What Your Patients Aren’t Telling You: How To Partner with Patients To Help Manage the Hidden Costs of Healthcare

Cost-of-Care Conversations Practice Brief #2

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Aim / This Practice Brief provides you with information on the burden of indirect costs of care (e.g., transportation, child care, and lost wages) that your patients face, and tips for addressing those costs.

Key Takeaways /

- Discussions of potential “indirect costs” of care with patients – such as transportation, child care, and lost wages – are important as these may directly impact their access and ability to stay on a recommended care plan
- Understanding the “competing costs” (e.g., food, bills, and housing) that your patients face can help better target cost-of-care (CoC) conversations
- Indirect costs of care may affect any of your patients, regardless of their socioeconomic and insurance status, but they pose a greater burden to low- or fixed-income patients
- Help patients mitigate the financial hardship caused by the indirect costs of care by tailoring care plans to their needs and connecting them with appropriate resources
What Are the Indirect Costs of Care that Your Patients Are Facing?

“I don’t hear much about the cost of childcare, but I do have patients that, you ask them why they haven’t been seen in two months, and the reason is childcare.”

- Obstetrician-Gynecologist, Sinai Urban Health Institute/University of Illinois at Chicago study (1)

Patients often do not proactively share the reasons they miss appointments or are not able to stay on a treatment. Clinicians should explicitly ask patients questions, to help assess a patient’s needs and gain information that can support patients in achieving the best health outcomes.

Patients and families often report facing burdensome indirect costs of care that can increase their out-of-pocket (OOP) costs of care and impact their access to recommended care (1, 2). These indirect costs include:

- Cost of travel or transportation (e.g., gas, parking)
- Time of travel
- Cost of food (e.g., during travel to and time at appointments)
- Cost of child or elder care (needed for when patient is accessing care)
- Patient and family work productivity or lost wages
- Burden on family or caregivers
- Administrative burden (e.g., time spent communicating with insurance company, coordinating care)
- Required wellness activities (e.g., diet modifications and regular exercise)
- Patient and family education or skill building (e.g., learning how to self-inject, how to operate an oxygen tank)

Often more hidden than the indirect costs of care are the “competing costs” that patients face, related to basic needs such as paying for: food, bills, and housing. Addressing competing costs requires understanding a patient’s social determinants of health (SDOH). Some practices conduct SDOH screenings to understand patients’ needs. The incorporation of results from SDOH screenings into the medical record can help you: identify if your patients are experiencing significant competing costs, hold more targeted CoC conversations, and refer them to appropriate resources.
How To Assess the Indirect Costs of Care for Your Patients

“There’s so much more that goes into what’s keeping [patients] from coming to clinic: Transportation is a huge issue. Childcare is a huge issue. Unfortunately, sometimes medical care is not, in a patient’s view, a priority.”

- Support staff, Sinai Urban Health Institute/University of Illinois at Chicago study (1)

Patients need to weigh where they spend their money and are often forced to prioritize their immediate need. Sometimes a laboratory test, imaging study, medication, or appointment can feel optional rather than urgent and is therefore treated as a secondary priority. By acknowledging the financial impact of a treatment plan, clinicians can help patients achieve better health.

Estimating the indirect costs of care for your patients can be challenging. However, doing so can help you foresee important barriers that your patients might face to stay on treatment plans and access recommended care that they might not proactively raise or expect. The Sinai Urban Health Institute and the University of Illinois at Chicago study documented the monetary impact attending appointments can have on patients and demonstrated that the frequency and duration of appointments can create a significant hidden cost burden for patients (1). This is especially true for patients who have intensive care plans, such as high-risk pregnant women who may require up to 27 visits over the course of their pregnancies.

### Approximate indirect costs for high-risk pregnancy appointments

<table>
<thead>
<tr>
<th>Visit #</th>
<th>1st trimester total</th>
<th>2nd trimester total</th>
<th>3rd trimester total</th>
<th>TOTAL COST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointment time</td>
<td>$1</td>
<td>$2</td>
<td>$3</td>
<td>$6</td>
</tr>
<tr>
<td>Food cost</td>
<td>$4</td>
<td>$5</td>
<td>$6</td>
<td>$15</td>
</tr>
<tr>
<td>Travel time</td>
<td>$8</td>
<td>$9</td>
<td>$10</td>
<td>$27</td>
</tr>
<tr>
<td>Lost income</td>
<td>$12</td>
<td>$13</td>
<td>$14</td>
<td>$39</td>
</tr>
<tr>
<td>TOTAL cost</td>
<td>$30</td>
<td>$31</td>
<td>$32</td>
<td>$93</td>
</tr>
</tbody>
</table>

Figure 1. Calculation by the Sinai Urban Health Institute and the University of Illinois at Chicago grantee of the indirect costs associated with clinic visits for women experiencing high-risk pregnancies.
Figure 1 illustrates a sample calculation of the indirect costs associated with a high-risk pregnancy for a woman in Chicago, based on the duration and frequency of her appointments over the course of her pregnancy. Indirect costs such as food, transportation, and lost income are directly related to the patient’s number of clinic visits and the length of her appointments. These costs, which might seem less significant, can add up quickly. For example, Figure 1 shows that a pregnant woman taking the bus to her appointments could spend on average $2,672.50 throughout her pregnancy, due to costs associated with food, transportation, and lost income. Therefore, by engaging in CoC conversations that include discussions about indirect costs, clinicians can help patients appropriately plan and budget to offset those costs over the course of their care experience.

