

# Addressing Cancer-Related Financial Toxicity in Oncology Care Settings



**Stephanie B Wheeler, PhD MPH**  
 Professor of Health Policy and Management  
 Gillings School of Global Public Health  
 Associate Director of Community Outreach and Engagement  
 Lineberger Comprehensive Cancer Center  
 University of North Carolina at Chapel Hill

and

**Donald L. Rosenstein, MD**  
 Professor of Psychiatry and Medicine  
 Division Head, General Adult Psychiatry  
 Director of the Comprehensive Cancer Support Program  
 Lineberger Comprehensive Cancer Center  
 University of North Carolina at Chapel Hill



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**Medicare Pays \$415M Annually For Breast Cancer Screenings in Women Over 75**

Medicare spends almost as much money screening for breast cancer as it does treating it, according to a new study published in JAMA Internal Medicine.

**Cancer treatment costs can be prohibitive, even with insurance**

By Michelle Andrews October 10, 2011

**Waste in Cancer Drugs Costs \$3 Billion a Year, a Study Says**

By CARDINER HARRIS MARCH 1, 2016

**Economic Impact of Cancer**

The financial costs of cancer are high for both the person with cancer and for society as a whole.

The Agency for Healthcare research and Quality (AHRQ) estimates that the direct medical costs (total of all health care costs) for cancer in the US in 2015 were **\$80.2 billion**.

- 52% of this cost is for hospital outpatient or doctor office visits
- 38% of this cost is for inpatient hospital stays

**Tackling the financial toll of cancer, one patient at a time**

McGinty April 9, 2016

**The New York Times** | <https://nyti.ms/OA0x88>

The Opinion Pages | OP-ED CONTRIBUTOR

**In Cancer Care, Cost Matters**

By PETER B. BACH, LEONARD B. SALTZ and ROBERT E. WITTES OCT. 14, 2012

AT Memorial Sloan-Kettering Cancer Center, we recently made a decision that should have been a no-brainer: we are not going to give a phenomenally expensive new cancer drug to our patients.

The reasons are simple: The drug, Zaltrap, has proved to be no better than a similar medicine we already have for advanced colorectal cancer, while its price — at \$11,063 on average for a month of treatment — is more than twice as high.

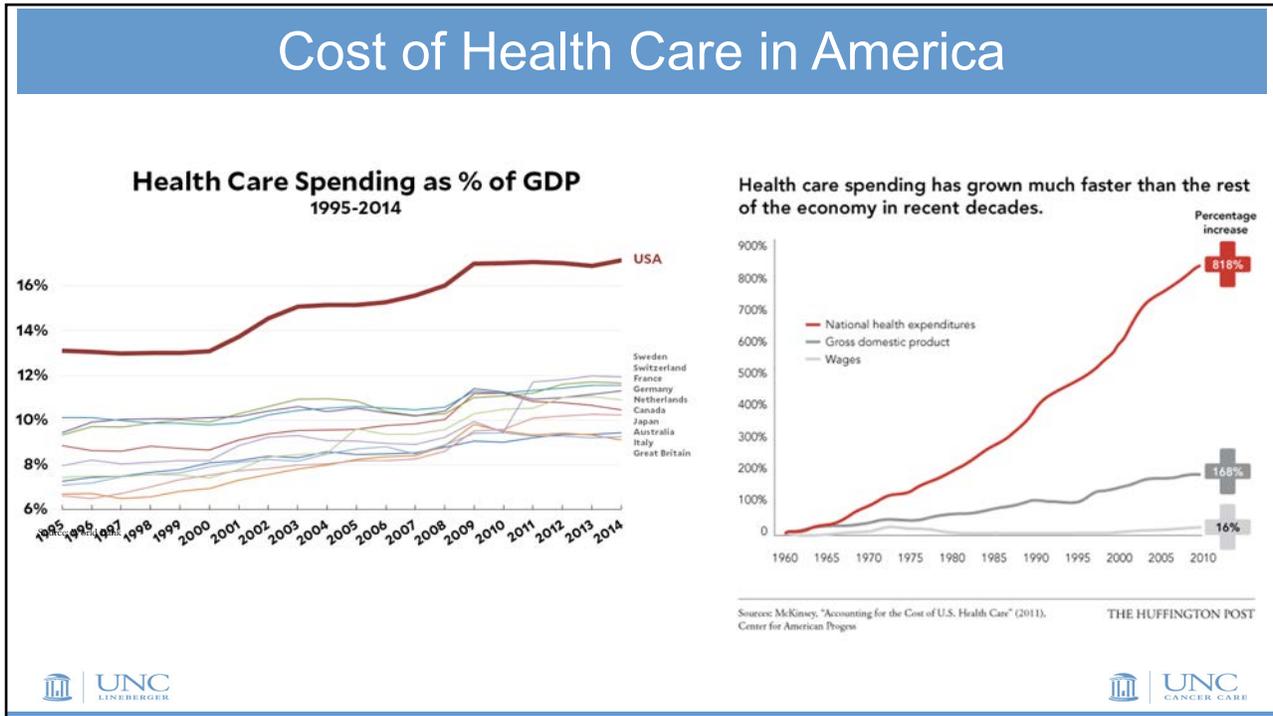
**THE WALL STREET JOURNAL.**

IN DEPTH

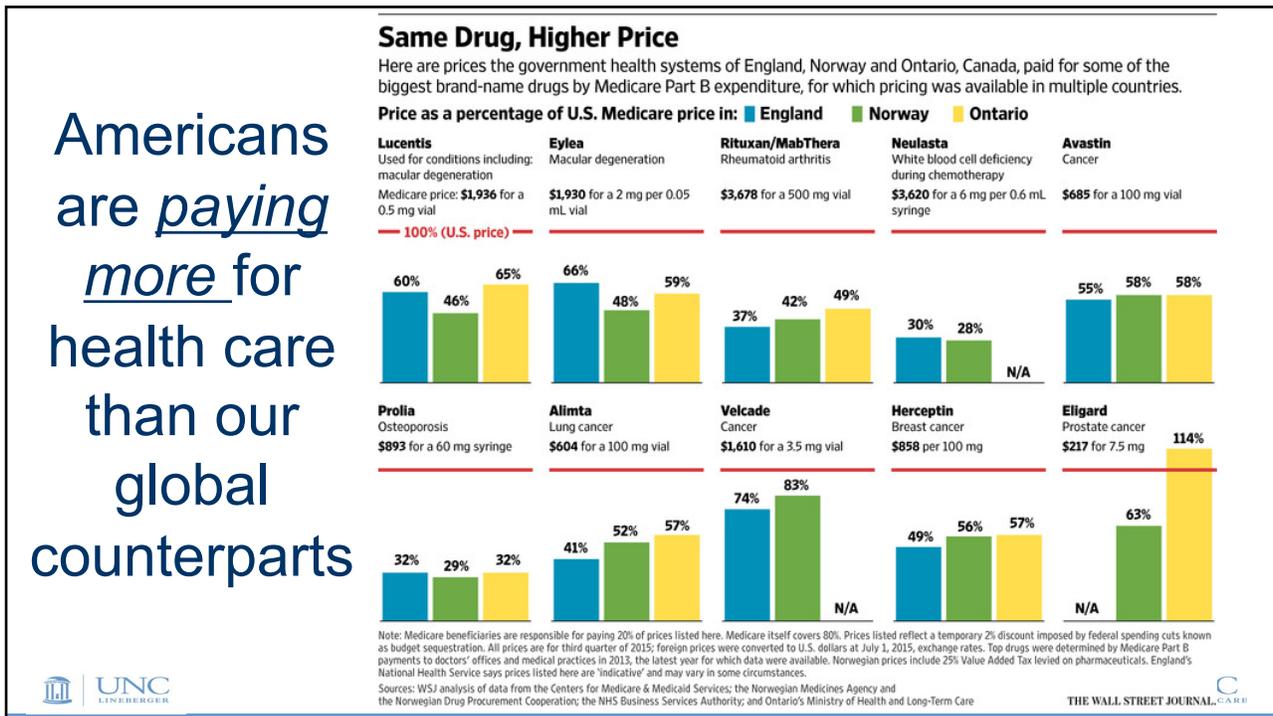
**Patients Struggle With High Drug Prices**

Out-of-pocket costs for pricey new drugs leave even some insured and relatively affluent patients with hard choices on how to afford them

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## Financial Toxicity



The adverse financial impact of cancer is a source of significant harm to patients, also known as *financial toxicity*, and affects **~30%** of cancer patients (Kent et al, 2013, *Cancer*)

The financial burden of cancer has been linked to:

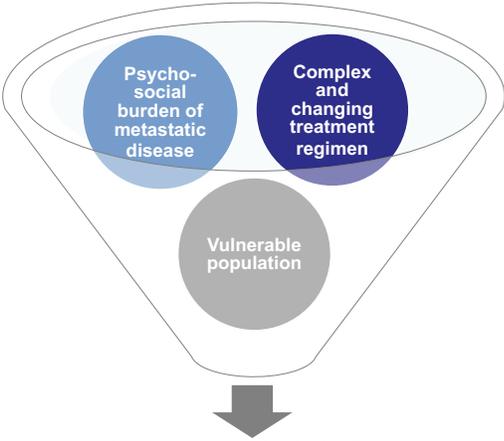
- Lower quality of life (Lathan et al, 2015, *JCO*; Zafar et al, 2015, *JOP*)
- Greater psychological distress (Yabroff et al, 2015, *JCO*)
- Delayed or discontinued treatment (Zafar et al, 2013, *Oncologist*)
- Bankruptcy (Yabroff et al, 2015, *JCO*; Ramsey et al, 2013, *Health Affairs*)
- Mortality (Ramsey et al, 2016, *JCO*)




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## Financial Toxicity in Metastatic Cancer

Patients with *metastatic cancer* face unique challenges and little is known about financial toxicity for this population



*increased risk for financial toxicity*




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## Research Objective

- We conducted a national, online survey in partnership with the Metastatic Breast Cancer Network to understand:
  - ❑ Socioeconomic characteristics- *baseline financial vulnerability*
  - ❑ Financial hardship- *material burden*
  - ❑ Emotional burden- *psychosocial distress*
  - ❑ Changes in work, medical and non-medical spending- *behavioral response*



