Addressing Cancer-Related Financial Toxicity in Rural Oncology Care Settings

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**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

**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.

**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.
The Cost of Health Care in America

Health Care Spending as % of GDP
1995-2014

- USA
- Sweden
- Switzerland
- France
- Germany
- Netherlands
- Canada
- Japan
- Australia
- Italy
- Great Britain

Health care spending has grown much faster than the rest of the economy in recent decades.

Source: World Bank

Sources: McKinsey, "Accounting for the Cost of U.S. Health Care" (2011), Center for American Progress
Americans are paying more for health care than our global counterparts.

<table>
<thead>
<tr>
<th>Drug</th>
<th>Condition/Indication</th>
<th>Price (U.S.)</th>
<th>Price (UK)</th>
<th>Price (Norway)</th>
<th>Price (Ontario)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lucentis</td>
<td>Macular degeneration</td>
<td>$1,930</td>
<td>$1,390</td>
<td>$1,670</td>
<td>$1,445</td>
</tr>
<tr>
<td>Eylea</td>
<td>Macular degeneration</td>
<td>$1,930</td>
<td>$1,100</td>
<td>$1,670</td>
<td>$1,445</td>
</tr>
<tr>
<td>Rituxan/MabThera</td>
<td>Rheumatoid arthritis</td>
<td>$3,678</td>
<td>$2,200</td>
<td>$2,700</td>
<td>$2,500</td>
</tr>
<tr>
<td>Neulasta</td>
<td>White blood cell deficiency during chemotherapy</td>
<td>$3,620</td>
<td>$2,200</td>
<td>$2,700</td>
<td>$2,500</td>
</tr>
<tr>
<td>Avastin</td>
<td>Cancer</td>
<td>$685</td>
<td>$400</td>
<td>$570</td>
<td>$530</td>
</tr>
<tr>
<td>Prolia</td>
<td>Osteoporosis</td>
<td>$893</td>
<td>$500</td>
<td>$670</td>
<td>N/A</td>
</tr>
<tr>
<td>Alimta</td>
<td>Lung cancer</td>
<td>$604</td>
<td>$350</td>
<td>$470</td>
<td>N/A</td>
</tr>
<tr>
<td>Velcade</td>
<td>Cancer</td>
<td>$1,610</td>
<td>$950</td>
<td>$1,200</td>
<td>$1,050</td>
</tr>
<tr>
<td>Herceptin</td>
<td>Breast cancer</td>
<td>$858</td>
<td>$500</td>
<td>$670</td>
<td>$630</td>
</tr>
<tr>
<td>Eligard</td>
<td>Prostate cancer</td>
<td>$217</td>
<td>$130</td>
<td>$160</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note: Medicare beneficiaries are responsible for paying 20% of prices listed here. Medicare itself covers 80%. Prices listed reflect a temporary 2% discount imposed by federal spending cuts known as budget sequestration. All prices are for third quarter of 2013; foreign prices were converted to U.S. dollars at July 1, 2015, exchange rates. Top drugs were determined by Medicare Part B payments to doctors' offices and medical practices in 2013, the latest year for which data were available. Norwegian prices include 25% Value Added Tax levied on pharmaceuticals. England’s National Health Service says prices listed here are “indicative” and may vary in some circumstances.

Sources: WSJ analysis of data from the Centers for Medicare & Medicaid Services; the Norwegian Medicines Agency and the Norwegian Drug Procurement Cooperation; the NHS Business Services Authority; and Ontario’s Ministry of Health and Long-Term Care.
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)
Study Objectives

• Aim 1. Characterize the rural (& non-rural) oncology practice context to prepare for FN implementation.

• Aim 2. Assess FN implementation determinants and implementation outcomes in rural (& non-rural) oncology practices.

• Aim 3. Evaluate the effectiveness of FN in improving patient outcomes of care in rural (& non-rural) oncology practices.
<table>
<thead>
<tr>
<th>Rural Community Partners</th>
<th>Non-Rural Community Partners</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Carteret Health Care Cancer Center</td>
<td>• CarolinaEast Health System</td>
</tr>
<tr>
<td>• UNC Pardee</td>
<td>• Novant Health</td>
</tr>
<tr>
<td>• Nash UNC Health Care</td>
<td>• Vidant Medical Center</td>
</tr>
<tr>
<td>• The Outer Banks Hospital</td>
<td>• Wake Forest University Health Sciences</td>
</tr>
<tr>
<td>• UNC Lenoir Health Care</td>
<td></td>
</tr>
</tbody>
</table>
Locations of Study Clinics

