Addressing Financial Hardship in Cancer Care

The Role of the Oncology Community

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Co-Director, Hutchinson Institute for Cancer Outcomes Research,
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A multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and health care provider and patient behaviors affect access to cancer care, the quality and cost of cancer care, and ultimately the health and well-being of cancer patients and survivors.

- **Generation of new knowledge to inform practice change**
- **Diverse practice settings**


NCI Community Oncology Research Program: Research areas National Cancer Institute [http://ncorp.cancer.gov/research](http://ncorp.cancer.gov/research)
The Health Care Delivery System

Institute of Medicine, Lowering Costs and Improving Outcomes, 2011
Objectives

• What is financial hardship / toxicity and why does it matter? What are the contributing factors?

• What can the oncology community do to address this problem?

• Ongoing research in the field
The U.S. Spends Twice as Much as Comparable Countries on Health

Health spending per capita, by spending category, 2018

United States (Total: $10,637 per capita)
- Inpatient and outpatient: $6,624
- Prescription drugs and medical goods: $1,397
- Administrative: $937
- Long-term: $516
- Preventive: $854
- Other: $309

Comparable Country Average (Total: $5,527 per capita)
- Inpatient and outpatient: $2,718
- Prescription drugs and medical goods: $884
- Administrative: $1,111
- Long-term: $439
- Preventive: $201
- Other: $175
U.S. Healthcare Spending

- Quicker access to newer therapies? ✔
- Greater and more equitable access to health and cancer care? ✗
- Improved care quality? 🤔
- Better survival? 🤔

Downing N. et al. NEJM. April 2017
Yezefski, T. et al. JCO Oncology Practice. May 2020
Khaki et al. JCO Oncology Practice. Nov 2021
Cancer Drug Spending

- Launch prices and post-launch prices increasing faster than inflation; not correlated with clinical benefit

- Combination and chronic therapies (and improved survival)

- “Less toxic” therapies (e.g. immunotherapy)
  - Poorer PS
  - “Hail mary” situations

Vokinger, K. et al. JAMA Oncology. July 2021
Desai, A. et al. JAMA Open. Jan 2022
Cancer Drug Utilization

Utilization in last 30 days of life

Khaki, A. et al. JCO Oncology Practice. May 2021
Cancer Drug Spending

Immuno-Oncology Spending US$Bn, 2011-2025

Source: IQVIA Institute, Feb 2021
Exhibit Notes: Historic data points based on marketed immuno-oncology checkpoint inhibitors, PD-1/PDL1 Inhibitors: atezolizumab, avelumab, cemiplimab, durvalumab, nivolumab and pembrolizumab. Forecast periods include potential future immuno-oncology medicines, of which there are over 60 immune-system related targets in research.
Report: Global Oncology Trends: Outlook to 2025. IQVIA Institute for Human Data Science, June 2021
Annual Insurance Costs are Rising

Multi-tiered Drug Formularies

Americans are Financially Fragile

How Americans pay for unexpected expenses

How would you deal with a major unexpected expense, such as $1,000 for an emergency room visit or car repair?

Annual out-of-pocket limits under ACA (2022)

- $8,700 (individual)
- $17,400 (family)

Bankrate 2017 Financial Security Index Survey
Financial Hardship (Toxicity)

- Younger age
- Lower income
- Female
- Minority Race
- Cancer severity

Not Just Drugs!

Other medical costs (not drugs)

Non-medical Costs
• Transportation
• Housing

Indirect Costs
• Lost employment and income (patient and caregiver)
• Missed raises/promotions
Limitations of Previous Studies

• Retrospective (Recall bias)

• Not longitudinal

• Focus on long term cancer survivors

• Limited information on caregiver/household financial impact
Cumulative Incidence of Financial Hardship in Patients with Metastatic Colorectal Cancer: Primary Results of S1417CD

Veena Shankaran, MD, MS; Joseph M. Unger, PhD; Amy K. Darke, MS; J. Marie Suga, MD, MPH; James L. Wade, III, MD; Peter J. Kourlas, MD; Sreenivasa R. Chandana, MD, PhD; Mark A. O’Rourke, MD; Suma P. Satti, MD; Diane Liggett, BS; Dawn L. Hershman, MD, MS; Scott D. Ramsey, MD, PhD
Study Setting

The NCI Community Oncology Research Program (NCORP) brings cancer research studies and results to patients in a variety of community settings across the United States.

