

# A Research Agenda to Address Cancer-Related Financial Hardship

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# Talking points

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*The high cost of cancer care, other cancer-related expenses and employment disruption can lead to financial hardship*

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*NCI priorities for research to address cancer-related financial hardship*

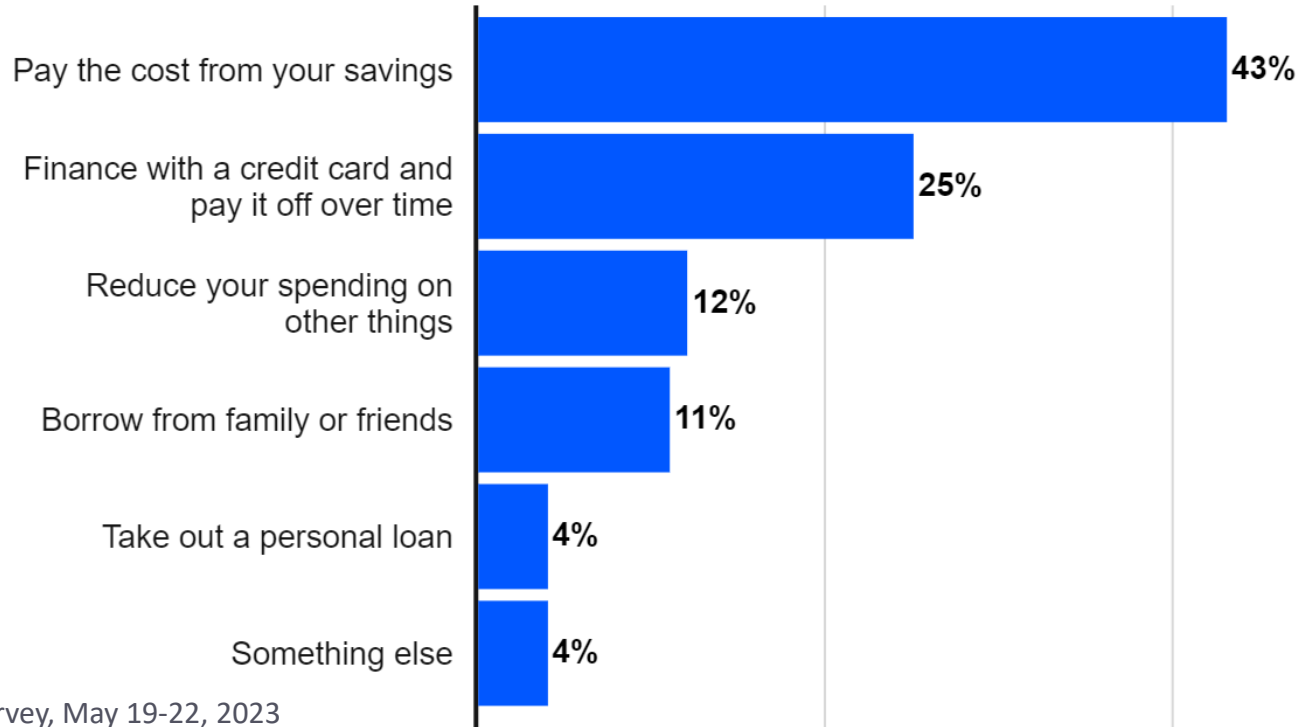
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*Ongoing research to identify and address financial concerns among cancer patients and their families*

# Economic well being of households in the United States

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- How households would pay for a \$1,000 surprise expense.

