

Addressing Cancer-Related Financial Toxicity in Oncology Care Settings

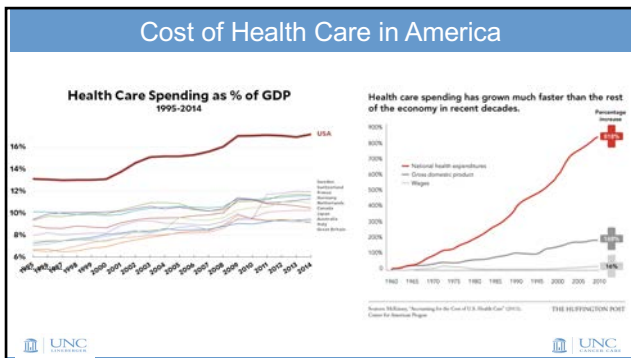
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 Lineberger Comprehensive Cancer Center
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and

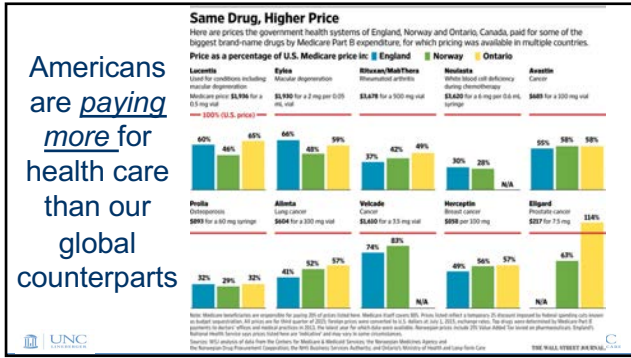
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 Lineberger Comprehensive Cancer Center
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Financial Toxicity

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

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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
N	738 (70%)	316 (29%)	
Age, mean (SD)	42.2 (10.1)	42.6 (5.7)	0.53
Race			<0.001
Non-Hispanic White	576 (78.0%)	121 (38.3%)	
Non-Hispanic Black	23 (3.1%)	72 (22.8%)	
Hispanic	43 (5.8%)	27 (8.5%)	
Non-Hispanic Other	96 (13.0%)	96 (30.4%)	
Time with Metastatic Disease			<.001
<1 year	211 (28.6%)	37 (11.7%)	
1-2 years	151 (20.5%)	151 (47.8%)	
2-5 years	106 (14.4%)	106 (33.5%)	
5+ years	22 (3.0%)	22 (7.0%)	
Marital Status			<0.001
Married, or living with a partner	544 (74.0%)	252 (79.7%)	
Never married	159 (21.6%)	18 (5.7%)	
Divorced/Widowed/Separated	32 (4.4%)	46 (14.6%)	
Living with Dependents			0.003
<15,000	654 (88.7%)	299 (94.6%)	
15,000-29,999	13 (1.8%)	38 (12.0%)	
30,000-49,999	87 (11.9%)	87 (27.5%)	
50,000 or more	309 (41.7%)	153 (48.4%)	
Household Income			<0.001
<15,000	231 (31.6%)	38 (12.0%)	
15,000-29,999	448 (60.9%)	10 (3.2%)	
30,000-49,999	200 (27.2%)	233 (73.7%)	
50,000 or more	61 (8.3%)	57 (18.0%)	
Current Work Status			
Not working	27 (3.7%)	16 (5.1%)	
Working full time			
Working part time			
Self employed (full or part time)			

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

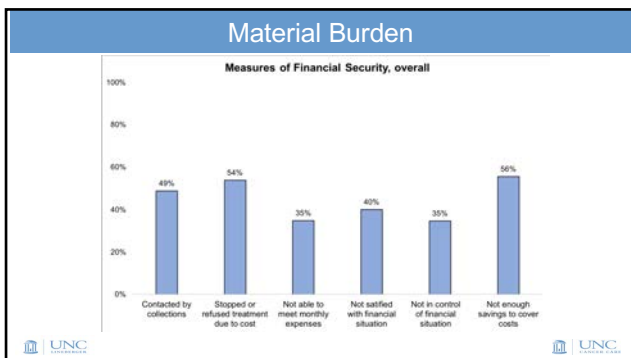
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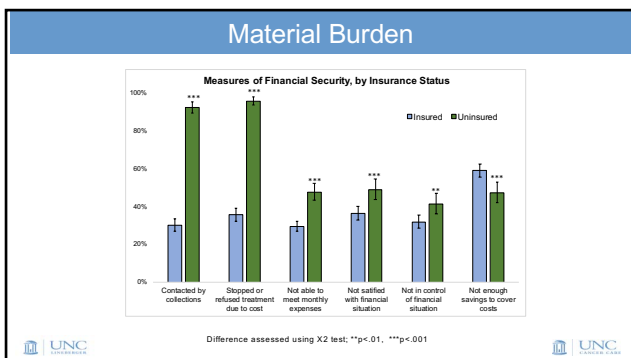
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Uninsured participants reported significantly lower income but were much more likely to be working full time jobs

