If you have to ask, you can’t afford it: Addressing financial toxicity among NC cancer patients

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and

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Professor and Vice Chair
Division of Hospital Psychiatry
Director, Comprehensive Cancer Support Program
Lineberger Comprehensive Cancer Center
University of North Carolina at Chapel Hill
The Washington Post

Health & Science

Cancer treatment costs can be prohibitive, even with insurance

By Michelle Andrews  October 10, 2011

The Washington Post

Health & Science

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

By Michelle Andrews  April 8, 2016

The New York Times

In Cancer Care, Cost Matters

By PETER B. BACH, LEONARD B. SALZT 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 Cost of Health Care in America

Health Care Spending as % of GDP
1995-2014

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

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.
Financial Toxicity

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

The financial burden of cancer has been linked to:

- 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*)
Summary of Our Work to Understand and Mitigate the Adverse Financial Impact of Cancer

- Analyzed 2,500 surveys from women with breast cancer and found significant financial distress at 2-years post-diagnosis, with greater burden in black and in rural women (2017)
- Conducted a national survey of oncology care providers (2018) to assess perceptions of financial burden and financial resources
- Conducted a national patient survey of >1,000 women about cancer-related financial needs among metastatic breast cancer patients (2018)
- Conducted surveys (2016), in-depth interviews (2017), and collaborative process mapping (2017) to understand health system financial barriers to care
- Secured funding to test and evaluate a financial navigation clinic at NC Cancer Hospital (2018)
Many women feel financially worse off since breast cancer diagnosis (Wheeler et al, JCO, 2018)
Black women with breast cancer are more financially vulnerable than whites at diagnosis (Wheeler et al, JCO, 2018)

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<thead>
<tr>
<th></th>
<th>White</th>
<th>Black</th>
<th>p-value (X²)</th>
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<tbody>
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<td>1265</td>
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<td><strong>Annual Household Income</strong></td>
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<tr>
<td>&lt;$15,000</td>
<td>76 (6.4%)</td>
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<tr>
<td>$15,000-29,999</td>
<td>154 (12.9%)</td>
<td>293 (25.6%)</td>
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<td>$30,000-49,999</td>
<td>206 (17.3%)</td>
<td>236 (20.6%)</td>
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<tr>
<td>&gt;$50,000</td>
<td>758 (63.5%)</td>
<td>331 (29.0%)</td>
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<td><strong>Insurance status</strong></td>
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<td>734 (61.0%)</td>
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<tr>
<td>Medicare</td>
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<tr>
<td>Medicaid</td>
<td>66 (5.3%)</td>
<td>287 (23.8%)</td>
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<tr>
<td>Uninsured</td>
<td>37 (2.9%)</td>
<td>92 (7.6%)</td>
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Black race is a significant predictor of adverse financial impact of cancer at 2yrs post-diagnosis, even after adjustment (Wheeler et al, JCO, 2018)

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Black Race (ref: White)</td>
<td>+5.42*</td>
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<td>(2.16)</td>
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<tr>
<td>Age</td>
<td>-0.70***</td>
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<td>(.10)</td>
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<td>Income (ref: &gt;50,000)</td>
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<tr>
<td>&lt;15,000</td>
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<td>(3.33)</td>
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<td>30,000-49,999</td>
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<td></td>
<td>(2.86)</td>
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<td></td>
<td>(4.48)</td>
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<td>Medicaid</td>
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p<0.05; ** p<0.01; *** p<0.001

Also controls for stage, treatments received, comorbidities, education, and marital status.
Rural women with breast cancer have worse employment outcomes than urban women.

(In preparation)
Much of the rural/urban difference in employment outcomes post-breast cancer is due to clinical and socioeconomic factors.

(In preparation)
Oncology Navigator Perspectives of Financial Burden

<table>
<thead>
<tr>
<th>Percent</th>
<th>Yes</th>
<th>No</th>
<th>I don't know</th>
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<tr>
<td>Percent</td>
<td>45%</td>
<td>26%</td>
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Of the patients you work with who need financial assistance, are the majority of them able to get help?

What key obstacles exist to helping these patients find financial assistance?

![Bar chart showing obstacles to financial assistance](chart.jpg)

- Language/literacy barriers: 11%
- Lack of knowledge of resources: 47%
- Lack of resources: 50%
- Difficult/complex to access: 20%
- Communication Barriers: 20%

Oncology Provider Survey: What kinds of financial support does your institution offer?