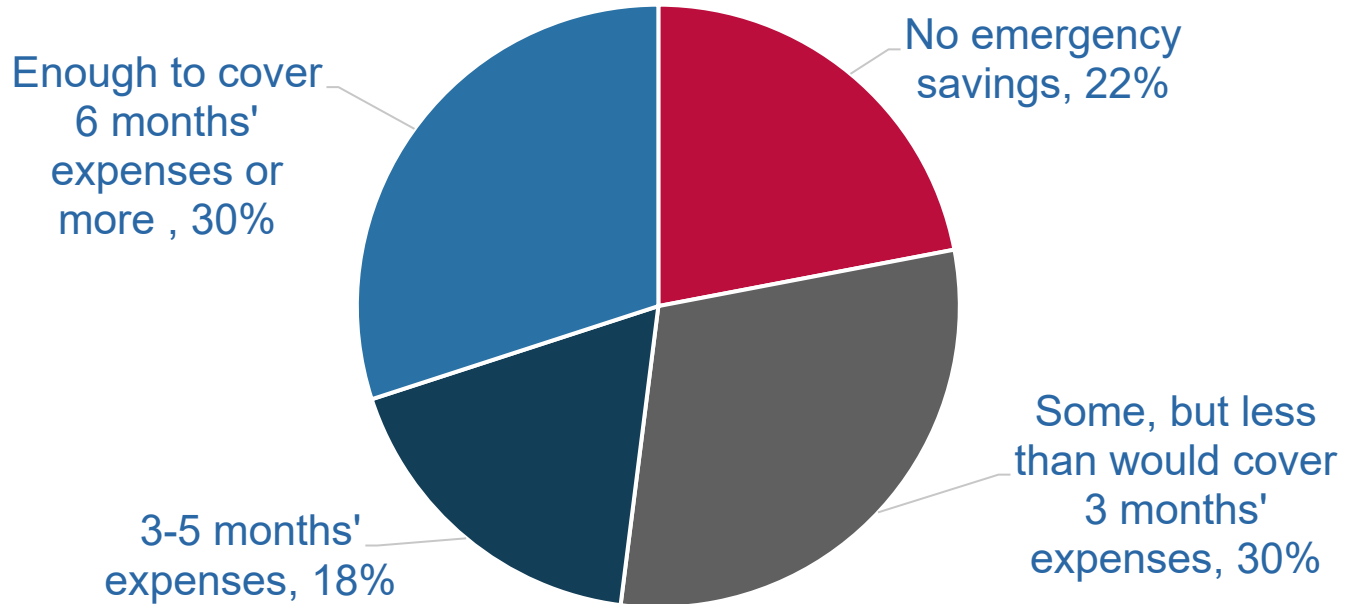


Source: Bankrate survey, May 19-22, 2023

# Economic well being of households in the United States

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- Money in emergency savings (e.g., money readily available in a checking account, savings account, or money market)



## Percentage of civilian workers with access to paid leave by income strata

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Leave benefit	<b>Lowest 10 percent</b>	Lowest 25 percent	Second 25 percent	Third 25 percent	Highest 25 percent	Highest 10 percent
Family	<b>6%</b>	14%	26%	30%	41%	48%
Holidays	<b>46%</b>	60%	84%	90%	85%	86%
Personal	<b>15%</b>	26%	49%	56%	67%	67%
Sick	<b>40%</b>	58%	84%	88%	95%	96%
Vacation	<b>43%</b>	55%	83%	90%	82%	84%

# Conceptual framework for thinking about the financial burden of cancer



**>50%** of working age survivors report at least 1 material, psychological or behavioral domain of financial hardship

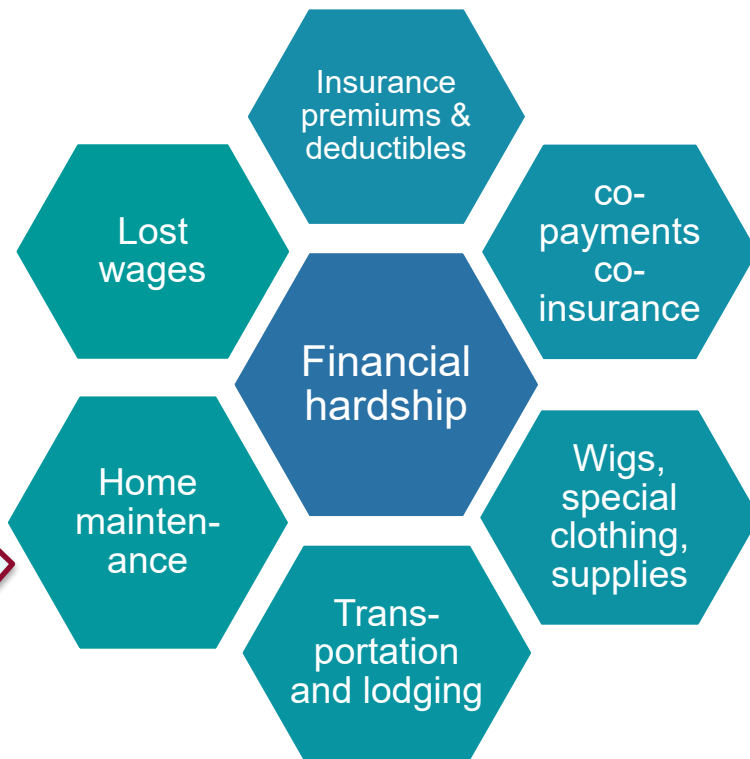
*(Cancer Epidemiol Biomarkers Prev (2020) 29 (2): 308–317.)*

- **Material conditions:** OOP costs for medical care and other cancer-related expenses, lost wages.
- **Psychological response:** distress and poor quality of life.
- **Coping behaviors:** delaying or forgoing recommended medical care to save money.