RESEARCH BASES
- Develop and coordinate clinical trials and cancer care research

32 + MINORITY/UNSERVED COMMUNITY SITES

14 LOCATIONS
- at diverse, community-based hospitals, private practices and more

7 reSEARCH BASES
- for NCI approved trials to patients

1,000+ LOCATIONS

NCORP.cancer.gov
Study Schema and Assessments

Initiation of systemic therapy (days -60 to +30)

Registration
- Baseline Questionnaire
- Credit report

Diagnosis ≤ 120 days

3 month
- Questionnaire

6 month
- Questionnaire
- Credit Report

9 month
- Questionnaire

12 month
- Questionnaire
- Credit report
Primary Objective

To estimate the cumulative incidence of self-reported major financial hardship (MFH) at 12 months.

- New debt accumulation
- Selling/refinancing home
- ≥ 20% income decline
- Borrowing money/Loans to pay for cancer treatment
Secondary Objectives

- Determine risk factors for major financial hardships
- Explore whether financial hardship predicts poorer health-related quality of life
- Determine feasibility of recruiting and surveying patients’ primary caregivers about financial hardship
- Correlate self-reported measures with credit reports
Developing a process to obtain consumer credit reports (TransUnion)

- Consumer credit reports have never been linked prospectively with patient data
- Legal review and contract
- Collection of SSNs and addressing patient privacy concerns
- Assurances that obtaining credit reports for research will not affect credit scores
## Data Elements Required for Credit Linkage

<table>
<thead>
<tr>
<th></th>
<th>Required/Collected Routinely by SWOG</th>
<th>Required specifically for credit linkage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name</strong></td>
<td>No (Initials only, Name optional)</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>SSN</strong></td>
<td>No (Requested but optional)</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Full Street Address</strong></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Zip Code</strong></td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Birth Date</strong></td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Accrual Timeline

Patient and Caregiver Accrual by Quarter

- 380 patients
- 152 caregivers (40%)

- 60.2 median age
- 78% white
- 2% uninsured
- 62% employed
- 58% income ≤ $50K
- 92% patients have credit data
Major Financial Hardship

<table>
<thead>
<tr>
<th>Time</th>
<th>Selling home</th>
<th>Refinancing home</th>
<th>≥ 20% income decline</th>
<th>Loans</th>
<th>Debt</th>
<th>Any MFH</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 mo</td>
<td>0.5%</td>
<td>0.3%</td>
<td>2.4%</td>
<td>19.2%</td>
<td>8.7%</td>
<td>24.6%</td>
</tr>
<tr>
<td>6 mo</td>
<td>1.6%</td>
<td>1.9%</td>
<td>6.8%</td>
<td>20.1%</td>
<td>1.9%</td>
<td>24.6%</td>
</tr>
<tr>
<td>9 mo</td>
<td>1.9%</td>
<td>2.2%</td>
<td>11.8%</td>
<td>23.7%</td>
<td>11.8%</td>
<td>61.8%</td>
</tr>
<tr>
<td>12 mo</td>
<td>2.6%</td>
<td>3.4%</td>
<td>2.6%</td>
<td>25.8%</td>
<td>2.6%</td>
<td>56.7%</td>
</tr>
</tbody>
</table>

Shankaran, V. et al. JNCI. Jan 2022
## Risk Factors for Financial Hardship

<table>
<thead>
<tr>
<th>Factor</th>
<th>Level</th>
<th>Hazard Ratio (95% CI)</th>
<th>P-value</th>
<th>Cumulative Incidence (%) at 6 mos</th>
<th>Cumulative Incidence (%) at 9 mos</th>
<th>Cumulative Incidence (%) at 12 mos</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>&lt; 65 years</td>
<td>1.10 (0.96-1.39)</td>
<td>.45</td>
<td>47.6</td>
<td>61.1</td>
<td>72.5</td>
</tr>
<tr>
<td></td>
<td>≥ 65 years</td>
<td></td>
<td></td>
<td>38.2</td>
<td>52.2</td>
<td>68.1</td>
</tr>
<tr>
<td>Race</td>
<td>Non-white</td>
<td>1.25 (0.97-1.61)</td>
<td>.09</td>
<td>48.3</td>
<td>60.6</td>
<td>76.3</td>
</tr>
<tr>
<td></td>
<td>White</td>
<td></td>
<td></td>
<td>41.6</td>
<td>57.9</td>
<td>70.3</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Unmarried</td>
<td>1.11 (0.88-1.41)</td>
<td>.37</td>
<td>43.1</td>
<td>59.2</td>
<td>69.0</td>
</tr>
<tr>
<td></td>
<td>Married/Partner</td>
<td></td>
<td></td>
<td>40.8</td>
<td>56.3</td>
<td>72.2</td>
</tr>
<tr>
<td>Employment Status</td>
<td>Unemployed</td>
<td>0.88 (0.69-1.11)</td>
<td>.28</td>
<td>38.0</td>
<td>51.3</td>
<td>62.9</td>
</tr>
<tr>
<td></td>
<td>Any employment</td>
<td></td>
<td></td>
<td>47.2</td>
<td>59.0</td>
<td>75.6</td>
</tr>
<tr>
<td>Household Income</td>
<td>&lt; $50,000/yr</td>
<td>1.20 (0.94-1.52)</td>
<td>.14</td>
<td>43.8</td>
<td>59.5</td>
<td>72.7</td>
</tr>
<tr>
<td></td>
<td>≥ $50,000/yr</td>
<td></td>
<td></td>
<td>38.0</td>
<td>56.0</td>
<td>69.1</td>
</tr>
</tbody>
</table>