- Charity Care: 80%
- Assistance applying to Medicaid/ACA: 80%
- Medication Assistance: 80%
- Financial Counseling: 80%
- Payment Plan/Discount: 70%
- Transportation/Housing: 60%

Preliminary data from N=134 oncology care providers (e.g., oncologists, nurses, etc.) surveyed online
Oncology Provider Survey: What concerns do you have about discussing financial matters with your patients?

- If patients have concerns, there may not be a way to address them
- Mentioning costs may make patients worry about the quality of care
- I am not aware of costs
- Patients may be offended or embarrassed if I bring up the subject
- I do not have time
- I do not feel it is appropriate for me to discuss the cost of care

[Bar chart showing percentages of concerns]
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
- Vulnerable population
- Psycho-social burden of metastatic disease
- Complex and changing treatment regimen

*UNC Lineberger*
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 *(data not presented here)*- *behavioral response*
### Survey Participants

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1054 individuals from 41 states completed the survey, of which 30% were uninsured.
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<tr>
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Uninsured participants were more likely to identify as a racial or ethnic minority.
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Uninsured participants reported significantly lower income but were much more likely to be working full time jobs.
Material Burden

Measures of Financial Security, overall

- Contacted by collections: 49%
- Stopped or refused treatment due to cost: 54%
- Not able to meet monthly expenses: 35%
- Not satisfied with financial situation: 40%
- Not in control of financial situation: 35%
- Not enough savings to cover costs: 56%
Material Burden

Difference assessed using X2 test; **p<.01, ***p<.001
Psychosocial Distress

Measures of Financial Stress, overall

- Worry about the financial problems as a result of cancer: 68%
- Out-of-pocket expenses are more than expected: 49%
- Feel financially stressed: 44%
- Frustrated at inability to work/contribute: 41%
- Distressed by not knowing what cancer care cost would be: 36%
- Worried about the financial stress on my family: 31%
Psychosocial Distress

Difference assessed using X2 test; **p<.01, ***p<.001
Bars represent 95% confidence intervals. Estimates are from generalized linear models using a Poisson family and log link. Models control for age, race, time since diagnosis with metastatic disease, marital status, dependents in household, education, income, and work status.
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
Summary of Cancer-related Financial Challenges to Patients

- Lack of systematic and ongoing identification of financial need
- Lack of coordinated, streamlined applications once need is identified
- Lack of resources for underinsured
- Lack of a dedicated navigator to assist patients and families through financial aspects of care
- Potentially heavier burden in mBC, black, and in rural populations
“IF YOU CAN’T KEEP UP, WE COULD GO BROKE, THEN YOU’D HAVE TO BAIL US OUT, AND THAT COULD LEAD TO EUROPEAN-STYLE SOCIALISM!”
Comprehensive Cancer Support Program

[Image of group photo]
Comprehensive Cancer Support Program

- Patient and Family Resource Center (Shaban)
- Psycho-oncology Service (Park)
- Survivorship (Mayer); Nutrition (Spring)
- Adolescent and Young Adult Program (Lux)
- Outpatient Palliative Care (Winzelberg)
- Integrative Oncology (Asher); Exercise and Wellness (Bailey)
- Financial Assistance and Legal Clinic (Rogers); Caregiver Support (Muss)
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* HCS Care Management (MSWs); Genetic Counseling; Chaplains
Dilemmas in a General Theory of Planning

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ABSTRACT
The search for scientific bases for confronting problems of social policy is bound to fail, because of the nature of these problems. They are "wicked" problems, whereas science has developed to deal with "tame" problems. Policy problems cannot be definitively described. Moreover, in a pluralistic society there is nothing like the undisputable public good; there is no objective definition of equity; policies that respond to social problems cannot be meaningfully correct or false; and it makes no sense to talk about "optimal solutions" to social problems unless severe qualifications are imposed first. Even worse, there are no "solutions" in the sense of definitive and objective answers.
“Wicked” Problems

1. There is no definitive formulation of a wicked problem.
2. Wicked problems have no stopping rules.
3. Solutions to wicked problems are not true or false but good-or-bad.
4. No immediate and no ultimate test of a solution to a wicked problem.
5. Every solution to a wicked problem is a “one-shot operation.”
6. No enumerable set of potential solutions.
7. Every wicked problem is essentially unique.
8. Every wicked problem can be considered to be a symptom of another problem.
9. Discrepancies can be explained in numerous ways.
10. The planner has no right to be wrong.