# Conceptual framework for thinking about the financial burden of cancer

Over 41% of cancer survivors report making employment changes such as taking extended time off, making schedule changes or switching to a less demanding job (J Natl Cancer Inst. 2020;113(5):641-4.)

Annual patient time costs among those <2 years from diagnosis were \$1,229 for adults aged <65 and \$1,623 for adults aged 65+ (J Natl Cancer Inst, Volume 113, Issue 12, December 2021, Pages 1670-1682)

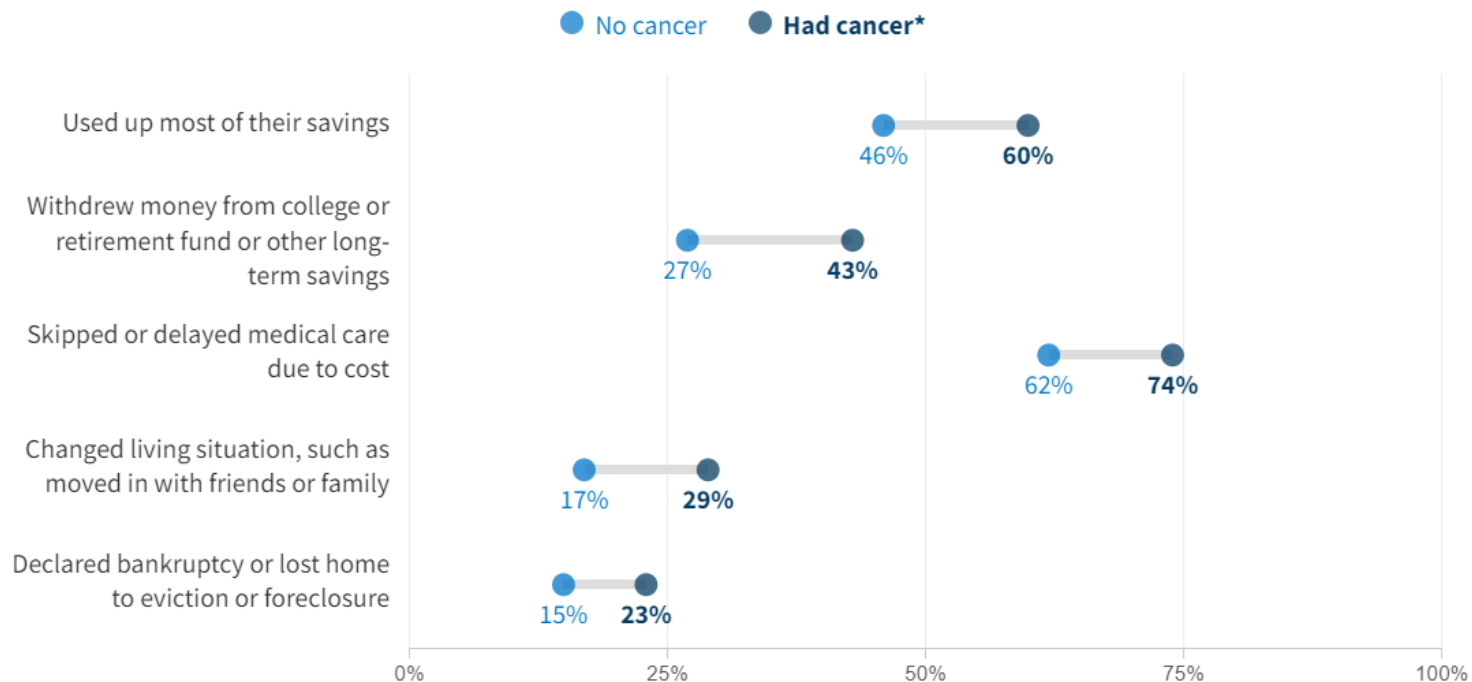


Annual patient out-of-pocket costs among those <2 years from diagnosis were \$1,560 for adults aged <65 and \$1,854 for adults aged 65+ (J Natl Cancer Inst, Volume 113, Issue 12, December 2021, Pages 1670-1682)

Patient travel expenses for each cycle of outpatient treatment have been estimated as \$40-\$100 (J Clin Oncol. 2013;31(31\_suppl):270.)