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## Survey Participants

		Insured	Uninsured	p-value
<b>N</b>		<b>738 (70%)</b>	<b>316 (30%)</b>	
<b>Age, mean (SD)</b>		42.2 (10.1)	42.6 (5.7)	0.53
<b>Race</b>	Non-Hispanic White	576 (78.0%)	121 (38.3%)	<0.001
	Non-Hispanic Black			
	Hispanic			
	Non-Hispanic Other			
<b>Time with Metastatic Disease</b>	<1 year			.001
	1-2 years			
	2-5 years	153 (20.8%)	106 (33.5%)	
	5+ years	25 (3.4%)	22 (7.0%)	
<b>Marital Status</b>	Married, or living with a partner	544 (74.0%)	252 (79.7%)	<0.001
	Never married	159 (21.6%)	18 (5.7%)	
	Divorced/Widowed/Separated	32 (4.4%)	46 (14.6%)	
<b>Living with Dependents</b>		654 (88.7%)	299 (94.6%)	0.003
<b>Household Income</b>	<15,000	13 (1.8%)	38 (12.0%)	<0.001
	15,000-29,999	87 (11.9%)	87 (27.5%)	
	30,000-49,999	399 (54.7%)	153 (48.4%)	
	50,000 or more	231 (31.6%)	38 (12.0%)	
<b>Current Work Status</b>	Not working	448 (60.9%)	10 (3.2%)	<0.001
	Working full time	200 (27.2%)	233 (73.7%)	
	Working part time	61 (8.3%)	57 (18.0%)	
	Self employed (full or part time)	27 (3.7%)	16 (5.1%)	

1054 individuals from 41 states completed the survey, of which 30% were uninsured



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Uninsured participants were more likely to identify as a racial or ethnic minority

Uninsured participants reported significantly lower income but were much more likely to be working full time jobs




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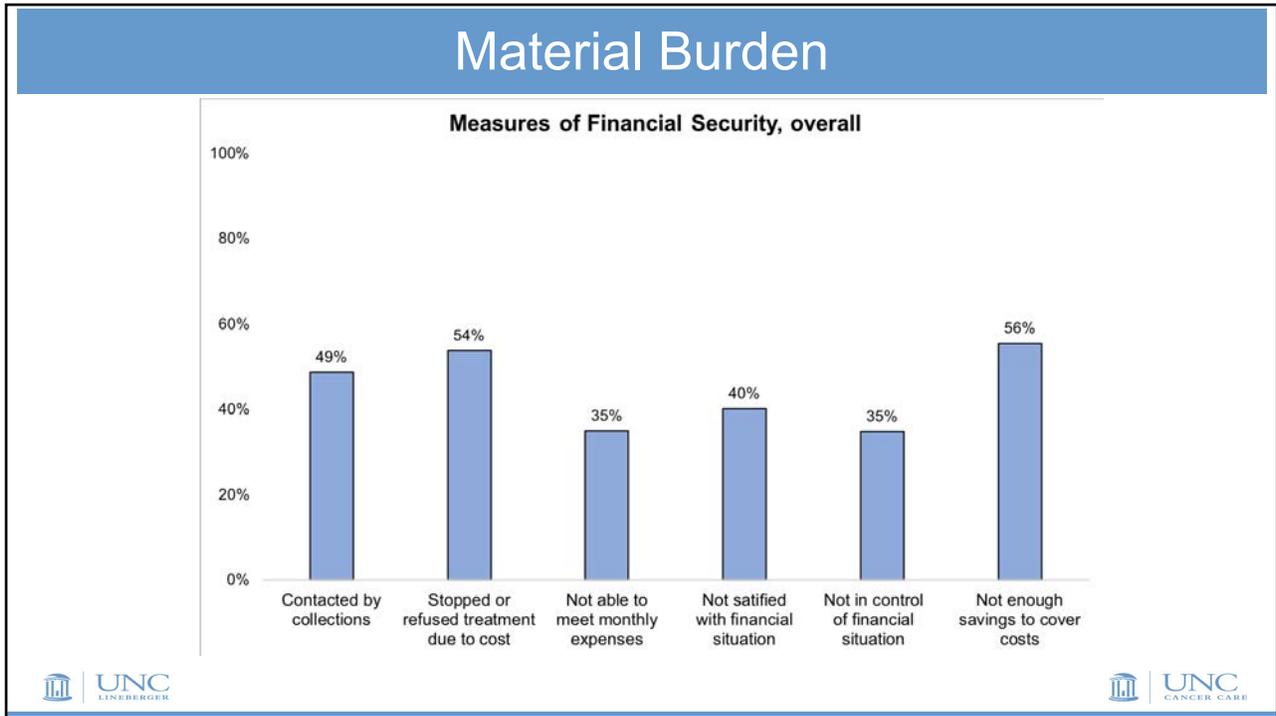
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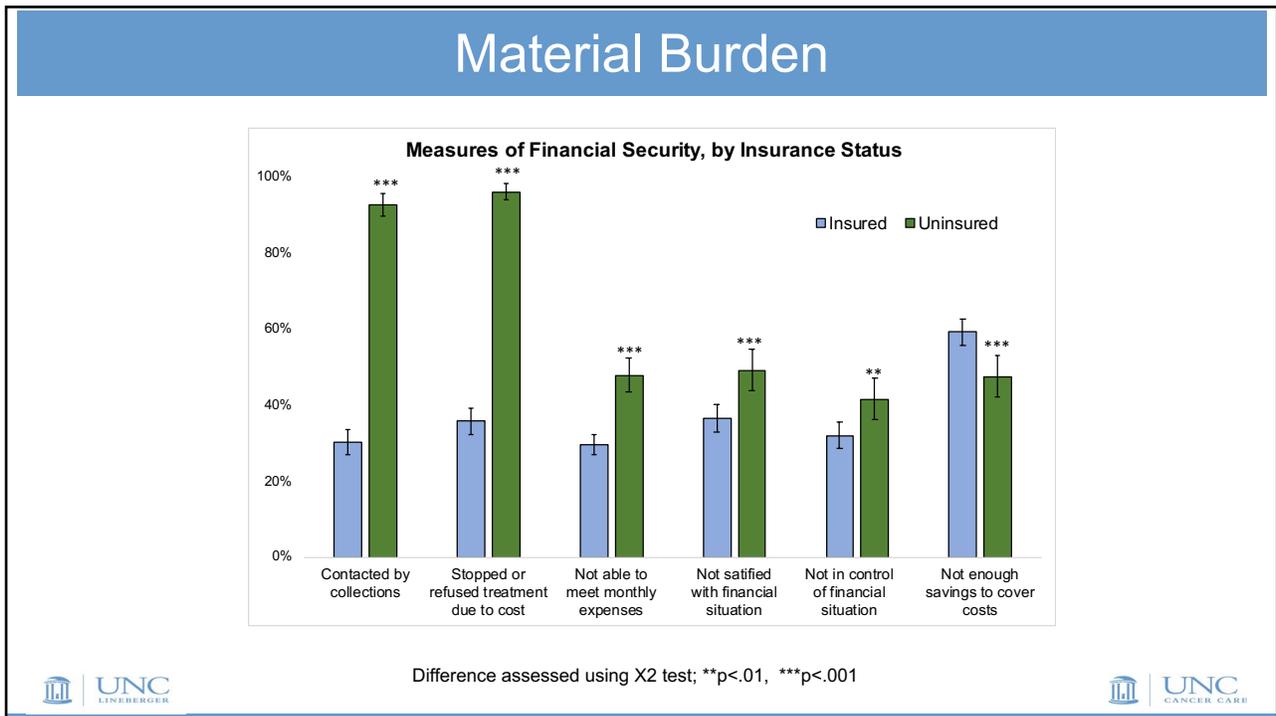
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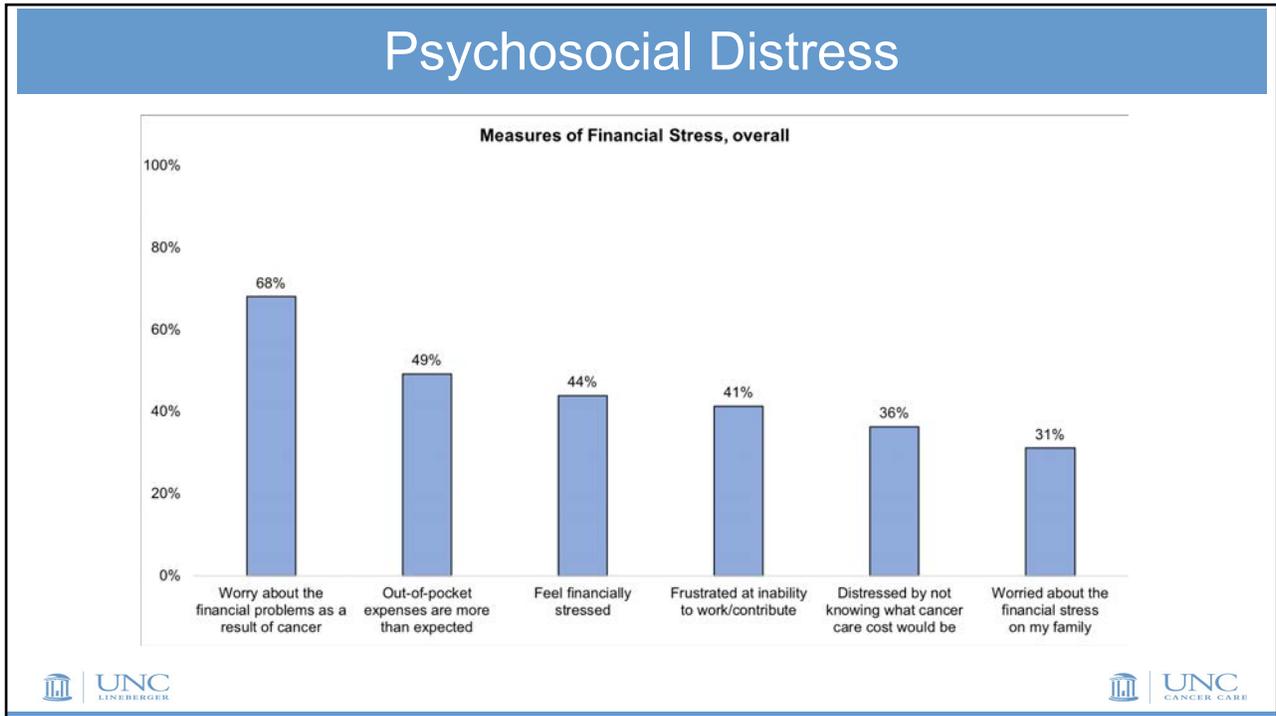