NCCH Provider Interviews

• Conducted 14 in-depth interviews with:
  - Pt. Assistance Coordinator  
  - Social Workers  
  - Pharmacists  
  - Pharmacy Administration  
  - Nurse Navigators  
  - Financial Administrators  
  - Financial Counselors

• Mapped the financial resources they mentioned
• Visual depiction of 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.
Describes resources (squares), important decision points (circles), and key individuals (diamonds) involved in the process.

Arrows indicate connections (patient-activated or provider/staff-activated).

Relevant quotes are included from key informant interviews.

Note: this map represents the impression key informants have of the process; the map may be incomplete or include mistaken information.
“Which do you want first, the good news that sounds better than it is or the bad news that seems worse than you expected?”
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.

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

Uninsured Identification of Need | Navigation through application process | Underinsured Identification of Need | Navigation through application process
“Now! ... That should clear up a few things around here!”
What ought “financial navigation” look like?

Patient with cancer and financial needs  

?  

Meaningful financial and clinical outcomes
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)
Financial Distress Screening

• 15 patient interviews testing various measures:
  • COST, Epic, InCharge, NCCN/Pfizer questions
• Final screener is COST-Plus:
  • Full 11 item COST instrument plus 6 additional questions
• Administered by FN (MSW intern) after patient is referred to CCSP/SW and expresses financial concerns
  • COST Score $\leq 22 = $ full intervention; Score $\geq 23 = $ usual care
COST (COmprehensive Score for financial Toxicity)

Additional Questions (the Plus)

• distressed by not knowing cancer care cost
• worried re financial stress on family
• stopped or refused treatment
• contacted by a collection agency
• taken money from savings
• filed for disability
• “just getting by”
• confident about a financial emergency
• trouble for paying for basics
COST Financial Distress Measure\textsuperscript{1}
Baseline Financial Intake Assessment\textsuperscript{2}
Post-visit Checklist\textsuperscript{3}
Patient Satisfaction Survey\textsuperscript{4}

STUDY GROUP 1

Low Financial Distress Score \rightarrow Baseline Financial Intake Assessment\textsuperscript{2} \rightarrow Financial Navigation Intervention

STUDY GROUP 2

High Financial Distress Score \rightarrow Patient Education Materials

POST INTERVENTION ASSESSMENTS
COST Financial Distress Measure\textsuperscript{1}
Patient Satisfaction Survey\textsuperscript{4}
NCCH Financial Workgroup (FY18 NCCH Strategic Goal)

**Pre-authorization**
If self-pay, patient referred to NCCH Financial Clearance and Navigation (financial counselors)

**Referral pathways to study**
- NCCN Financial Navigators (complex pts)
- Clinical MSWs
- Distress Screening
- PFRC/CCSP
- Self-referral

**Intervention**
"Jimmy Model"
- “COST-Plus” screen
- Assignment to intervention or TAU
- Intensive intake process
- Hands-on help and close follow-up
Study Measures

• COST-Plus
  – Screener to determine level of FT

• Financial Intake Form
  – Includes patient-specific data:
    • Individual financial situation
    • Employment status
    • Total monthly income
    • NCCH billing information
    • Insurance status
    • Resources
    • Referrals
    • Benefits
Study Measures (cont.)

• Post First Visit Checklist
  – Re-cap of eligible benefits and referrals along with paperwork needed

• Check-In Form
  – 2 week check-in with patient to discuss progress; help with applications

• Patient Satisfaction
  – Measure of acceptability and satisfaction with intervention
Rosenstein - Improving Financial Navigation Services

Quick Tasks
- Codebook
- Survey Distribution Tools
- Export data
- Create a report

The Codebook is a human-readable, read-only version of the project’s Data Dictionary and serves as a quick reference for viewing field attributes.

Invite participants to complete your survey by emailing a public survey link or building a participant list for batch notification.

Export your data from REDCap to open or view in Excel or various stats packages.

Build custom reports for quick views of your data, and export reports to Excel/CSV.

Project Dashboard
The tables below provide general dashboard information, such as a list of all users with access to this project, general project statistics, and upcoming calendar events (if any).
• Study opened Jan 5, 2019
• 14 patients enrolled to date
• All screened positive for FT; eligible for Group 1 full intervention
• Recruitment goal
  – 50 patients in Group 1 by May 31, 2019
  – Up to 50 additional patients in Group 2 (usual care), if needed
Next Steps

• Refinement of navigation intervention
• RO1 application (Rosenstein and Wheeler)
  – Financial navigation (FN) for rural cancer populations
    • 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.
• Robert Wood Johnson application (Reeder-Hayes and Wheeler)
Conclusions

- Health insurance expansion is necessary, but insufficient to address cancer-associated financial burden.