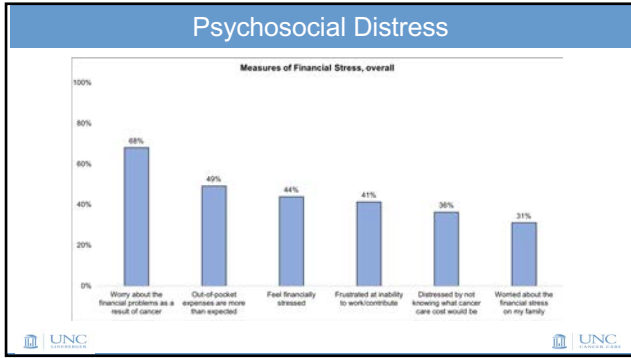
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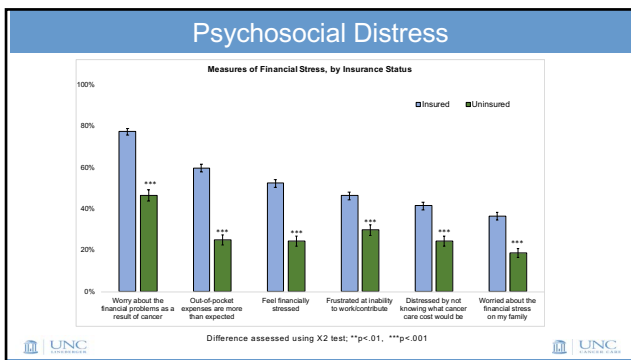
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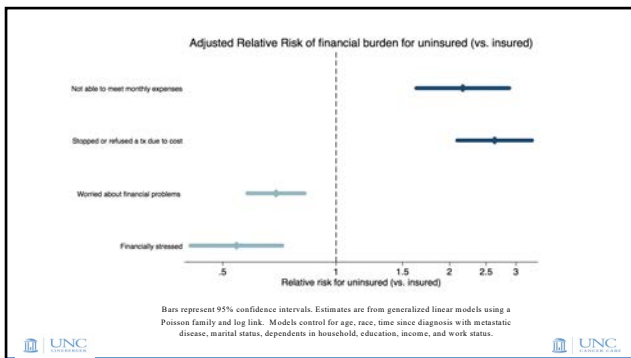
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What did we learn from the metastatic experience?

Patients with metastatic breast cancer reported an unprecedented level of cancer-related financial harm.

Identifying those who report the most distress may not capture those with highest material need (greater financial insecurity).

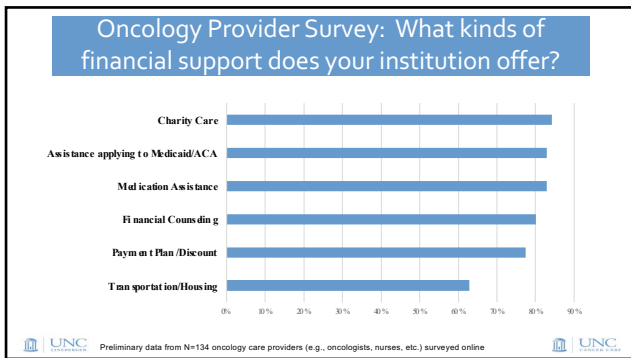
Material Burden / Financial Security

- Unable to cover medical and non-medical costs
- High medical debt
- Stopped, refused or delayed treatment due to cost burden

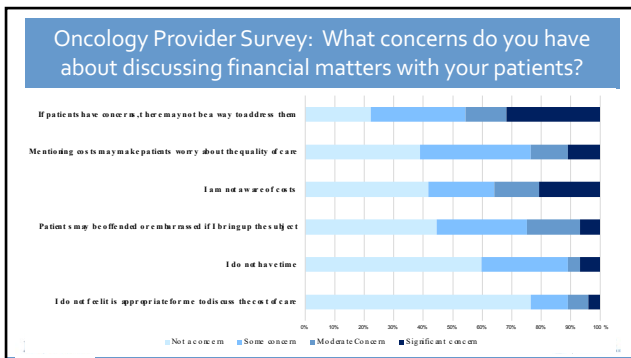
Financial-Related Psychosocial Distress

- Anxiety about high cost of care
- Worried about family/financial future
- Distressed by not knowing costs

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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

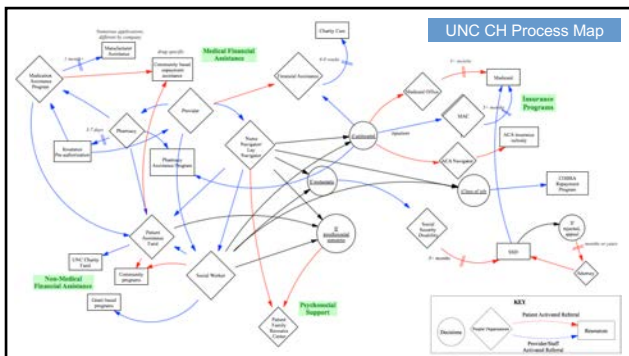
Uninsured patients have far more resources to access than do under-insured patients. A number of processes rely on patients to navigate complex, duplicative applications- additional navigation support is needed and may help patients successfully reach and obtain help from existing resources.