# The High Financial Toll of Cancer

Share of indebted adults who say they or someone in their household have done the following due to health care debt:



**Note:** \*They or an immediate family member received treatment for cancer in the past five years.

Source: KFF Health Care Debt Survey of 2,375 U.S. adults, including 1,674 with current or past debt from medical or dental bills, conducted Feb. 25 through March 20. The margin of sampling error for the overall sample is 3 percentage points.

Credit: Alyson Hurt/NPR and Noam N. Levey/KHN



# Risk factors for financial hardship

## Demographic

Younger age groups  
Lower socioeconomic status  
Rural residence  
Minority race/ethnicity  
Assets/debt

## Health insurance

Less than age 65 with public insurance  
Uninsured  
High cost-sharing

## Employment

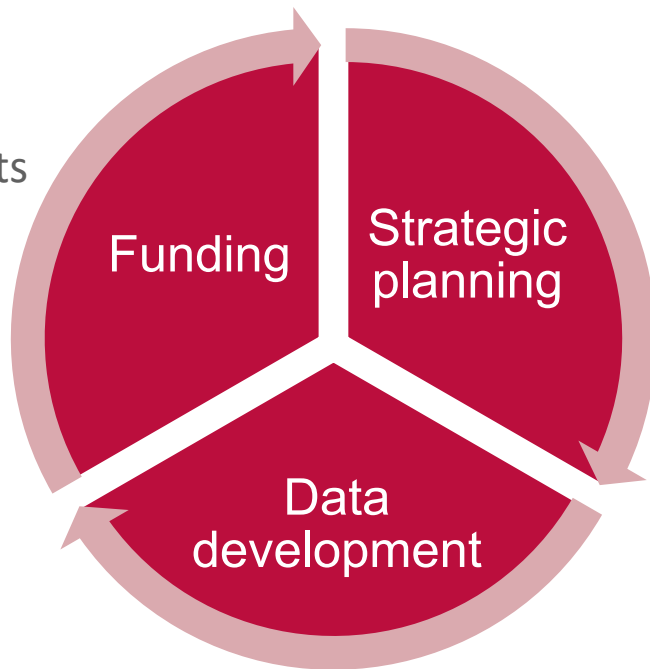
Wage-earner status  
Lack of employer accommodations  
Employment disruption due to cancer

## Clinical

Advanced disease  
Greater treatment intensity and duration

# Cancer health economics research at the National Cancer Institute

- Grants
- Cooperative agreements
- Administrative supplements



- Convening relevant stakeholders
- Scientific priority setting

- National surveys
- Data linkages
- Clearinghouse



**CANCER HEALTH  
ECONOMICS**



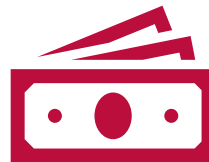
# Priority areas to address cancer-related financial hardship



Identify patients at risk for cancer-related financial hardship



Develop and test sustainable models of financial navigation



Integrate financial hardship screening and service delivery into care

# Need for financial hardship screening

- Out-of-pocket costs for treatment are high due to the cost of cancer care and insurance cost-sharing requirements.
- Many patients with financial need are currently not being identified.
  - Patients are reluctant to ask for help when they need it.
  - Oncologists are reluctant to discuss financial issues with patients.
- Screening normalizes discussions about financial concerns and removes the burden for patients initiate a conversation.
- Screening is the first step towards linking patients to available resources.

# Availability of screening programs in cancer care delivery

- Studies describing the availability of financial hardship screening find that most practices have some level of screening.
  - 72% of NCI's Community Oncology Research Program practices (Cancer Epidemiol Biomarkers Prev. 2021 Apr; 30(4): 669–675)
  - 75% National Comprehensive Cancer Network (NCCN) centers (J Natl Compr Canc Netw. 2020 Jul;18(7):825-831)
  - 95% of NCI-designated cancer centers (unpublished data).
- Outstanding research questions
  - What is the best way to screen patients for financial hardship?
  - What patients are falling through the cracks?
  - What is needed to integrate screening and subsequent referral into clinical workflows?

