Another key issue is that the outcome of AC visits was defined by healthcare claims from care through the comprehensive cancer center and, therefore, focused on oncology care. Patients may have also sought acute care outside the hospital system, and these encounters were not captured.

Conclusion

In this prospective study of acute oncology care utilization outcomes among adult cancer patients reporting a spectrum of financial burdens, FT measured using the validated multidimensional ENRICh tool was a predictor of a higher burden of acute care visits. The strongest association was demonstrated in patients reporting the most severely depleted FT coping resources (material, practical, and social resources), who subsequently were at risk for repeated ED visits and unplanned inpatient admissions. Findings emphasize the potential value of FT as a patient-reported outcome not only for predicting adverse downstream medical and economic outcomes seen in prior studies but also for predicting care delivery outcomes that impact individuals and healthcare systems. Future studies are needed to identify whether early FT screening and intervention efforts may help to mitigate urgent acute care utilization burdens.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by MD Anderson Cancer Center Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The Ethics Committee/Institutional Review Board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because it was a minimal risk, confidential electronic survey study where written informed consent would be burdensome on participants.

Author contributions

SP, RV, SG, Y-CS, GS, and C-FW contributed significantly to the experimental design. JS, JM, SP, Y-SC, KK, and KD implemented the data. JS, JM, KD, SP, C-FW, Y-CS, and GS analyzed and interpreted the data. All authors contributed to the writing or revision and approval of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1209526/full#supplementary-material

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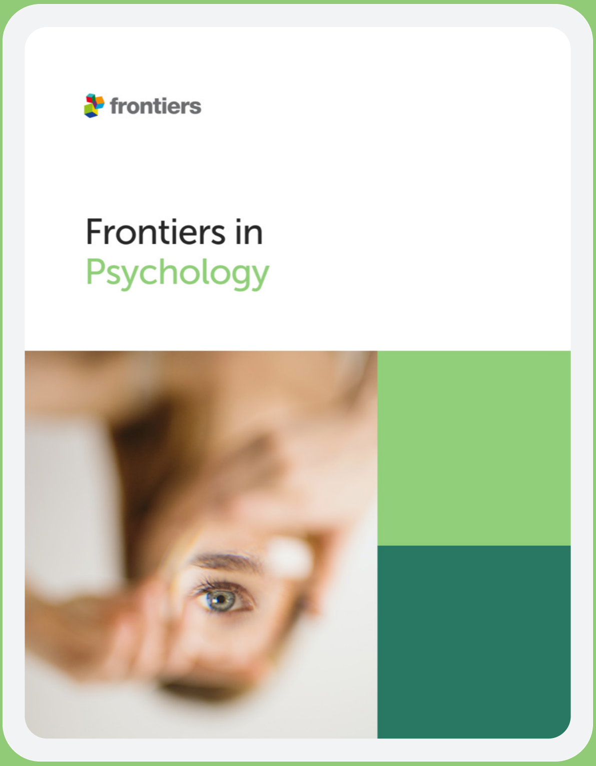

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