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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.

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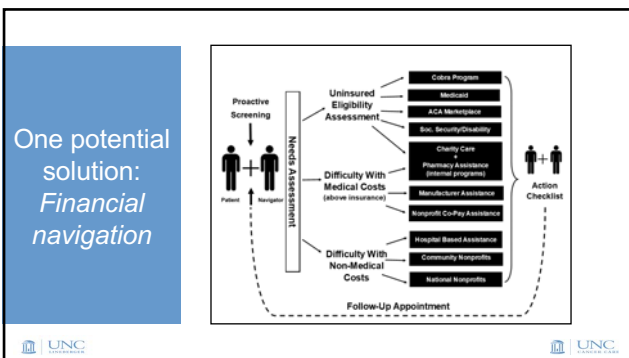


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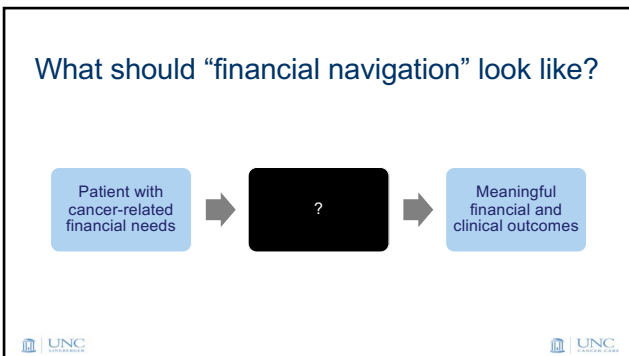
Summary of
Cancer-related
Financial
Challenges to
Patients

- 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

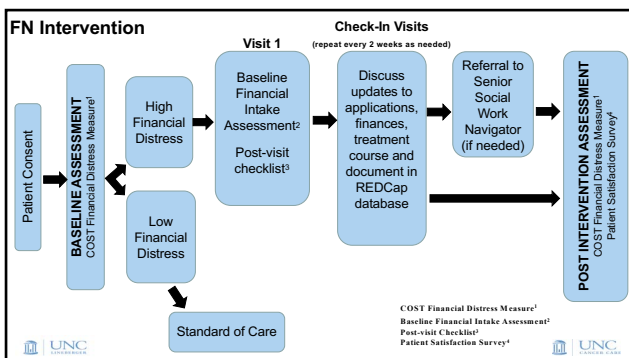
- Funded by UNC Center for Health Innovation (1 year; \$49,749)

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Study
Design

- 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

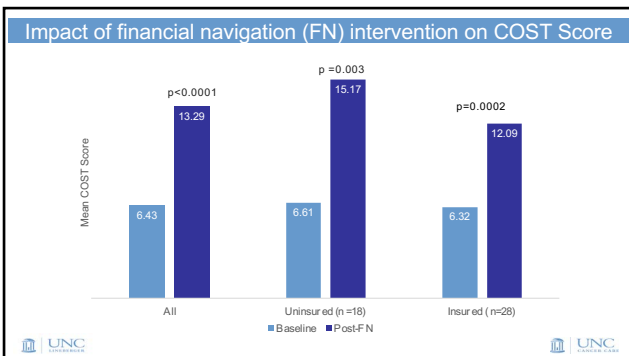
- Intake assessment of financial needs and vulnerability
- Initial one-on-one consultation with a trained financial navigator
- Triage to financial support services matching patients' needs
- Multiple follow up appointments (every 2 wks) with navigator assistance based upon:
 - Patients' employment status, 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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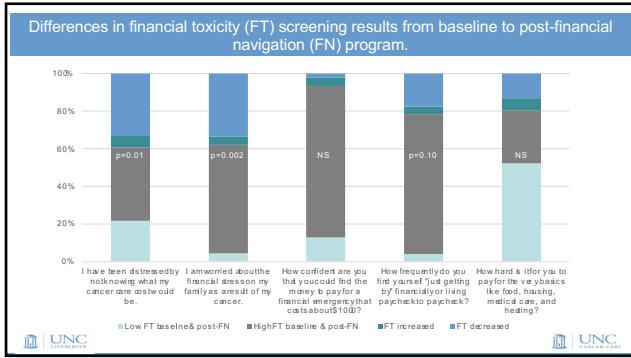
Results: Financial Navigation Participants (n=46)