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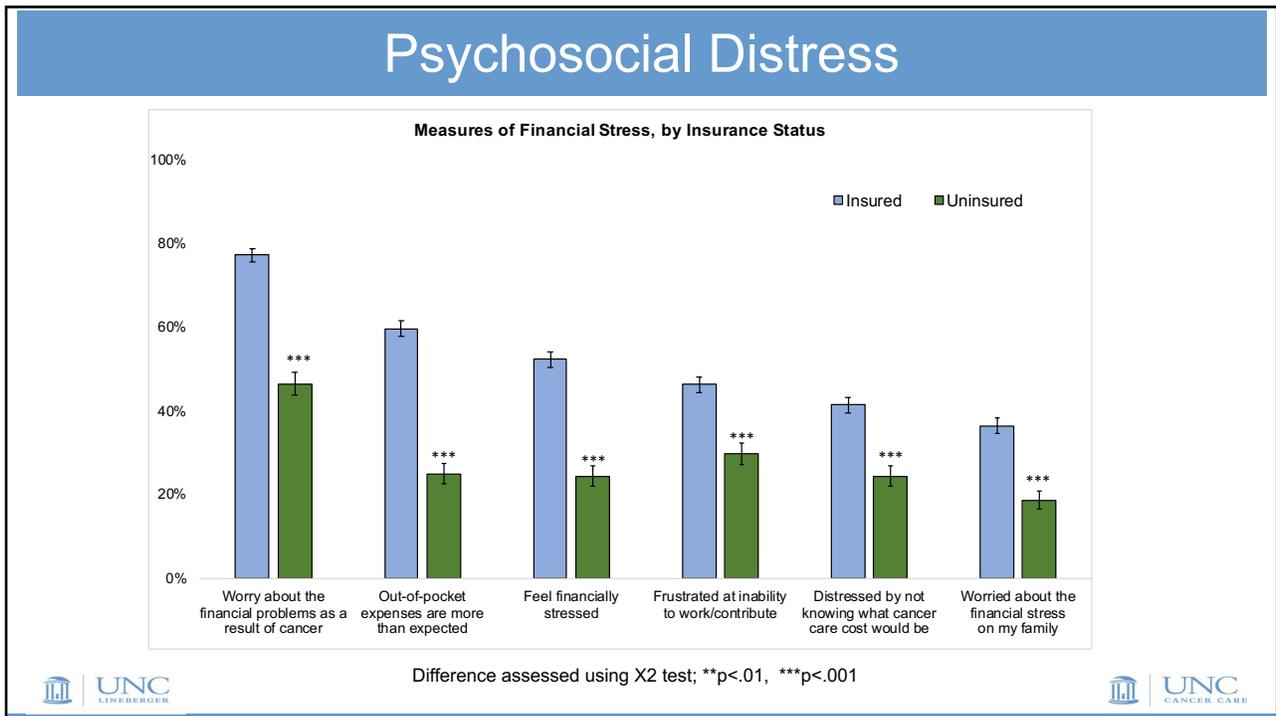
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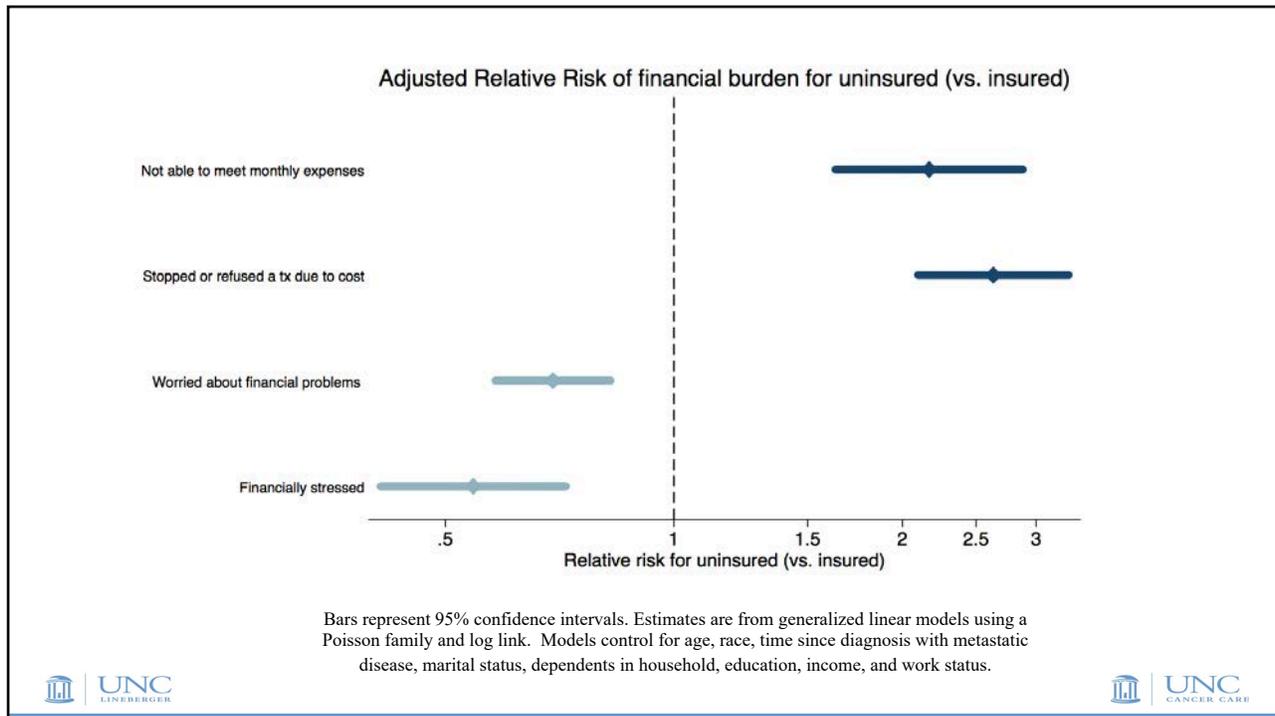
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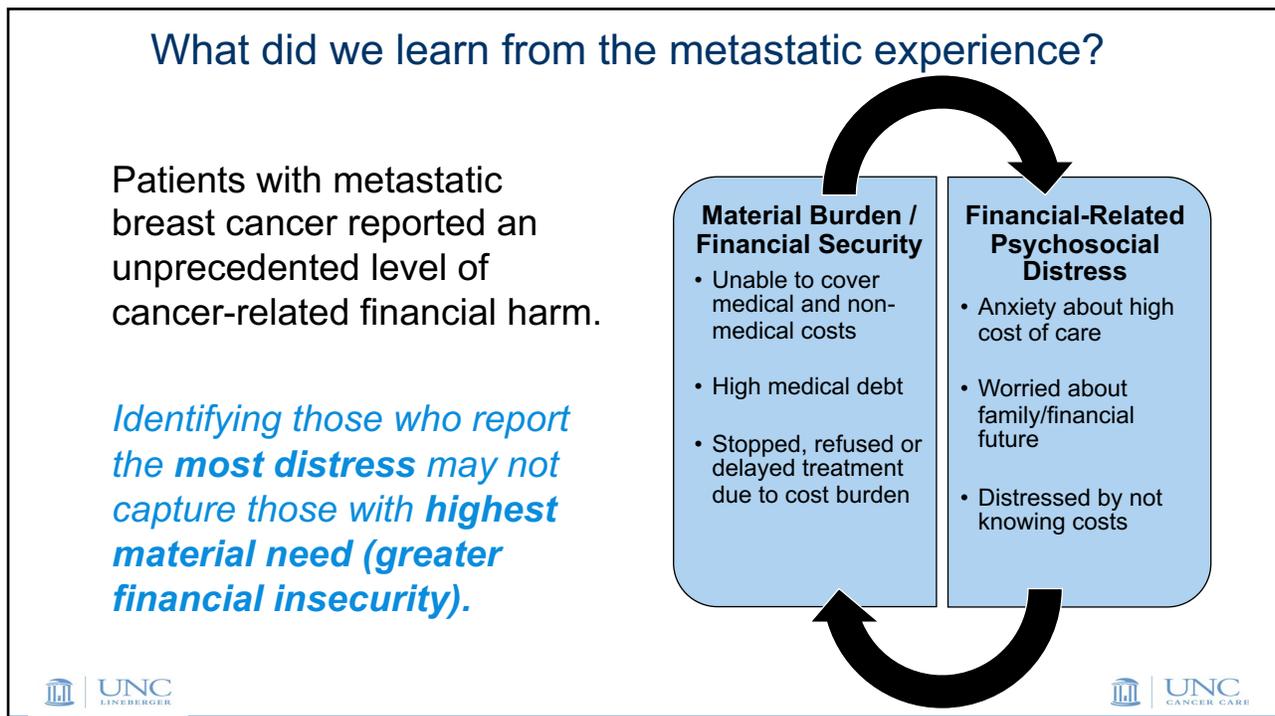
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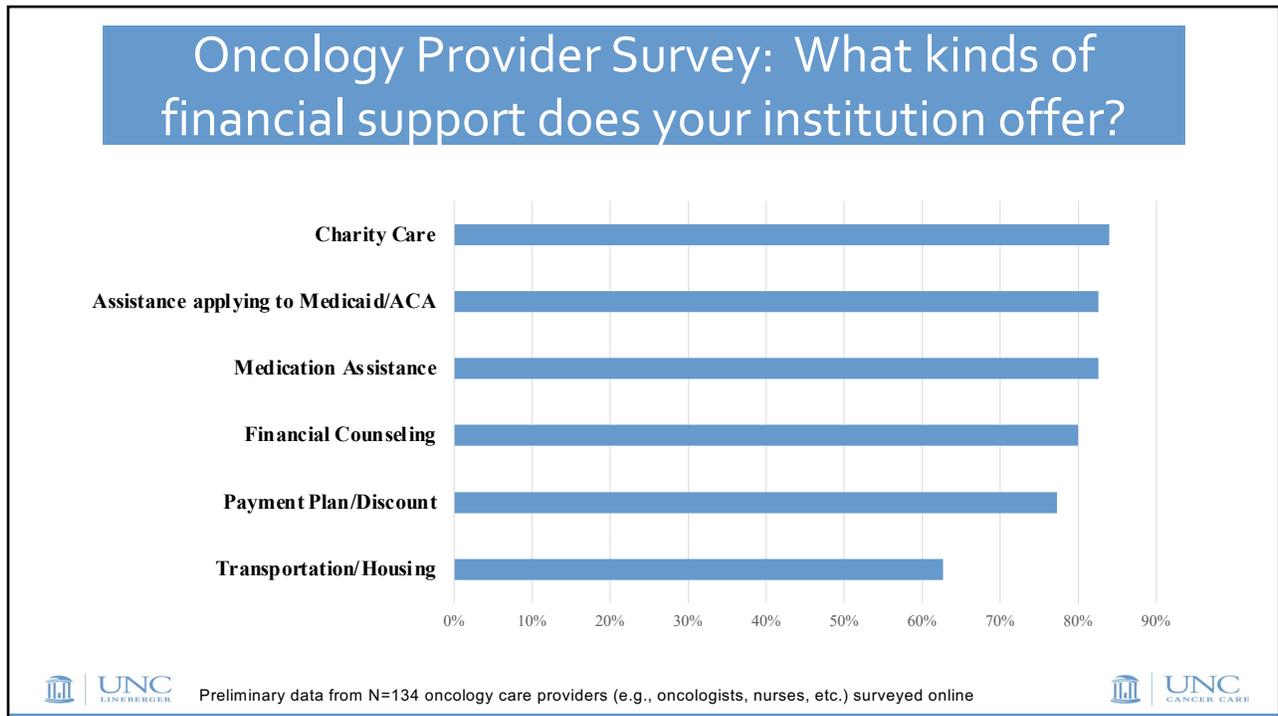
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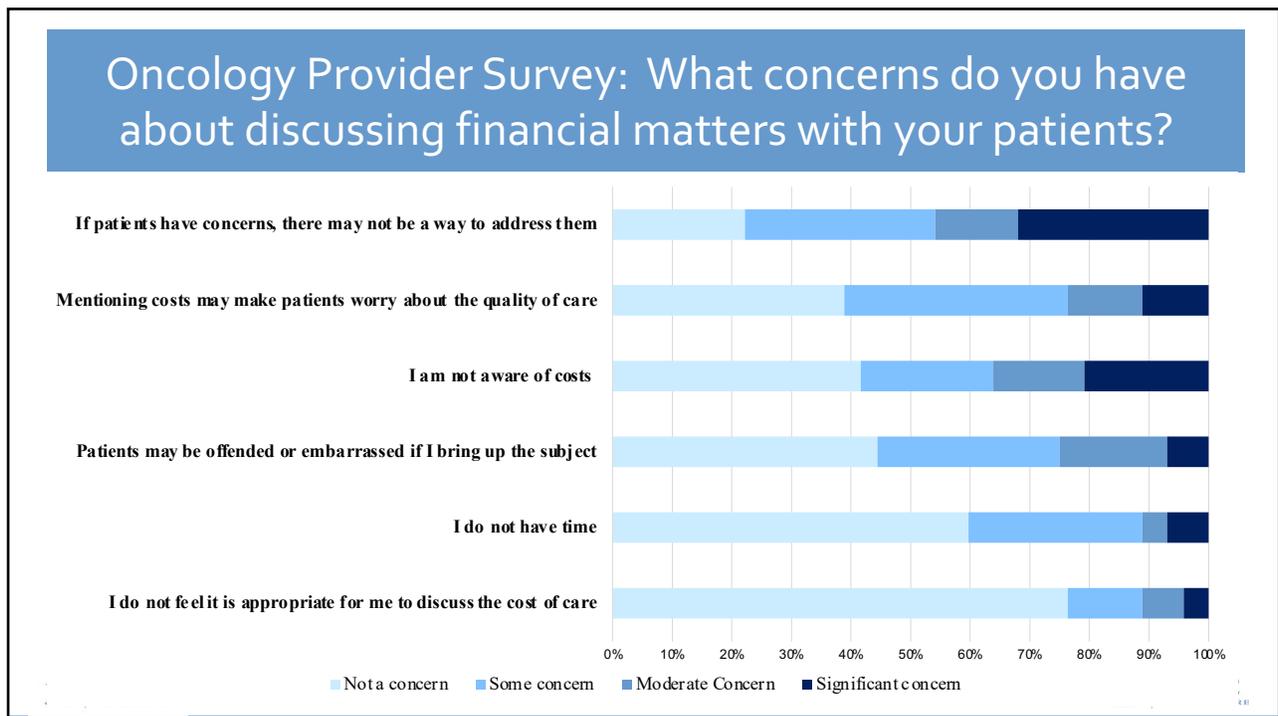
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Resource	Uninsured		Underinsured	
	Systematic Identification of Need	Navigation through application process	Systematic Identification of Need	Navigation through application process
Medicaid	Yes	Yes- if inpatient	--	--
Affordable Care Act Subsidy	Yes	No	--	--
Social Security Disability	Yes	No	No	No
Cobra Repayment	No	Yes	--	--
Charity Care	Yes	Yes	No	Yes
Pharmacy Assistance Program	Yes	Yes	--	--
Medication Assistance Program	Yes	Yes	Yes	Yes
Community Based-Copay Assistance	No	No	No	No
External Non-Profits (non-medical)	No	No	No	No