# Financial navigation definition and goals

- Financial navigation focuses on treating and preventing financial toxicity by guiding patients through the healthcare system to help them gain access to care by reducing financial barriers. (adapted from the Patient Access Network Foundation)
- Goals of financial navigation (Association of Community Cancer Centers)
  - Help patients understand insurance benefits, financial liability for care and available resources.
  - Help patients make insurance coverage decisions that align with their goals.
  - Increase patient adherence to treatment by removing barriers to care.
  - Improve access to care and ensure equitable care.

# Current landscape of financial navigation

- **Integrated delivery:** Screening and service delivery are conducted on-site. Activities need to be integrated into clinical workflow. Potential to efficiently identify patients in need and tailor treatment plans where appropriate.
- **Remote delivery:** Financial navigation provided by third-party organizations. Can decrease the administrative burden to cancer centers and serve as a venue for patients to seek assistance from an organization not involved with medical billing.
- **Tech and app solutions:** Patient-facing apps can facilitate identification of financial assistance resources and out-of-pocket cost reduction. Effectiveness depending upon patient engagement. Potential to interface with the electronic health record and other hospital systems.

# Barriers to financial navigation

	% Strongly agree or agree	% Neither agree nor disagree	% Disagree or strongly disagree
It is difficult to determine how much a cancer patient's treatment will cost.	72	16	12
Oncologists are reluctant to discuss financial issues with cancer patients.	70	21	9
The applications for financial assistance are complex and time consuming.	67	10	23
Cancer patients are reluctant to ask for help when they need it.	54	27	19
The pathways or workflows to connect cancer patients with existing financial services are unclear.	46	28	26
Staff do not have enough time or capacity to coordinate financial navigation services for cancer patients	44	18	38
There is a lack of staff awareness about available financial navigation services for cancer patients.	40	16	44
There are few financial navigation services available to offer cancer patients.	40	11	49
Staff are not equipped to discuss financial issues with cancer patients (e.g. due to lack of relevant information)	39	23	38



# Cancer center supplements to address cancer-related financial hardship (n=11)

- ✓ Characterize facilitators and barriers to financial hardship screening
- ✓ Develop and test new screening tools
- ✓ Collect and document information about financial hardship
- ✓ Implement financial navigation

## Challenges and Opportunities for Addressing Financial Hardship as Part of Cancer Care Delivery

Home / News & Events / Events / Challenges and Opportunities for Addressing Financial Hardship as Part of Cancer Care Delivery

### Challenges and Opportunities for Addressing Financial Hardship

October 6, 2022  
12:00 - 4:30 PM ET

#### Overview

Overview

Agenda & Recordings


Background Materials

Speakers




# Select findings

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**Screening tool development:** The Dan L Duncan Cancer Center at Baylor St. Luke's Medical Center developed and validated a 5-item screening tool (FINTOX) with stakeholder input. Financial hardship more common among patients treated in safety net system. Tool used to screen patients who are eligible for treatment trials and connect to existing financial support program.

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**Screening with existing tools:** O'Neal Comprehensive Cancer Center at the University of Alabama at Birmingham combined a question about difficulty affording medication (asked at intake), the NCCN distress thermometer, the COST + financial needs checklist (both asked by lay navigators). Clear referral pathways were established depending on responses. Easy to incorporate screening into practice using lay navigators.

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**Establishing new workflows:** Iterative study at the James Cancer Hospital and Solove Research Institute at the Ohio State University where clinic staff use a question in the EMR to trigger a referral to social work or patient navigation. Developed a process dictating who was responsible for referrals, referral modality, and responsibility for follow up.

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**Testing a financial navigation intervention:** The Lineberger Comprehensive Cancer Center at UNC Chapel Hill tested the *Lessening the Impact of Financial Toxicity* Intervention in 9 community practices. Intervention connects patients to assistance with pharmaceuticals, help with insurance and payment and/or resources available on-site or through foundations.

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**Referral to existing services:** Georgetown Lombardy Comprehensive Cancer Center used the NCCN Distress Thermometer and other information gathered during patient intake and clinical interactions to screen for financial and health-harming legal needs. Patients referred to financial navigation or the *Cancer LAW Project*.