- Additional interventions, such as financial navigation (Shankaran, 2017, JCO), to prevent and mitigate financial harm are urgently needed.

- Important to identify patients with low-psychosocial distress, but high material burden
**Prevention** - More systematic, early identification of patients at risk for high financial burden
  - Financial distress screening

**Treatment** - Use of navigation to help patients identify resources, understand eligibility, and complete applications.
  - New financial navigation positions

**Simplification** - Better coordination of current efforts & reduction in duplicative processes.
  - A ‘universal’ or ‘common’ application for multiple resources
Thank You!

• **Study Team**
  - Jimmy Fulcher (MSW student)
  - Mindy Gellin, BSN
  - Michelle Manning, MPH
  - Hyman Muss, MD
  - Neda Padilla, BS
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  - Cindy Rogers, JD

  - Cleo A. Samuel, PhD
  - Jean Sellers, RN MSM
  - Jennifer Spencer, MSPH

• **Funding**
  - National Comprehensive Cancer Network/Pfizer
  - CDC, ACS
  - UNC Health Care Center for Innovation
For patients who are uninsured, one of the first goals is identifying whether they may qualify for subsidized insurance programs.
For those in inpatient care, Medicaid Assistance Coordinators (MACs) can facilitate the progress from beginning to end.

“If they are Medicaid-able, my Medicaid eligibility team will sit with the patient, take the application. They will sign a paper and be that patient’s representative. They send the information over to DFS... We send that application. We make sure that the patient is able to get the right verifications. If they get denied and we know that they should qualify, we appeal that for them ourselves at no charge to the patient.” [P11]
For those in outpatient care, no formal process was described; patients simply told they may be eligible and to check with DSS.
Other Financial Assistance for Medical Expenses

Beyond insurance, there are other programs—both internal and external—that may help cover medical expenses.
Charity Care and the Pharmacy Assistance Program can help pay for care if patients meet eligibility criteria. These were widely praised in our interviews, but some challenges do exist.

“Half the patients I see would not be able to get their treatment were it not for Charity Care and Pharmacy Assistance.” [P08]

“We’ve all seen patients who have come from other institutions where because they lost their insurance they could no longer get care at that hospital, and they come here and they get the same care as somebody with insurance.” [P01]
Main challenge for these programs is time delay between applying and final decision. 

“Charity Care can take like six weeks to know whether or not you’ve been approved. So that’s not great.” [P01]
“They ask for very similar, if not identical, information. But they’re two different applications”. [P01]

Second challenge for these two programs: duplication of paperwork
High copays for prescription medications can be identified during the pre-authorization process and these patients can be sent to MAP to assess whether the patient may qualify for manufacturer assistance.

"We would go ahead and look at different grants and co-pays that we can get for this patient from a manufacturer assistance perspective, would call the patient, tell them kind of what we're going to be sending them and what they're going to need to collect to send back to us. And then the patient would have to send all that documentation back to us, and then we would work through the manufacturer assistance company to get them enrolled into that." [P04]
Processing time and eligibility for these programs varies by manufacturer, and these delays & variations can create treatment uncertainty.

"Some of the manufacturer assistance programs are retroactive. So, we can go ahead and still dispense and then get recovery on the back end. But, a lot of them are moving to be proactive, and so I can't actually--you know, if the patient can't pay for it, then we actually have to get manufacturer assistance first before I can dispense it to them."[P04]
Finally, some community-based organizations have co-pay assistance programs, although the patients generally lead the application process for these programs.

“I think right now the only thing we have right now is Cancer Care, and I haven’t even checked today, but I mean this is like a daily thing where, you know, I’m going through like six, seven, eight, nine different co-pay assistance foundations out there just searching it because it does change day by day. And just searching through to see what they have available”. [P07]
Beyond insurance, there are other programs—both internal and external that may help cover expenses.
Non-Medical Assistance

“We have the one grant where we get $500 one time. We have another grant where we can get $250 worth of food and gas cards one time. And then we have some little dinky foundations where we get $100 here, $100 there. That's it.” P08

A number of internal and external sources exist to support needs beyond the cost of medical care.

“And so in addition to the resources that I have here at the hospital I can refer patients to outside charitable foundations that help them with household bills, the cost of transportation and lodging while they’re in treatment, maybe the cost of food while they’re in treatment, those sorts of things” [P01]