Uninsured patients have far more resources to access than do under-insured patients. A number of processes rely on patients to navigate complex, duplicative applications- additional navigation support is needed and may help patients successfully reach and obtain help from existing resources

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## Process Map

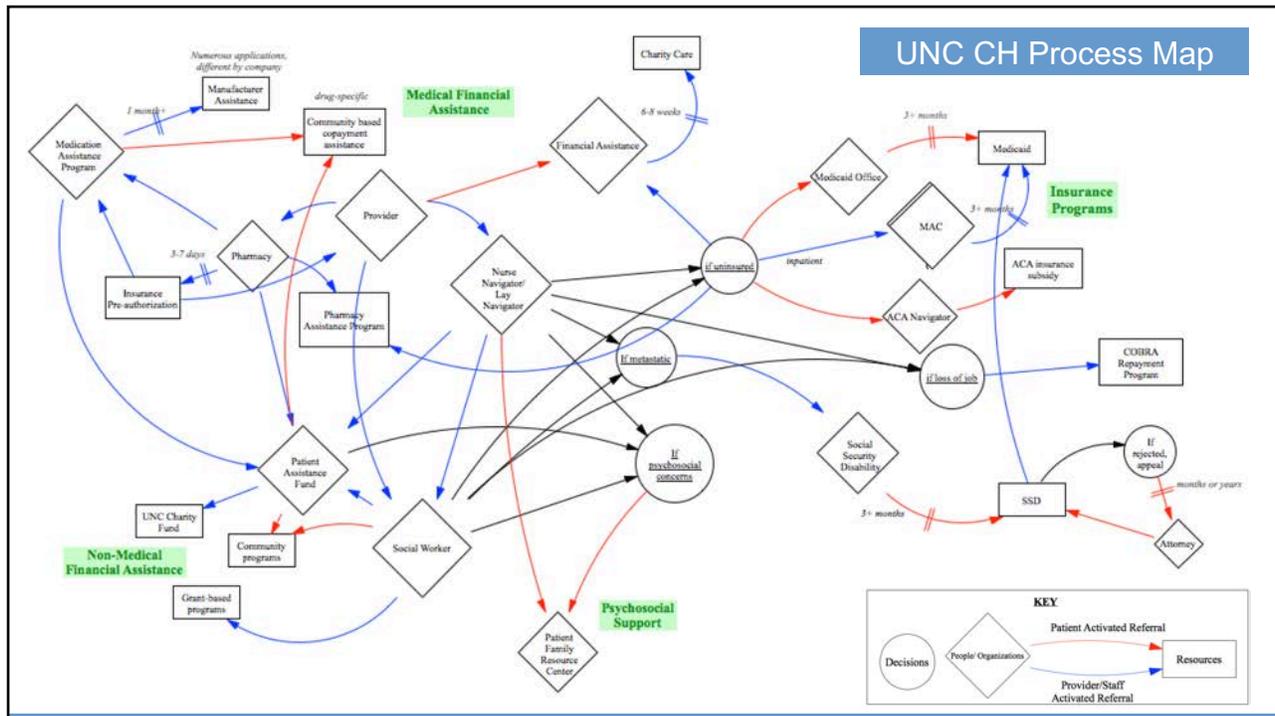
- Visually depicts a specific process to create a common vision and shared language for improving workflow.
- Identifies areas of redundancy and gaps; helps consolidate steps within a process.
- Reflects the **perception of the usual process** rather than describing the ideal or intended process.

```

graph TD
    Start([Start]) --> Step1[Step 1]
    Step1 --> Step2[Step 2]
    Step2 --> Decision{Decision?}
    Decision -- Yes --> StepY1[Step Y1]
    StepY1 --> StepY2[Step Y2]
    Decision -- No --> StepN1[Step N1]
    StepY2 --> Step3[Step 3]
    StepN1 --> Step3
    Step3 --> Done([Done])
    
```

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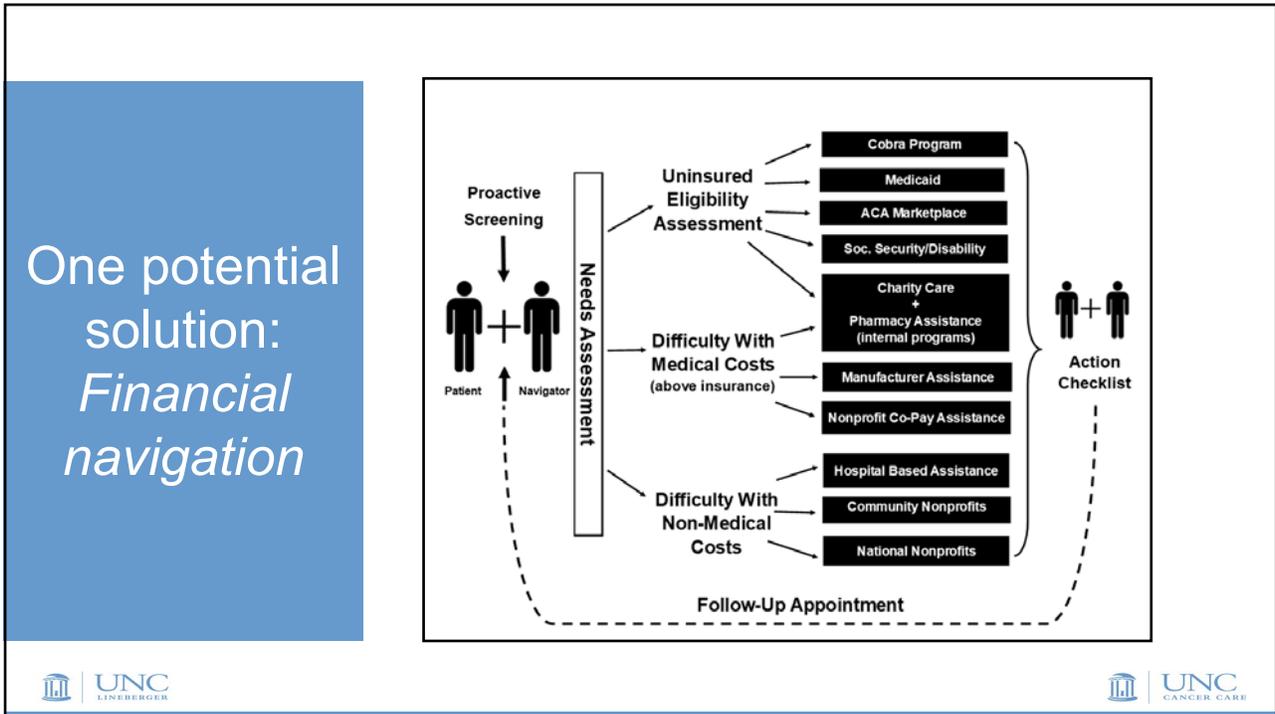


