

# Cost and Consequence: Trying to balance affordability and adherence

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# Low-income populations have lower rates of adherence and sustained disparities.

- Patient costs are increasing
- Cost is a commonly mentioned barrier to healthcare
- Up to 40% of patients report cost-related non-adherence to medications



# Digging Deeper into Cost

- Medical-Legal partnership approaches can be successful
- Cost barriers are a recurrent theme throughout our program of research on healthcare disparities
- The role of affordability is under-studied and under-valued



# We synthesized data from several past studies:

- **Study 1- Perceptions of Colon Cancer Screening in Low-Income Adults**
  - Interview and Focus Groups on Colon Cancer Screening
  - Cross-Sectional Survey
  - Community Health Centers in Kansas and Missouri
- **Study 2 – Photovoice Study on Colon Cancer Screening**
  - Photovoice includes photo-taking, group sessions and individual interviews
  - Community-based recruitment aimed at medically underserved neighborhoods in the St Louis metropolitan area
  - All photos in this presentation were taken by participants

R21 CA14779 (James); MRSCT CPPB-111068 (James); U54 CA153460 (Colditz)

# Analysis

- We compared study findings to elicit cross-cutting themes, sometimes going back to original data for confirmation or further information.
- Several common issues emerged across the studies.
- How did we get from colon cancer to medication adherence?



# It's not just one screening test.

“But the thing about it, you know, I didn’t want to get off from the cancer, the subject of cancer, but yeah, just stating...”

- People used other healthcare experiences to talk about colon cancer.
- In calculating affordability of a single healthcare decision, people often consider the range of their current or anticipated healthcare experiences and expenses.
- There were direct and indirect costs to any healthcare choice.



# Findings related to cost and healthcare

1. People are struggling financially.
2. People are trying very hard.
3. People worry about the healthcare they are delaying or missing.
4. It is important to consider multiple ways that people cost-cope.

# 1-There's not much money left at the end of the month.

- Beyond healthcare, people are having trouble making ends meet. They report challenges affording food and housing and other essential needs.
- In a cross-sectional study at a federally qualified health center, we found that nearly half of patients had delayed care due to cost but also:
  - 77% reported that having enough money for emergencies was a hassle.
  - 68% reported that having enough money for housing and utilities was a hassle.
  - 69% reported that having enough money for food and clothing was a hassle.



“That determines where you’re going to go. If you’re going to have enough money to even get the medicine. You know?”

Jacob R, Arnold LD, Hunleth J, Greiner KA, James AS. *American Journal of Health Behavior*. 2014. Smith et al., in preparation.



## 2- It's hard work to access affordable healthcare, but people are trying.

- Study participants described efforts to get healthcare despite financial constraints:
  - Support of family and friends
  - Free events and informal care
  - Working extra shifts, second jobs, or seeking informal employment

“I don't care if they pay me \$2.00 an hour if they give me benefits”.



Hunleth J, Steinmetz E, McQueen A, James AS. *Qualitative Health Research*. 2016. Smith et al, in preparation

### 3 - People are aware of, and often worry about, the healthcare they are missing.

- That is, they are very aware of the consequences of non-adherence or improvised adherence.
- “It’s all in the money.”
- “I’ve got to get on medicine that I can afford, because I’m just a common person”
- “Like somebody who knows that they can’t pay the bills, just doesn’t even want to open the envelope.”



It has been most disheartening to me. That has been one of...it has really depressed me knowing that I do not have medical care, I mean insurance. When I come here to [center] I have to pay \$25. I've had one doctor's appointment and I have another one this week that's past due but I don't have the money to go so...I haven't gotten all of my medicine and so it's very difficult ...

It's...this is very disheartening.

## 4 – People use many strategies to cost-cope.

People engage in purposeful behaviors to maximize the affordability of healthcare.

- Cutting back on extras
- Cutting back on necessities
- Putting expenses on credit, borrowing money, or going into debt
- Skipping prescribed medications or recommended tests

“you have 5 or 6 medications but you have to be trying to penny out this one and maybe that will help me hold on until I get some more money to get the main medication.”



# But, providers aren't talking to patients about cost

And patients might not bring it up....

“I knew I hadn't took my blood pressure medication because I couldn't afford it...And then when I talked to my doctor she said, 'well, you haven't come in and I could've broken [it] down,'. And I could've gotten it at Schnucks for \$4, but I didn't know that.”



So patients may be choosing on their own:

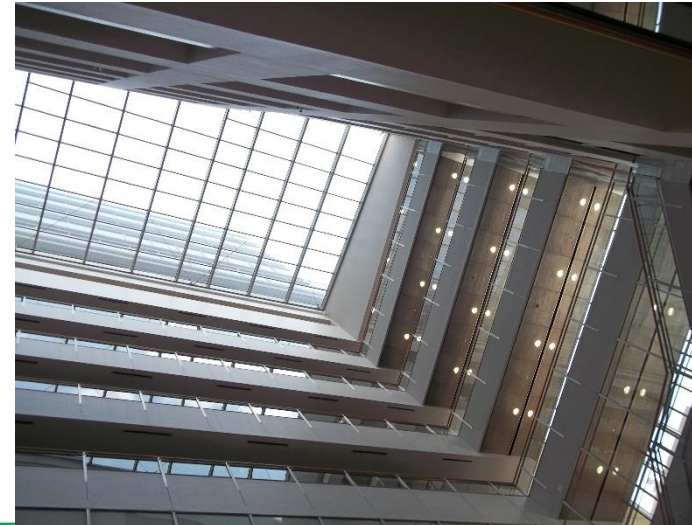
“Pick out what medicine you can really afford. And hope..[the] one medicine or two medicine you can afford do everything that needs to be done.”

The untold story is that we hope that we can keep it going because it takes money for the electric bill, the gas bill, the mortgage, and most of the time we don't have enough to fulfill it and then if we get sick we really don't have it...

The monies being so limited and we either have to choose between paying our bills or getting our medication, and that's where a lot of people's sickness comes in, too, when they have to make a decision like that...

# Discussion

- Cost-related nonadherence is common and costly
- Need to go further than telling people healthcare is important
  - They probably already know that!
- We need to examine the context of how people make healthcare affordable in their lives
- We are planning a study of cost-related nonadherence to hear from patients and providers



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