Among the 11 supplement projects, 5 studies used items from the COST, two projects used the NCCN distress thermometer, two screened patients using sociodemographic data from the EHR, and two developed new screening instruments

**COST – FACIT (Version 2)**

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
FT1	I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.....	0	1	2	3	4
FT2	My out-of-pocket medical expenses are more than I thought they would be .....	0	1	2	3	4
FT3	I worry about the financial problems I will have in the future as a result of my illness or treatment .....	0	1	2	3	4
FT4	I feel I have no choice about the amount of money I spend on care.....	0	1	2	3	4
FT5	I am frustrated that I cannot work or contribute as much as I usually do.....	0	1	2	3	4
FT6	I am satisfied with my current financial situation .....	0	1	2	3	4
FT7	I am able to meet my monthly expenses .....	0	1	2	3	4
FT8	I feel financially stressed.....	0	1	2	3	4
FT9	I am concerned about keeping my job and income, including paid work at home.....	0	1	2	3	4
FT10	My cancer or treatment has reduced my satisfaction with my present financial situation .....	0	1	2	3	4
FT11	I feel in control of my financial situation .....	0	1	2	3	4
FT12	My illness has been a financial hardship to my family and me .....	0	1	2	3	4



**NCCN Guidelines Version 2.2023  
Distress Management**

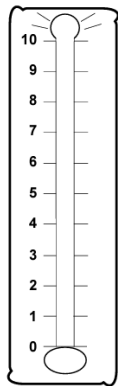
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**NCCN DISTRESS THERMOMETER**

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress



No distress

**PROBLEM LIST**

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

**Physical Concerns**

- Pain
- Sleep
- Fatigue
- Tobacco use
- Substance use
- Memory or concentration
- Sexual health
- Changes in eating
- Loss or change of physical abilities

**Emotional Concerns**

- Worry or anxiety
- Sadness or depression
- Loss of interest or enjoyment
- Grief or loss
- Fear
- Loneliness
- Anger
- Changes in appearance
- Feelings of worthlessness or being a burden

**Social Concerns**

- Relationship with spouse or partner
- Relationship with children
- Relationship with family members
- Relationship with friends or coworkers
- Communication with health care team
- Ability to have children

**Practical Concerns**

- Taking care of myself
- Taking care of others
- Work
- School
- Housing
- Finances
- Insurance
- Transportation
- Child care

- Having enough food
- Access to medicine
- Treatment decisions

**Spiritual or Religious Concerns**

- Sense of meaning or purpose
- Changes in faith or beliefs
- Death, dying, or afterlife
- Conflict between beliefs and cancer treatments
- Relationship with the sacred
- Ritual or dietary needs

**Other Concerns:**

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

# Global lessons learned from 11 pilot studies

- Screening for financial hardship can be integrated into existing clinical workflows. However, strong staff, provider and patient engagement are key.
- Specific tool matters less than the process.
- Clearly outlined pathways to direct patients to national, state, local, and institutional resources such as grants, social workers, financial counselors, or navigators should be determined before screening.
- Training, staff turnover, staff shortages, changes in project leadership, working across institutions are challenges.



# Ongoing clinical trials to address financial hardship

- NCI is currently funding 5 pragmatic trials to test patient-facing interventions to address different aspects of financial hardship.
- 3 studies evaluate personalized financial navigation embedded into the oncology or community setting (Lessening the Impact of Financial Toxicity (LIFT): a protocol for a multi-site, single-arm trial examining the effect of financial navigation on financial toxicity in adult patients with cancer in rural and non-rural settings; The Cancer Financial Experience (CAFÉ) study: randomized controlled trial of a financial navigation intervention to address cancer-related financial hardship; Addressing Cancer-Related Financial Hardship through Delivery of a Proactive Financial Navigation Intervention)
- 2 additional trials are evaluating interventions to address health insurance coverage and employment disruption (An interactive mobile application versus an educational booklet to promote job retention in women undergoing adjuvant chemotherapy for breast cancer: a randomized controlled trial; HIAYA CHAT study protocol: a randomized controlled trial of a health insurance education intervention for newly diagnosed adolescent and young adult cancer patients)

# Summary



Due to the high costs of cancer care, patient out-of-pocket costs for treatment can lead to financial hardship. Other cancer related expenses and employment disruption exacerbate financial burden.



Financial hardship can lead patients to delay or forego recommended medical care to save money, leading to poor patient outcomes.



The National Cancer Institute is current funding differnet types of studies to identify patients at risk for financial hardship, develop and test financial navigation interventions and to support the integration of screening and service delivery into care.



Priorities for future research include addressing the economic impact and patient outcomes associated with healthcare innovations and changes in how and where care is delivered.

Thank you



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