Both the Sinai Urban Health Institute/University of Illinois at Chicago and the Center for Health Progress grantees developed resources to support conversations around the indirect costs of care in collaboration with patients (1, 3). The poster in Figure 2 was developed by the Center for Health Progress in collaboration with low-income, Spanish-speaking populations in Adams County, Colorado (3); and the appointment tracker in Figure 3 was developed in collaboration with pregnant or recently post-partum women, clinicians, and support and executive staff in Chicago (1). Given their development process, both of these resources were highly relevant to and accepted by patients in their respective studies for supporting CoC conversations. Developing CoC conversation resources with patients helps ensure the needs of specific populations are met and the resources are useful to them.

Figure 2. Poster developed by the Center for Health Progress grantee that invites patients to discuss costs with their clinicians. Click here for a full-size version of this resource

Figure 3. Appointment tracker developed by the Sinai Urban Health Institute and the University of Illinois at Chicago grantee to support pregnant women and their clinicians discuss the expected frequency and duration of appointments over the course of their pregnancies. Click here for a full-size version of this resource
Key Considerations for Addressing Your Patients’ Indirect Costs

Clinicians should ask about the financial needs of their patients to ensure that their patients can access the best possible healthcare and achieve their desired outcomes.

Consider using planning tools with all of your patients to invite and support CoC conversations that include discussions of indirect costs, such as those developed by the Center for Health Progress and Sinai Urban Health Institute/University of Illinois at Chicago grantees (1, 3). Additionally, if patients express concern about specific indirect costs, try to create a care plan that addresses their concern and meets their healthcare needs. For example:

- Are there care options that require fewer visits to the hospital or clinic?
- Are there care options that can be administered at home or remotely?
- Can you provide them with a 90-day prescription refill so that they can make fewer trips to the pharmacy?
- Can you connect your patient with someone in your organization (e.g., social worker, financial navigator, front desk staff) who can provide your patient with resources to help alleviate the indirect costs of their care? See Figure 4 for a non-exhaustive list of national organizations that you can refer your patients to for support with indirect costs of care. This list should be augmented with local and state-based organizations.

<table>
<thead>
<tr>
<th>Organization/Resource / Description /</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Advocate Foundation’s National Financial Resource Directory, National Underinsured Resource Directory, and National Uninsured Resource Directory</strong></td>
</tr>
<tr>
<td><strong>Patient Advocate Foundation’s My Resource Search App</strong></td>
</tr>
<tr>
<td><strong>NIH National Cancer Institute’s Financial and Support Services for Cancer Patients</strong></td>
</tr>
</tbody>
</table>

Clinicians should ask about the financial needs of their patients to ensure that their patients can access the best possible healthcare and achieve their desired outcomes.
<table>
<thead>
<tr>
<th>Office of Disease Prevention and Health Promotions’ Financial Assistance</th>
<th>List of financial assistance programs across the US, including transportation, homecare, and child care assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>NeedyMeds’ Diagnosis-Based Assistance</td>
<td>Repository of financial assistance programs across the US, organized by diagnosis, including lodging, transportation, child care, and cosmetic (e.g., wigs) assistance</td>
</tr>
<tr>
<td>Patient Resource’s Financial Resources &amp; Pharmaceutical Assistance</td>
<td>Repository of financial assistance programs across the US, organized by basic living expenses, child care expenses, equipment/supplies expenses, government assistance, grants/scholarships/awards/camps, home health care expenses, and housing during treatment expenses</td>
</tr>
<tr>
<td>CancerCare’s Helping Hand</td>
<td>Repository of organizations providing financial or practical help, searchable by diagnosis and zip code</td>
</tr>
</tbody>
</table>

**Figure 4. National Organizations and Resources for Financial Assistance/Planning**

**Suggested Next Steps**

1. Verify whether your organization has a financial navigator(s) and/or social worker(s) on staff who are already supporting patients with their indirect costs of care

2. Consider identifying any existing partnerships with community-based organizations that you can leverage for your patients, e.g., Meals on Wheels, care navigation services

3. Develop patient-facing resources with patients and caregivers that can support conversations about the potential indirect costs of care

4. Consider estimating the impact of the indirect costs of care on your patient population and partner with patients, staff, and community-based organizations to prioritize interventions to overcome this barrier

**For Further Information**

This Practice Brief summarizes research funded by the Robert Wood Johnson Foundation and offers practical ways for both patients and care providers to improve the value and frequency of CoC conversations. For the full set of briefs, please see [here](#).
References