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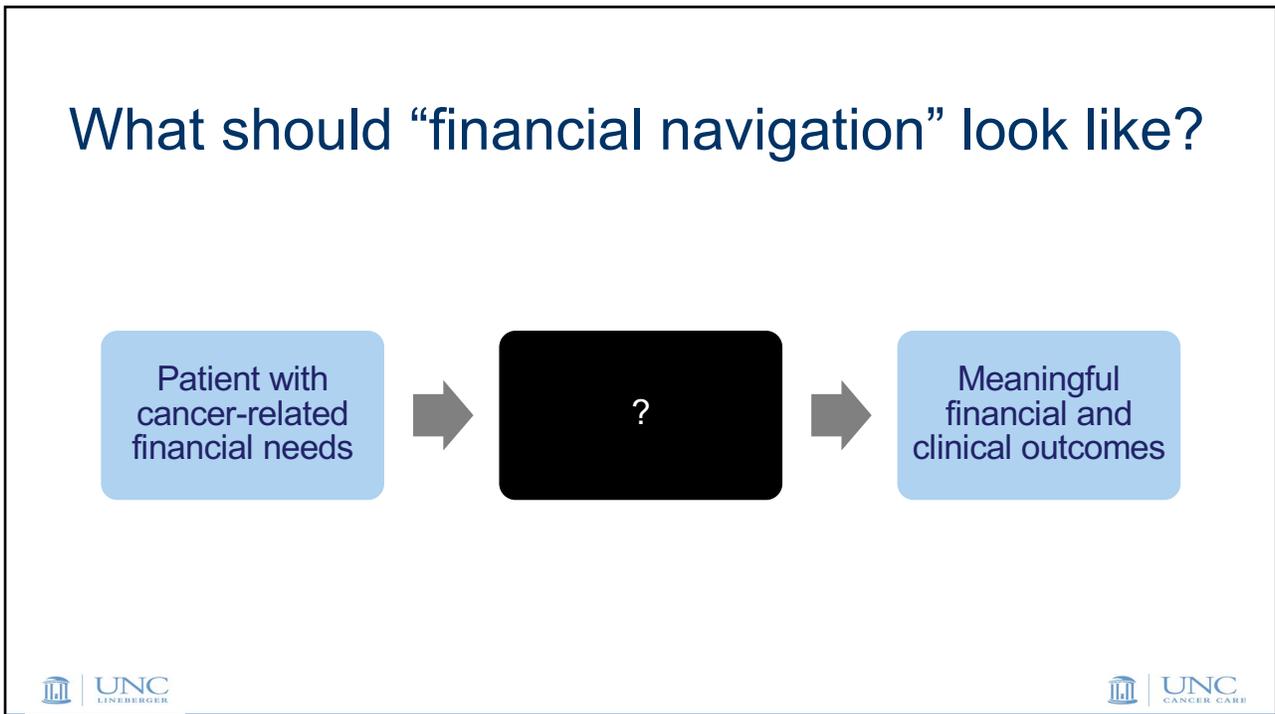
Summary of  
Cancer-  
related  
Financial  
Challenges to  
Patients

- **Heavier burden of FT** in metastatic, black, and rural populations
- Lack of **systematic and ongoing identification** of financial need
- **Financial distress** may not reflect the **material need (financial insecurity)**
- Lack of **coordinated, streamlined applications** once need is identified
- Lack of resources for **underinsured**
- Lack of effective **navigation** to assist patients and families

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**LCCC 1847:  
Improving  
Financial  
Navigation in  
the UNC CH: A  
Model for UNC  
Health Care**

## Pilot Study Goals

Goal 1. To develop a financial distress screening strategy for NCCH patients

Goal 2. To design, implement, and evaluate a new financial navigation clinic for 50 NCCH patients who screen positive for high levels of financial distress

- Funded by UNC Center for Health Innovation (1 year; \$49,749)




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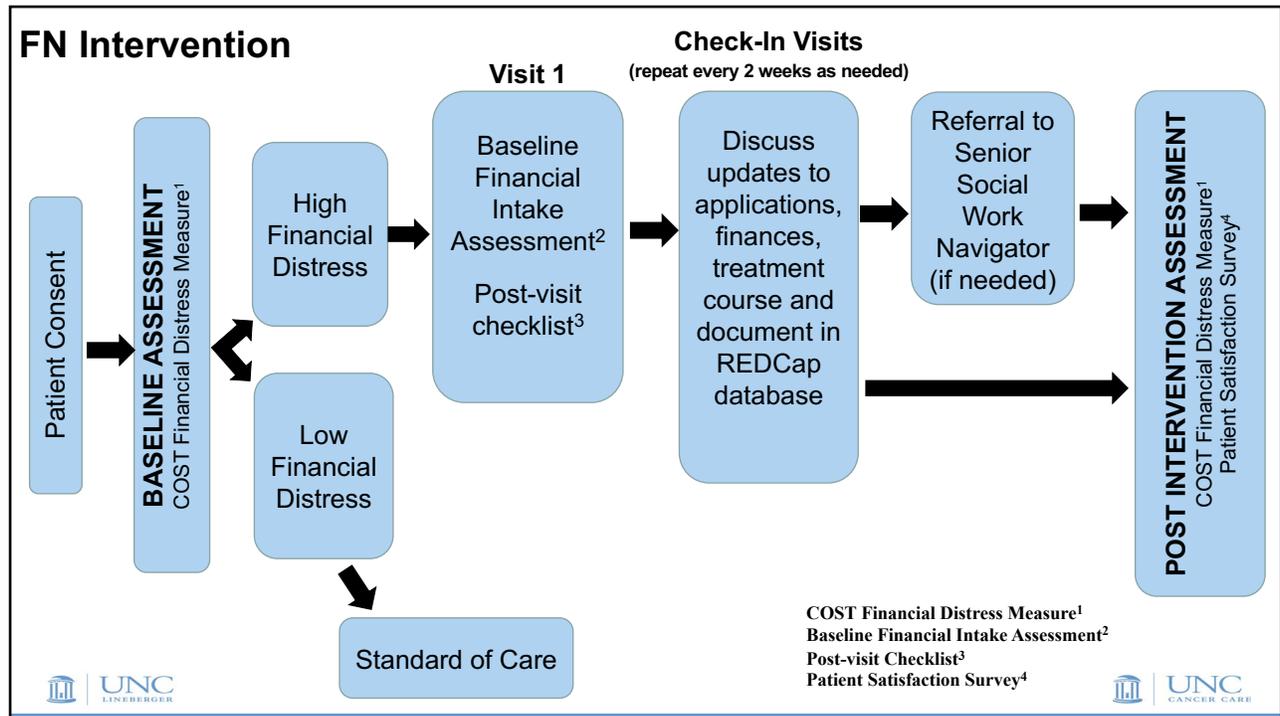
**Study  
Design**

## Pilot Study Goals

- Pre/post-intervention design
- Study opened Jan 5, 2019
- Eligible patients:
  - All cancer types
  - Referred by care team or social workers
  - Scored less than 22 points (indicating significant FT) on the COmprehensive Score for financial Toxicity (COST) instrument
- All 50 patients approached screened positive for FT, were eligible for full navigation intervention, and enrolled within 6 months
- Outcome data collection included pre/post-intervention COST scores, patient satisfaction with the intervention, and intervention fidelity




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## Pilot Intervention Components

- Intake assessment of financial needs and vulnerability
- Initial one-on-one consultation with a trained financial navigator
- Triage to financial support services matching patients' needs
- Multiple follow up appointments (every 2 wks) with navigator assistance based upon:
  - Patients' employment status, income, assets, billing and insurance status
  - Referral to appropriate financial and social services resources offered by the hospital, government, nonprofit and private corporations
  - Assistance with application completion and tracking of application status
  - Checklist of resources they were eligible for and the required paperwork

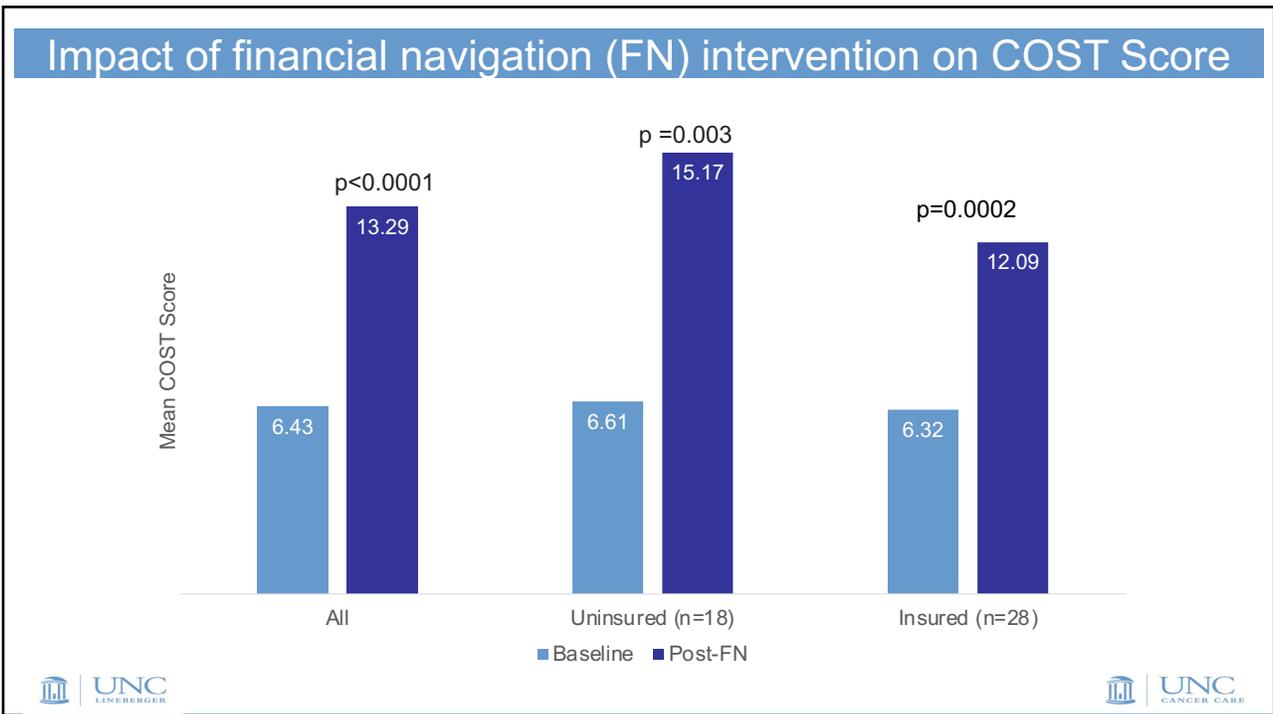
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## Results: Financial Navigation Participants (n=46)