*indicates R01-engaged rural practices participating in FN; +indicates non-rural practices participating in FN through the new supplement
Aim 1 Phases

- **Aim 1:** Characterize rural oncology practice context pre-FN implementation
  - Phase 1: Interview up to 50 key informant stakeholders to understand practice structure, climate, FN readiness, existing resources
  - Phase 2: Map the process of patients' access to financial support based on interviews
  - Phase 3: Report back to stakeholders, revise process map, and develop strategies to support FN implementation
# Stakeholder Characteristics

## Roles of Stakeholders Interviewed

### All Sites

<table>
<thead>
<tr>
<th>Role</th>
<th>Overall (N=71)</th>
<th>Rural (N=41)</th>
<th>Non-rural (N=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrator/Leadership</td>
<td>20 (28%)</td>
<td>14 (34%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Oncology Nurse Navigator</td>
<td>12 (17%)</td>
<td>6 (15%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Financial Counselor</td>
<td>11 (15%)</td>
<td>5 (12%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>10 (14%)</td>
<td>7 (27%)</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>10 (14%)</td>
<td>5 (12%)</td>
<td>5 (17%)</td>
</tr>
<tr>
<td>Lay Navigator</td>
<td>3 (4%)</td>
<td>1 (2%)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>2 (3%)</td>
<td>2 (5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Medical Oncologist</td>
<td>1 (1%)</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Radiation Oncologist</td>
<td>1 (1%)</td>
<td>1 (2%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Other</td>
<td>11 (15%)</td>
<td>7 (17%)</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Not reported</td>
<td>4 (6%)</td>
<td>1 (2%)</td>
<td>3 (10%)</td>
</tr>
</tbody>
</table>

a. As it pertains to cancer patients; participants could select multiple roles as applicable

b. Other includes research nurse, pharmacy technician, oncology coordinator, radiation therapist, patient financial services nurse care manager, care coordinator
<table>
<thead>
<tr>
<th>Stakeholder Experience</th>
<th>Overall (N=71)</th>
<th>Rural (N=41)</th>
<th>Non-rural (N=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of cancer patients seen in past week (Mean, SD)</strong></td>
<td>13.8 (28)</td>
<td>14.9 (31.2)</td>
<td>12.2 (23.3)</td>
</tr>
<tr>
<td>0</td>
<td>41 (58%)</td>
<td>24 (59%)</td>
<td>17 (57%)</td>
</tr>
<tr>
<td>≤15</td>
<td>11 (15%)</td>
<td>4 (10%)</td>
<td>7 (23%)</td>
</tr>
<tr>
<td>&gt;25</td>
<td>10 (14%)</td>
<td>6 (15%)</td>
<td>4 (13%)</td>
</tr>
<tr>
<td><strong>Years of experience (Mean, SD)</strong></td>
<td>9.4 (8.1)</td>
<td>10.3 (8.9)</td>
<td>8.1 (6.8)</td>
</tr>
<tr>
<td>≤2</td>
<td>14 (21%)</td>
<td>8 (21%)</td>
<td>6 (22%)</td>
</tr>
<tr>
<td>3 – 5</td>
<td>15 (23%)</td>
<td>8 (21%)</td>
<td>7 (26%)</td>
</tr>
<tr>
<td>6 - 10</td>
<td>17 (26%)</td>
<td>10 (26%)</td>
<td>7 (26%)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>20 (30%)</td>
<td>13 (33%)</td>
<td>7 (26%)</td>
</tr>
<tr>
<td><strong>Years in role at current institution (Mean, SD)</strong></td>
<td>5.8 (5.6)</td>
<td>6 (5.7)</td>
<td>5.5 (5.5)</td>
</tr>
<tr>
<td>≤2</td>
<td>24 (36%)</td>
<td>14 (36%)</td>
<td>10 (37%)</td>
</tr>
<tr>
<td>3 – 5</td>
<td>15 (23%)</td>
<td>8 (21%)</td>
<td>7 (26%)</td>
</tr>
<tr>
<td>6 - 10</td>
<td>19 (29%)</td>
<td>12 (31%)</td>
<td>7 (26%)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>8 (12%)</td>
<td>5 (13%)</td>
<td>3 (11%)</td>
</tr>
</tbody>
</table>
Themes from Stakeholder Interviews

We analyzed stakeholder interviews and identified themes as they related to…

**Organization’s current structure**
- How does the current process for assisting patients with financial needs work?
  - Used this information to create the process map
- What gaps exist in the current resources available?