Hazard risk of major financial hardship for first factor level: Decreased, Increased

Shankaran, V. et al. JNCI. Jan 2022
Post-Hoc Analysis of Assets and Income

Cumulative Incidence of Financial Hardship
By Number of Adverse Risk Factors

Time after Registration

- Income <$100k and Total Assets <$100k (n=235)
- Either income >$100k or Total Assets >$100k (but not both; n=86)
- Both income >$100k and Total Assets >$100k (n=37)

49% increased risk of FH for each increase in risk level (HR=1.49, 95% CI: 1.21-1.85, p<.001)

Shankaran, V. et al. JNCI. Jan 2022
Conclusions

•Patients and caregivers are **willing to participate** in research that aims to address their financial concerns.

•MFH accumulates over time. Nearly 75% of pts experienced MFH at 12 mo despite access to health insurance.

•Clinical and policy interventions are needed to protect cancer patients from financial devastation during and after treatment.
Credit Records

• Rich source of detailed financial information

• Representative: 70-90% of Americans have credit histories, including younger and low-income individuals

• Timely: Lenders typically update credit agencies monthly, but it may take up to 6 months for financial events to show up in credit records

Cancer Registry + Credit data

CASES
Age ≥ 18
Diagnosed 2013-2018
Western Washington SEER Registry

CONTROLS
Age ≥ 18
Washington Voter Registration Records

CREDIT RECORDS
TransUnion
2012 - 2020

Cancer = 63,574
Non-cancer = 127,148

Primary Outcome

Adverse Financial Events (AFEs)

- Inability to pay bills
  - Third-party collections
  - Charge-offs

- Risk for creditor action against property
  - Tax liens
  - Delinquent mortgage payments

- Creditor assumes property
  - Foreclosures
  - Repossessions

Severity:
- Severe
- More severe
- Most severe

Adverse Financial Events (AFEs)

Any AFE: **4.3 % (cancer)** versus **2.4 % (control)** *p < 0.001*

OR **1.71 (95% CI 1.61-1.81)** adjusting for age, sex, credit line (pre-cancer), neighborhood

P value < 0.05 for all comparisons except foreclosures (0.08) and tax liens (p = 0.53)

Implications

• AFEs on credit reports have serious and long-lasting consequences on financial security, status, and credit worthiness.

• But some progress … On July 1\textsuperscript{st}
  • Paid medical collections will disappear from Equifax, Experian, and TransUnion credit reports (previously would remain for 7 years).
  • Unpaid medical collections will not appear on credit reports unless they have been in collections for a year.
  • Medical debts < $500 will no longer appear on credit reports
Contributing Factors

Societal / Policy
- Economic downturns
- Poor access to affordable health care
- Underinsurance
- Drug pricing

Clinical / Patient
- Poor financial literacy
- Lack of cost transparency / communication
- Inconsistent access to patient assistance

Provider
- Low value prescribing / testing (end of life)
Patient Navigation

Individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care through all phases of the cancer experience.

- Decreased ED/hospital use
- Improved uptake of cancer screening
- Greater cancer treatment initiation and completion
Financial Navigation

Overcome *financial* barriers to care:

- Copayment assistance
- Insurance enrollment and optimization
- Non-Medical costs (e.g. transportation, lodging)
Financial Navigation in Cancer Care Delivery: State of the Evidence, Opportunities for Research, and Future Directions

Anaeeze C. Offodile II, MD, MPH¹,²; Kathleen Gallagher, MPH³; Rebekah Angove, PhD³; Reginald D. Tucker-Seeley, ScD⁴,⁵; Alan Balch, PhD³; and Veena Shankaran, MD, MS⁶,⁷
Financial Navigation Infrastructure

44% of community oncology practices provide financial counseling – NCORP Landscape Survey

39% of financial navigators met proactively with patients to discuss insurance, cost of care, and copay programs – 2016 Association for Community Cancer Centers Report