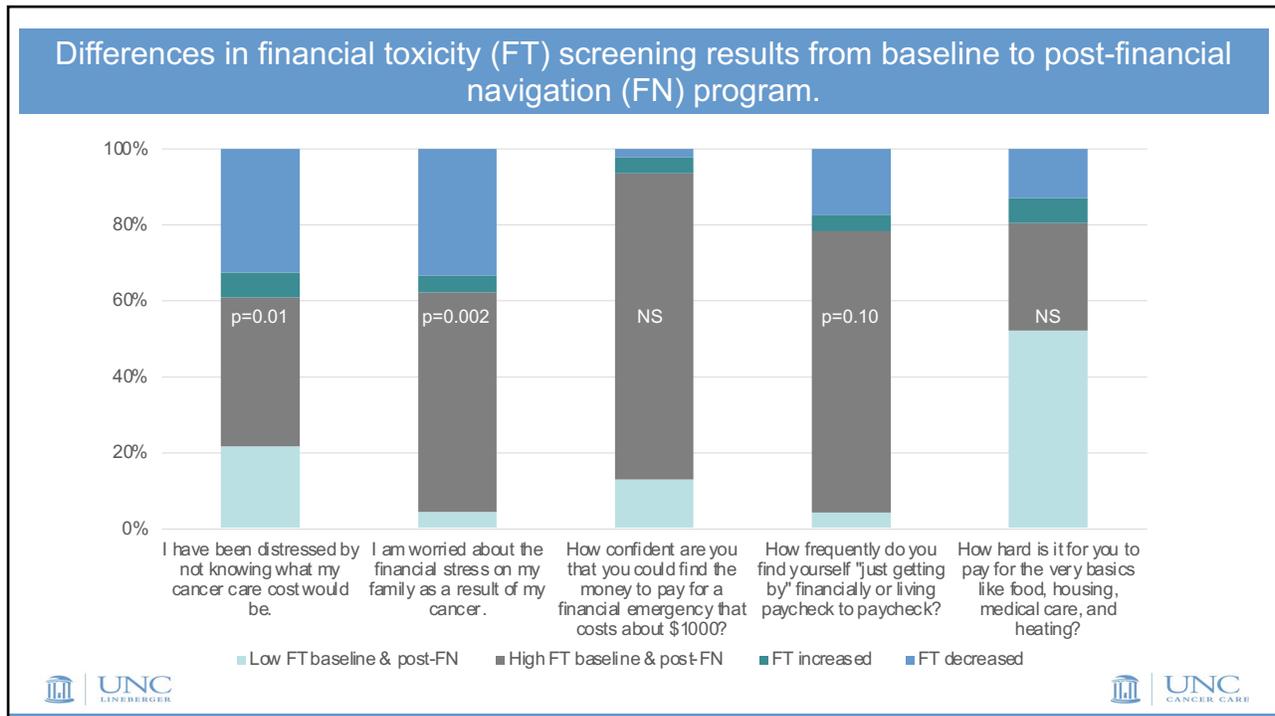
- Mean age: 48 years old
- 61% female
- Race
  - 61% White, 30% Black, 9% Other
- 80% less than college degree
- 85% not currently working
- Health Insurance
  - 39% uninsured, 28% public, 33% private
- Median monthly income: \$800



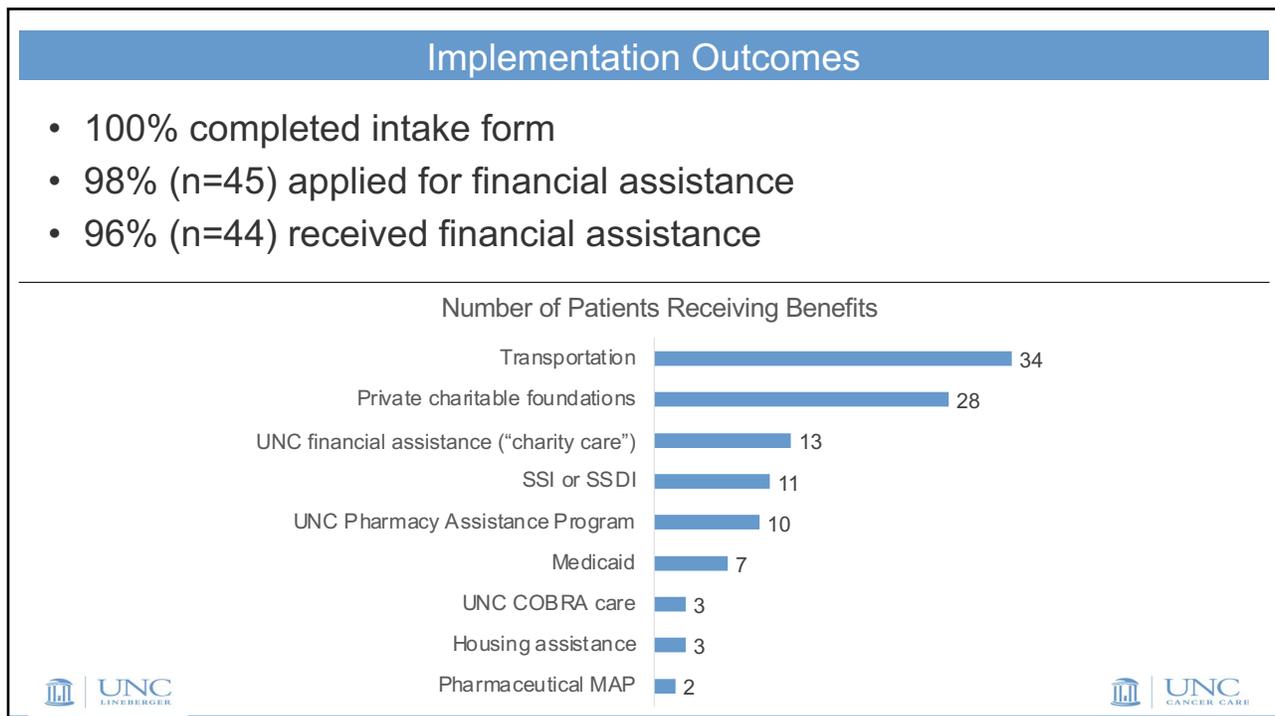

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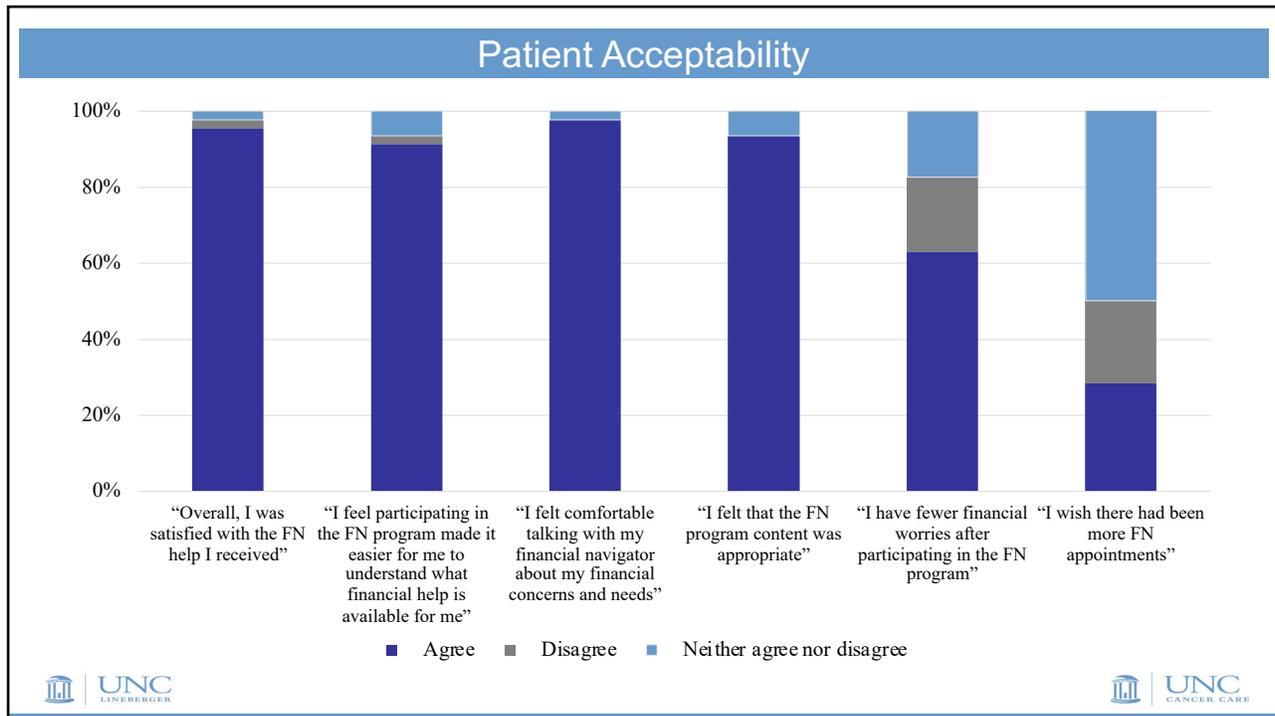
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## Next Steps...