**Perceptions of the intervention**
- How will the intervention will fit within the organization?
- What factors do we need to consider that might affect the success of the intervention?
Organizational Process Challenges

• Fragmented processes –
  • Separate systems between medical oncology and radiation oncology
  • Patient tracking (on paper, EMR, & separate EMRs)
  • “…the current organization is a hindrance, because we lose efficiency, it’s—we lose the ability to—or we’re challenged to communicate effectively and timely.” (Clinic 2)

• Growing administrative burden - Paperwork for applications, changing resources, increasing caseload
Patient Process Challenges

- Limited awareness of financial assistance programs
- Burden of Application(s)
  - Separate applications (Medicaid, disability, charity care)
  - Low patient literacy
  - Delays in receiving a determination regarding financial assistance

“I have found that navigating online for copay assistance grants is a little out of league for most of our patients...I don’t know how many of our patients wouldn’t do that, or be able to afford their medicines if they didn’t have that assistance. I do it for them, I just--I do it.” (Clinic 3)
Gaps in Existing Resources

- Limited community resources
  - Resources may be limited to one county
- Limited (or no) pharmacy assistance
  - No pharmacy assistance programs within clinic
  - Off-site office with manufacturer assistance program

“…we don't have a lot of resources from a county perspective to give them, so we might have to pull resources from other areas and, kind of, think outside the box, especially with some of our patients whose outside living conditions may or may not be—you know, some people who have--get diagnosed with cancer are homeless.” (Clinic 1)
**Effects of COVID on Current Process**

- Mixed perceptions on the effect of COVID on patient financial need
- Additional challenges to connecting with patients
  - No services physically in clinics
  - Less in-person interaction

“…if we have a patient that comes in Monday afternoon, and they’re the last patient seen at 3:30, and they need treatment, like tomorrow or the next day, we could have this—we could call the volunteer…**But because of COVID, we have to have at least like 7 to 10 days in advance to get anybody**--to make arrangements for their transportation.” (Clinic 2)
A process map can identify gaps or consolidate steps within a process. It reflects the **perception of the usual process** rather than describing the ideal or intended process.

We are using these process maps to better understand an organization’s system of assisting patients with financial needs **so we can adapt the intervention to the way an organization’s system is structured.**
Process Map Highlights

- Smaller size of cancer center = less complex pathways
  - Stakeholders committed to getting to know patients
  - **Social worker** is often financial and psychosocial assistance hub

- Mix of provider-only or patient and provider activated referral processes
  - NCCN distress thermometer
Perceptions of the Intervention
FN Intervention

**BASELINE ASSESSMENT**
- COST Financial Distress Measure
- Baseline Financial Intake Assessment
- Post-visit checklist

**Visit 1**
- Baseline Financial Intake Assessment
- Discuss updates to applications, finances, treatment course and document in REDCap database
- Referral to Patient Advocate Foundation (if needed)

**Check-In Visits**
(repeat every 2 weeks as needed)

**POST INTERVENTION ASSESSMENT**
- COST Financial Distress Measure
- Baseline Financial Intake Assessment
- Patient Satisfaction Survey

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COST Financial Distress Measure
Baseline Financial Intake Assessment
Post-visit Checklist
Patient Satisfaction Survey
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:
  - Detailed review of 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
  - Provision of resources checklist patients were eligible for and the required paperwork
## Organizational Readiness for Implementing Change

<table>
<thead>
<tr>
<th>People who work here…</th>
<th>Overall (N = 71)</th>
<th>Rural (N = 41)</th>
<th>Non-rural (N = 30)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change Efficacy Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>… feel confident that the org. can get people invested in implementing this change.</td>
<td>93% (64/69)</td>
<td>95% (39/41)</td>
<td>89% (25/28)</td>
</tr>
<tr>
<td>… are committed to implementing this change.</td>
<td>93% (63/68)</td>
<td>95% (38/40)</td>
<td>89% (25/28)</td>
</tr>
<tr>
<td>… feel confident that they can keep track of progress in implementing this change.</td>
<td>93% (64/69)</td>
<td>93% (38/41)</td>
<td>93% (26/28)</td>
</tr>
<tr>
<td>… will do whatever it takes to implement this change.</td>
<td>94% (65/69)</td>
<td>95% (39/41)</td>
<td>93% (26/28)</td>
</tr>
<tr>
<td>… feel confident that the organization can support people as they adjust to this change.</td>
<td>88% (60/68)</td>
<td>98% (40/41)</td>
<td>74% (20/27)</td>
</tr>
<tr>
<td>… want to implement this change.</td>
<td>93% (64/69)</td>
<td>95% (39/41)</td>
<td>89% (25/28)</td>
</tr>
<tr>
<td>… feel confident that they can keep the momentum going in implementing this change.</td>
<td>91% (62/68)</td>
<td>93% (37/40)</td>
<td>89% (25/28)</td>
</tr>
</tbody>
</table>