Over 70% of centers agreed that it was difficult to determine how much a patient’s treatment would cost and that oncologists are reluctant to discuss financial issues with cancer patients – 2020 NCI Survey of Financial Navigation Services at Comprehensive Cancer Centers
Financial Navigation Infrastructure (NCI)

• 52% would increase **financial navigator staff**
• 19% would improve the **transparency** of treatment costs
• 15% would provide **more financial assistance** to patients for direct and indirect costs of treatment
• 13% would create additional patient-facing financial navigation **resources, tools, or processes**
• 13% would streamline the integration of financial navigation services into the **clinical workflow**
Potential Practice Solutions

Training social workers and financial counselors in the clinic

Technology and Apps – cost estimation tools

Partnering with non-profit financial counseling organizations
Financial Navigation Pilot Studies

PAF/CENTS

• Money/budget management
• Finding copayment assistance for high-cost drugs
• Navigating and understanding health insurance plans

Shankaran V., et al. JCO Oncology Practice. 2018
Watabayashi, K. et al. JNCCN. 2020
Patient-Spouse Dyad

Intervention

1:1 Stratified by patient age, gender, hematologic vs. de novo solid tumor vs. recurrent, household financial fragility¹

Control

- Financial Literacy Training²

Study Assessments

All Participants: Consent, Complete Baseline Surveys, then Registration. Data Base Staff to Collect Credit Report

All Participants: Complete 3 Month Surveys Data Base Staff to Collect Credit Report Clinical

All Participants: Complete 6 Month Surveys Data Base Staff to Collect Credit Report

All Participants: Complete 12 Month Surveys Data Base Staff to Collect Credit Report

Monthly contact with CENTS and PAF x 6 months

- Direct Medical Cost and Healthcare Coverage Assistance
- Indirect and Non-Medical Cost Assistance
- Financial Counseling
- Financial Literacy Training³

¹ Household financial fragility index: couples’ ability to certainly/probably vs. certainly/probably not able to come up with $2,000 in 30 days for an unexpected expense (self-reported at the time of consent)

² Administered via online video within 14 days of enrollment
### Eligibility (N=1072 (536 Dyads))

#### Patient

**Inclusion criteria**
- Age ≥ 18
- Seen and treated at an NCORP clinical site
- Within 120 days of metastatic solid tumor or hematologic cancer diagnosis requiring treatment
- English or Spanish-speaking
- Zubrod performance status 0-2
- Willing to provide SSN
- Patients with a history of secondary malignancy if not diagnosed within the last 24 months, not on active therapy, and disease-free.

#### Spouse Caregiver

**Inclusion criteria**
- Age ≥ 18
- Legally married to eligible patient
- File tax returns as married filing jointly
- Be living with their spouse
- English or Spanish-speaking
- Willing to provide SSN
# Endpoints and Measurements

## Primary Endpoint

### Measurement (Data Source = CREDIT REPORTS)
- **Household Financial Hardship**
  - New loans (bank or home equity loans)
  - Declines in credit score by ≥ 1 category
  - Reaching limits on credit cards and home equity loans
  - Credit or other payment delinquencies
  - Lien, judgment, or credit collection process
  - Personal bankruptcy filings

## Secondary Endpoints

### Measurement (Data Source = SURVEYS/EMR)
- **Patient QOL**
  - EQ-5D (change in score)
- **Subjective financial distress**
  - COST-PROM (change in score)
- **Treatment adherence**
  - Self-reported (adapted from S1417CD)
- **ER and hospital utilization**
  - Medical record
- **Caregiver Burden / QOL**
  - CarGOQoL instrument (change in score)
Research Questions

When and how often to engage patients and caregivers?

How do we identify people at risk?

Impact on Outcomes – what outcomes?

Feedback to physician – patient decision-making?
Not pictured: Rachel Issaka MD; Cristina Merkhofer MD MS, Evan Hall MD,
Acknowledgements

Collaborators / Co-Is
Dawn Hershman
Joseph Unger
Amy Darke
Riha Vaidya
Shelby Langer
Ruth Carlos

CENTS
• Judge Karen Overstreet
• Tony Leahy

PAF
• Alan Balch
• Erin Bradshaw
• Kate Gallagher
• Rebekah Angove
• Jennifer Obenchain
Funding

Conquer Cancer Foundation
  – 2013 CDA
  – 2009 YIA

SWOG Hope Foundation
  – 2012 Charles Coltman Jr. Fellowship

Breast SPORE / Safeway Foundation
  – 2014 Pilot Award

NCI
  – R01CA248656-03

NCI/Eli Lilly 2019

Kathryn Butler Foundation
Texas 4000 Foundation