- **R01- Financial navigation (FN) for rural\* cancer patients**
  - Specific Aims:
    1. Characterize the rural oncology practice context to prepare for FN implementation
    2. Assess FN implementation determinants and implementation outcomes in rural oncology practices.
    3. Evaluate the effectiveness of FN in improving patient outcomes of care in rural oncology practices

\*Administrative Supplement approved to add 4 non-rural sites to study

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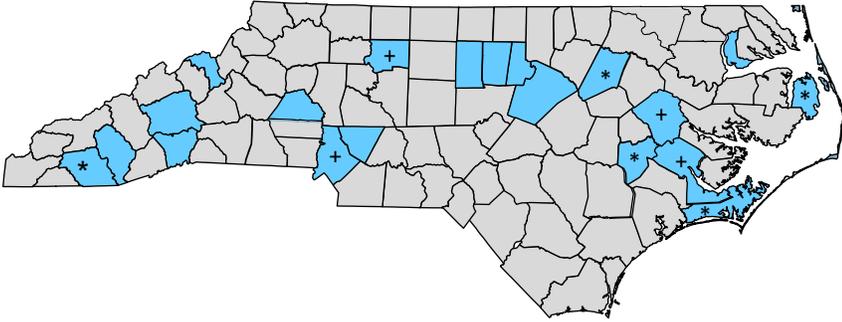
## Study Partners

<p><b>Rural Community Partners</b></p> <ul style="list-style-type: none"> <li>• Carteret Health Care Cancer Center</li> <li>• Nash UNC Health Care</li> <li>• The Outer Banks Hospital</li> <li>• UNC Lenoir Health Care</li> <li>• UNC Pardee</li> </ul>	<p><b>Non-Rural Community Partners</b></p> <ul style="list-style-type: none"> <li>• CarolinaEast Health System</li> <li>• Novant Health</li> <li>• Vidant Medical Center</li> <li>• Wake Forest University Health Sciences</li> </ul>
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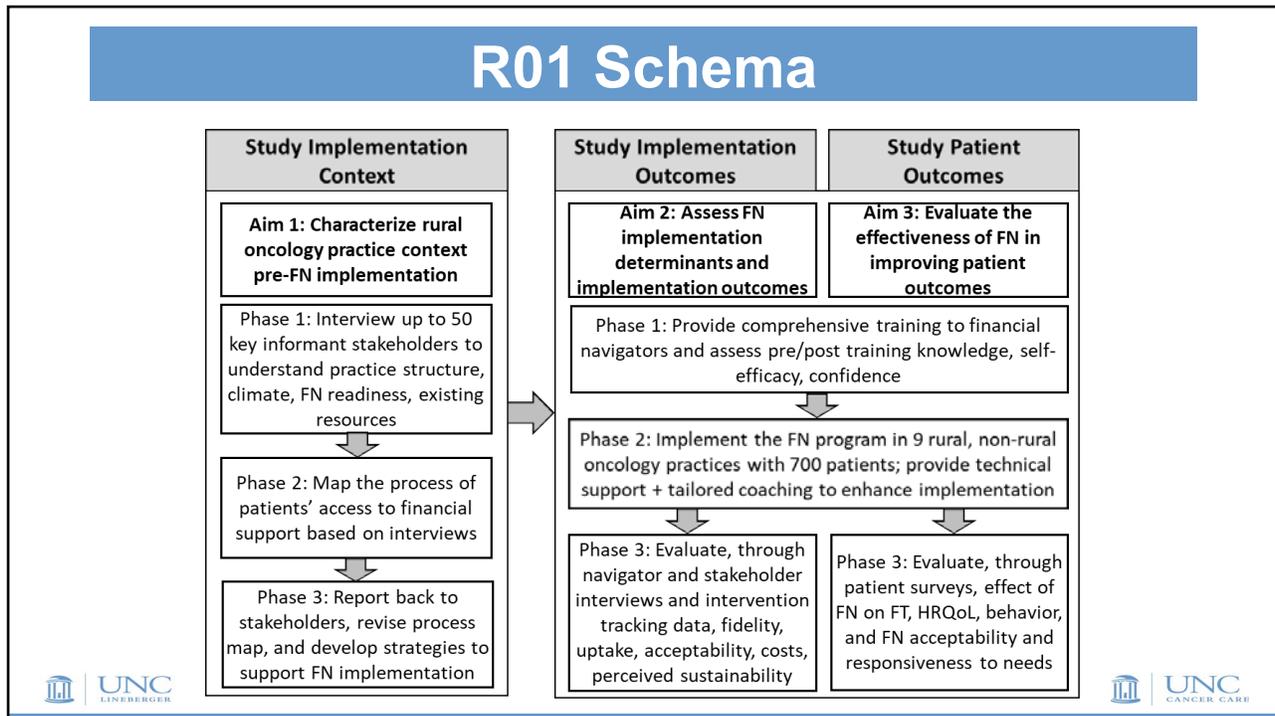
## NC-Cancer Survivorship Professionals Action Network (NC-CSPAN)



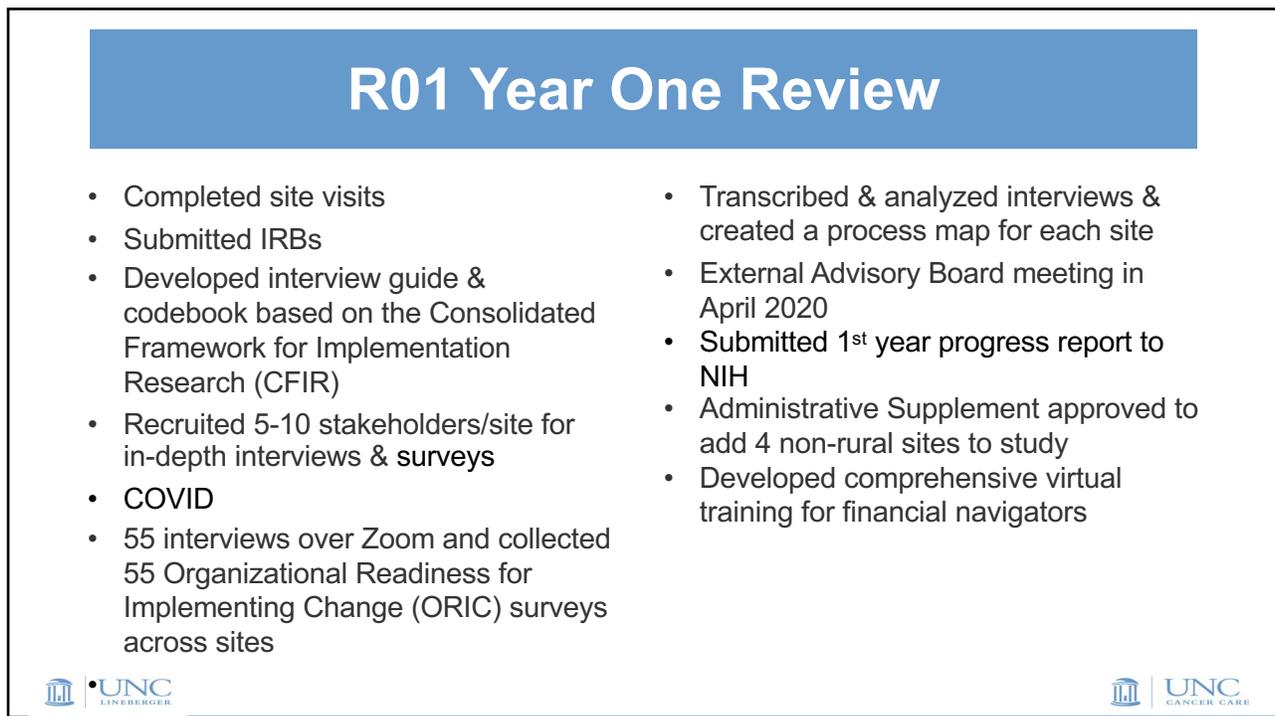
blue shaded counties are counties with active NC-CSPAN sites  
 \*indicates R01-engaged rural practices participating in FN; +indicates non-rural practices participating in FN through the new supplement



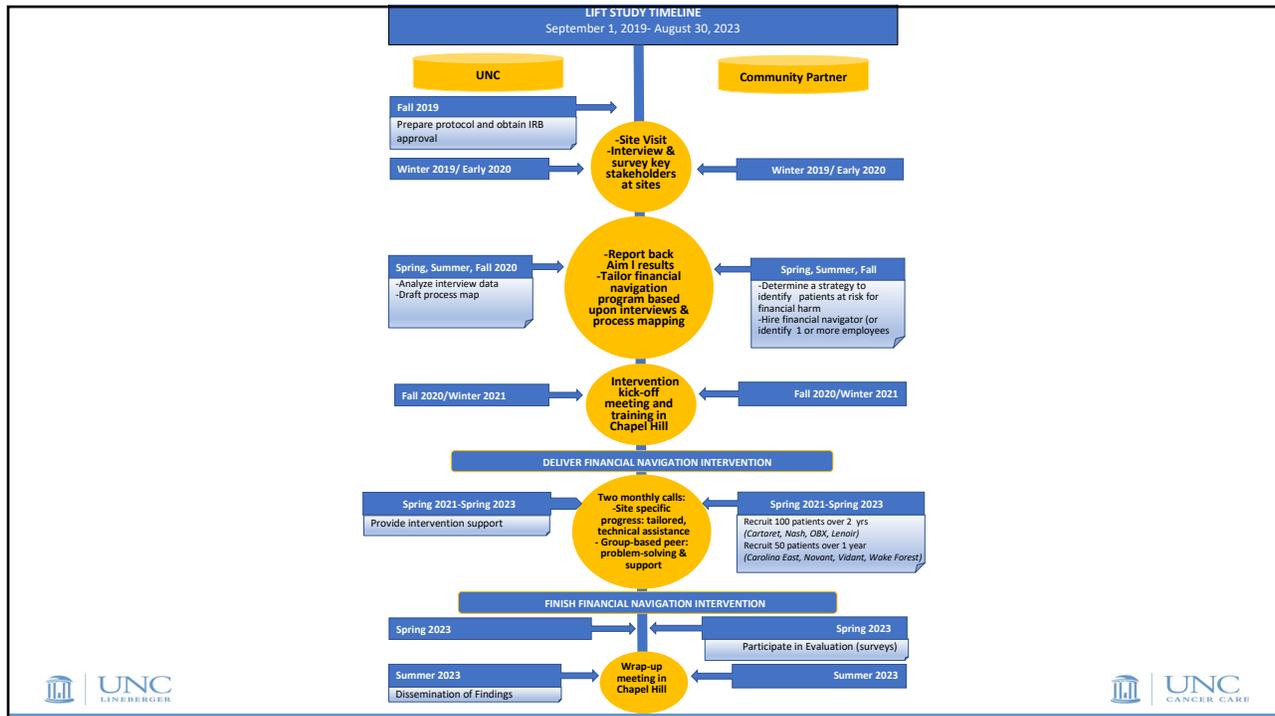

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# The Year Ahead

## Training

Virtual training experience via Zoom teleconference that includes:

- Team-building/Peer Support Activities
- Cancer-related FT Presentations & Discussions
- Financial Distress Screening Processes
- Review of Local and National Financial Support Resources and Eligibility Requirements
- Program Evaluation Practices
- Training on Program's Standard Operating Procedures (SOP) and Database tool
- 7-hour Financial Bootcamp
- Online Training offered by the Association of Community Cancer Centers (ACCC)

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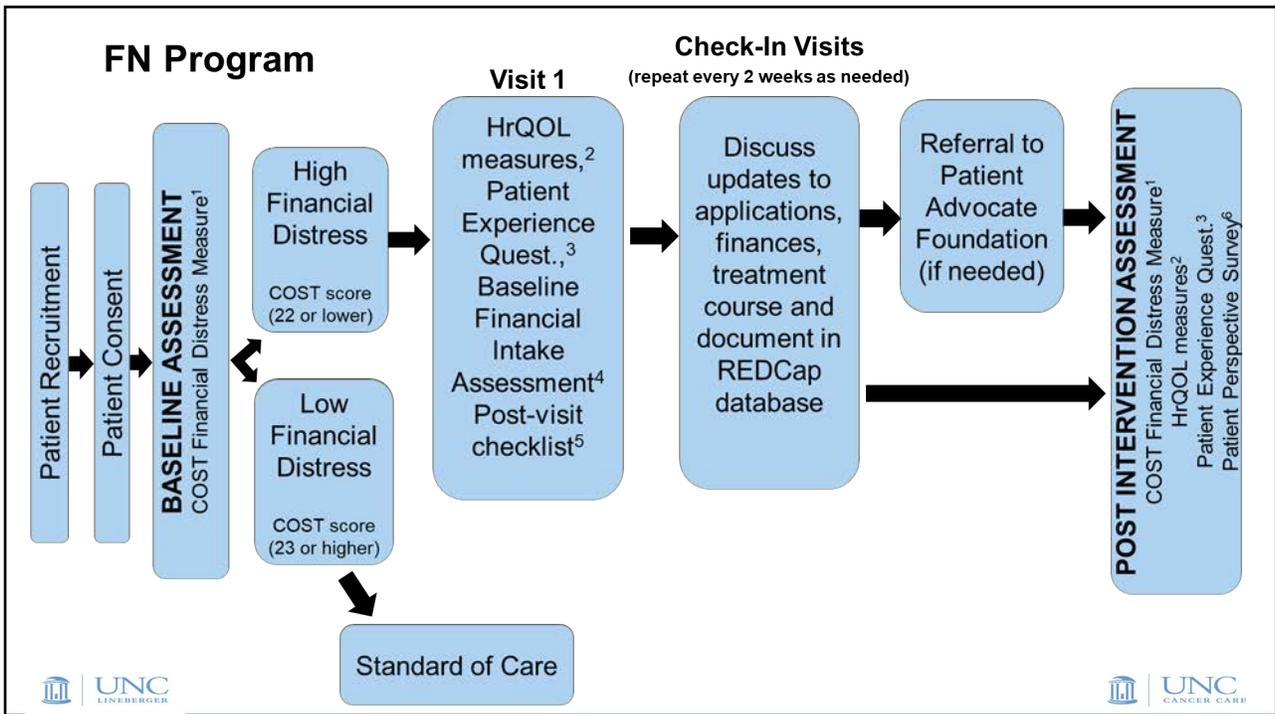
## The Year Ahead

### Financial Program

- Identify cancer patients with high financial distress
  - Complete a comprehensive assessment to determine each patient’s financial needs
  - Assist with applications for financial support resources, including eligibility determination, application completion, and follow-up
- Track and monitor patients’ financial and health outcomes in an electronic database
  - Refer patients to PAF if needed
  - Participate in the evaluation of the FN intervention (surveys and interviews)




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## RO1 Study Measures and Tools

- Aim 1 (navigators and stakeholders):
  - ☑ Stakeholder interview guide
  - ☑ Organizational readiness survey (ORIC)
  - ☑ Organization-specific process map
- Aim 2 (navigators):
  - Training/Standard operating procedures (SOP) manual
  - Notes from peer navigator meetings and technical assistance meetings with UNC team
  - REDCap notes/checklists about patient encounters
  - Pre/Post-Program interviews and surveys



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## RO1 Study Measures and Tools

- Aim 2 and 3 (patients):
  - COST screener to determine level of FT
  - Patient outcomes surveys (health related QOL)
  - Financial Intake Form
    - Includes patient-specific data: Individual financial situation, employment status, monthly income, billing information, insurance status, resources, referrals and benefits
  - Initial Appointment Summary
    - Re-cap of eligible benefits/referrals along with paperwork needed
  - Mid-Program Check-In Form (every 2 weeks re: progress)
  - Patient Perspective (acceptability and satisfaction) surveys
  - Patient Experience surveys



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## COST (Comprehensive Score for Financial Toxicity)

1. Please select a response below indicating your response as it applies to the past 7 days.

	Not at All	A little bit	Somewhat	Quite a bit	Very much
I know that I have enough money in savings, retirement or assets to cover the cost of my treatment	<input type="radio"/>				
My out-of-pocket medical expenses are more than I thought they would be.	<input type="radio"/>				
I worry about the financial problems I will have in the future as a result of my illness or treatment	<input type="radio"/>				
I feel I have no choice about the amount of money I spend on care	<input type="radio"/>				
I am frustrated that I cannot work or contribute as much as I usually do	<input type="radio"/>				
I am satisfied with my current financial situation	<input type="radio"/>				
I am able to meet my monthly expenses	<input type="radio"/>				
I feel financially stressed	<input type="radio"/>				
I am concerned about keeping my job and income, including work at home	<input type="radio"/>				
My cancer or treatment has reduced my satisfaction with my present financial situation	<input type="radio"/>				
I feel in control of my financial situation	<input type="radio"/>				

Souza, Jonas A., et al. *Cancer* 120.20 (2014): 3245-3253.




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## Database for Navigators

REDCap Database

REDCap Tutorial




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# Discuss Patient Resources

**QUICK GUIDE TO FINANCIAL RESOURCES**

**HERE AT UNC:** all services listed below are free of charge. Check with your financial assistance coordinator. Some services at all hospitals which may be most up to date information: <http://unclineberger.org/patientcare/support/ncg/finance>.

<p><b>The Comprehensive Cancer Support Program (CCSP) Patient Assistance Coordinator</b> and N.C. Cancer Hospital Social Workers can help you find resources that may help with the financial burden of cancer including copays, deductibles, and other government benefits and services, and private insurance options. Ask your health care provider for a referral to our outpatient social work and patient assistance team who will assess your eligibility for services.</p> <p><b>UNC Double Financial Counselor:</b> If you do not have insurance, or are self-insured and not paying for your medical bill, please contact the social financial counselors at 919-874-6449.</p> <p><b>Counseling and Support:</b> The Comprehensive Cancer Support Program's group of counselors, psychologists and paymentists provide compassionate support for the challenges that often come with a cancer diagnosis. If you or your loved one is interested in speaking with a member of our counseling team, call 919-874-6449.</p> <p><b>The UNC Cancer Pro Bono Legal Clinic</b> This free service helps cancer patients and their caregivers to prepare legal documents that are important to their health care planning. Services provided are: advanced directives (living wills), health care powers of attorney and durable powers of attorney. Call 919-874-6449 to make an appointment.</p>	<p><b>UNC Pharmacy Assistance Program:</b> Pharmacy financial assistance requires a separate application. See the pharmacy coordinator at the main pharmacy, located on the ground floor of the NC Cancer Hospital to get an application.</p> <p><b>Respite, Information and Referrals:</b> Visit the Patient and Family Resource Center on the ground floor of the NC Cancer Hospital for more information on a variety of cancer-related topics or call from 919-874-6449.</p> <p><b>Questions about your bill:</b> Customer Services Representatives are available to handle all of your questions Monday-Friday, 9 am - 5 pm at 919-874-6449. Outlines or copies are available at 919-874-6449. If you have trouble reaching them, you can also call the Double Financial Counselor at 919-874-6449 and also to talk to someone about billing issues.</p> <p><b>Transportation:</b> If you have Medicaid, call your local department of social services office to arrange for transportation to your medical appointments.</p> <p><b>Legal:</b>  <ul style="list-style-type: none"> <li>Chapel Hill Trust: 919-898-4900</li> <li>Orange Public Trust: 919-835-2008</li> <li>Triangle Trust: 919-835-2008</li> <li>Orange, Durham and Wake counties: 919-446-6900, <a href="http://www.occac.com">www.occac.com</a></li> <li>Prothonotary for Regional Transportation (providing legal review, copies and notary services): 919-852-7379</li> </ul>                     The National Cancer Society's "Road to Recovery" program may be able to provide assistance or information on other transportation resources specific to your area. Call 1-800-573-7343.                 </p>
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Please visit our website <http://unclineberger.org/patientcare/support/ncg/finance>.

Handout

**Financial and Legal Assistance**

A cancer diagnosis can affect so many parts of our lives, including finances. We all know that even without cancer finances can cause stress in our lives. Many people have unplanned expenses related to their care. Let us help you find ways to address these concerns.\*

**FOR MORE INFORMATION CHOOSE FROM THE OPTIONS BELOW:**

 <p>Here at UNC</p>	 <p>Health Insurance</p>	 <p>Housing Assistance</p>
 <p>Legal</p>	 <p>Medication &amp; Treatment Cost Assistance</p>	 <p>Organizations that can Help</p>
 <p>Seniors &amp; Caregivers</p>	 <p>Transportation/Travel</p>	 <p>Work</p>

\*This list is meant to be used as a guide and is not comprehensive. The information provided was the most current information available at the time of publication. Some material may change or become dated. The sponsors and individuals listed assume no responsibility for this.

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# Study Team

## UNC Study Team

- Stephanie Wheeler, PhD, MPH
- Donald L. Rosenstein, MD
- Sarah Birken, PhD
- Cleo A. Samuel, PhD
- Katherine Reeder-Hayes, MD
- Michelle Manning, MPH
- Mindy Gellin, BSN
- Neda Padilla, BS
- Lisa Spees, PhD
- Caitlin Biddell, MSPH, PhD student
- Victoria Petermann, RN, PhD student
- Gabriel Blanchard, RN, OCN, AGNP-O student
- Jenny Spencer, PhD

## Advisory Board

- Kate Gallagher, Patient Advocate Foundation
- Rachel A. Greenup, MD
- Mark Holmes, PhD
- Jennifer Leeman, MPH, DrPH, Mdiv
- Catherine L. Rohweder, DrPh MDiv
- Chris Shea, PhD
- Patient member from each partner site

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# Thank You!