- 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

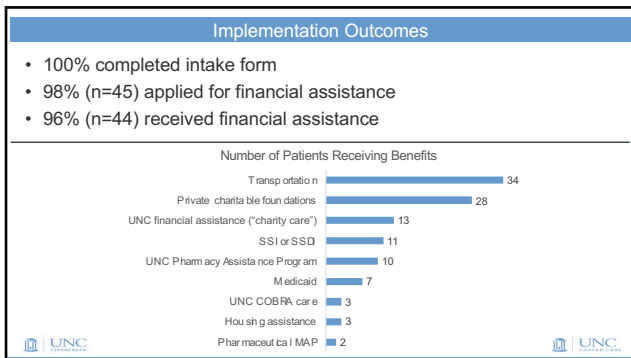
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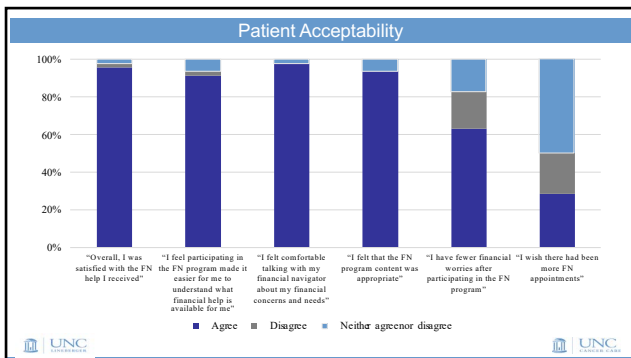
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Next Steps...

- **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



Rural Community Partners	Non-Rural Community Partners
• Carteret Health Care Cancer Center	• CarolinaEast Health System
• Nash UNC Health Care	• Novant Health
• The Outer Banks Hospital	• Vidant Medical Center
• UNC Lenoir Health Care	• Wake Forest University Health Sciences
• UNC Pardee	




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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)

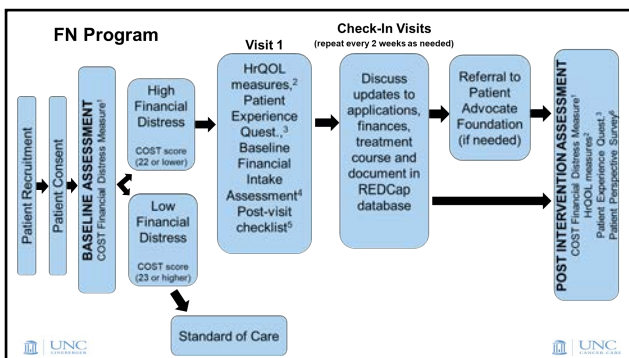
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The Year Ahead

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.

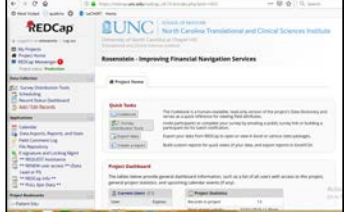
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I know that I have enough money in savings, retirement or assets to cover the cost of my treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My out-of-pocket medical expenses are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

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

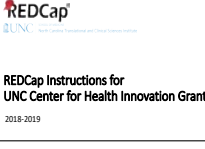



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Database for Navigators




REDCap Database




REDCap Tutorial

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Discuss Patient Resources



Handout



Website

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Study Team

UNC Study Team

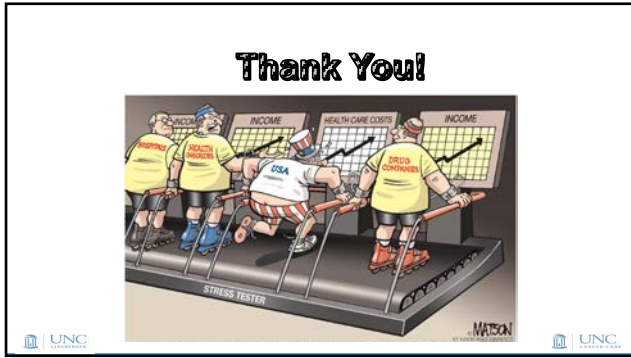
- Stephanie Wheeler, PhD, MPH
- Donald L. Rosenstein, MD
- Sarah Birken, PhD
- Cleo A. Samuel, PhD
- Katherine Reeder-Hayes, MD
- Michelle Manning, MPH
- Mindy Gellin, BSN
- Neda Padilla, BS
- Lisa Spees, PhD
- Caitlin Biddell, MSPH, PhD student
- Victoria Petermann, RN, PhD student
- Gabriel Blanchard,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