**NOTES:**
Scaled responses were dichotomized into ‘agree/somewhat agree’ and ‘disagree/somewhat disagree/neither agree nor disagree’.
Missing values excluded from percentage calculation.
# Organizational Readiness for Implementing Change

<table>
<thead>
<tr>
<th>People who work here…</th>
<th>Overall (N = 71)</th>
<th>Rural (N = 41)</th>
<th>Non-rural (N = 30)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change Commitment Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>... feel confident that they can handle the challenges that might arise in implementing this change.</td>
<td>88% (61/69)</td>
<td>90% (37/41)</td>
<td>86% (24/28)</td>
</tr>
<tr>
<td>... are determined to implement this change.</td>
<td>93% (63/68)</td>
<td>95% (38/40)</td>
<td>89% (25/28)</td>
</tr>
<tr>
<td>... feel confident that they can coordinate tasks so that implementation goes smoothly.</td>
<td>91% (63/69)</td>
<td>93% (38/41)</td>
<td>89% (25/28)</td>
</tr>
<tr>
<td>... are motivated to implement this change.</td>
<td>96% (66/69)</td>
<td>95% (39/41)</td>
<td>96% (27/28)</td>
</tr>
<tr>
<td>… feel confident that they can manage the politics of implementing this change.</td>
<td>83% (57/69)</td>
<td>88% (36/41)</td>
<td>75% (21/28)</td>
</tr>
</tbody>
</table>

**NOTES:**
Scaled responses were dichotomized into ‘agree/somewhat agree’ and ‘disagree/somewhat disagree/neither agree nor disagree’.
Missing values excluded from percentage calculation.
Intervention Fit

Several factors positively influenced the fit of the financial navigation intervention at rural oncology clinics:

1. Intervention is in alignment with clinic’s values
2. Universal enthusiasm for an additional mechanism to help patients
3. Presence of existing structures and communication pathways to assist patients with financial needs
Participants expressed a universal desire to help patients and be receptive to their needs:

“*I'm always trying to look for every…in any direction that we can be reaching out that we can be part of something that helps support those who have less and are in need of that help.*” (Clinic 1)

“I think we have a fantastic team, and they're very committed to this, committed to our patients, you know, people here love their work. The program is growing rapidly, we have a fabulous medical staff…that…you know, so wholeheartedly support our patients, and our community, and our team.” (Clinic 2)

“I will go outside into the parking lot and--you know, and just kind of kneel there by the car and talk to them and do whatever we need to do.” (Clinic 3)
Intervention Fit: Enthusiasm

Staff routinely expressed excitement about the FN intervention because it will:

• Help to reach more patients & reduce burden on staff currently helping patients
• Ensure that patients follow-through with FA applications by having a single person dedicated to patient financial needs

“I think having one person to consistently handle that would be good so that the patient would know who to go to and the staff would know who's handling that.” (Clinic 3)
Intervention Fit: Existing Structures

Existing systems will provide structure within which to implement the FN intervention.

- Structured referral processes (i.e., distress screening)
- Multiple opportunities for staff to discuss or assess patient needs (due to small size of cancer center)

“So, there’s lots of avenues of helping the patients as far as getting their treatments. But it starts from the very beginning of when we get the referral.” (Clinic 2)
Implementation Success Factors

Patient Considerations

• Sensitivity needed in approaching patients about finances
• Patients can have difficulties balancing the stress of their diagnosis and finances

Organizational Considerations

• Identifying physical space in clinic for navigator
• Clearly define roles
• Ensure leadership and staff are supportive of FN.
Recruitment for Financial Navigation Program starting next month!
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
- Caitlin Biddell, MSPH, PhD student
- Victoria Petermann, RN, PhD student

Advisory Board
- Katie Gallager, 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
Thank You!

Contact Information:
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lspees21@live.unc.edu