

# **COST DISTRESS SCREENING AND CONVERSATION GUIDE**

#### Introduction

Financial cost distress describes the harmful personal financial burden faced by patients receiving medical care. <sup>1,2</sup> This cost distress can span a range of adverse effects, including changes in household spending, subjective distress, and catastrophic financial burden. <sup>3</sup> Health care quality of life, treatment compliance, and mortality has also been linked to cost distress experienced by patients. <sup>2,4</sup> The scope of personal financial burden experienced by patients has been captured by several recent studies, with the Centers for Disease Control and Prevention reporting one in three Americans experiencing financial burden as a result of medical care. <sup>5</sup>

To address this significant issue, optimizing our identification or assessment processes (see proposed Cost Distress Diagnostic Strategy, below) and improved shared decision making that includes discussions of the financial impact of health care (see proposed Cost Conversation Guide, below) are imperative. These tools can help start the conversation to help address causes of financial distress. Furthermore, while evidence suggests that both patients and physicians perceive cost discussions to be prudent in optimal patient-centered care, <sup>6-8</sup> studies have indicated that these discussions are not occurring in most patient visits. <sup>3</sup> To really optimize patient-centered care, providers can implement these identification or initial screening procedures to start cost conversations during the patient visit.

#### **Cost Distress Identification or Screening Tool**

While cost distress is a reality experienced by one in three patients, few actually discuss this concern with their providers. Many patients are reluctant and uncertain of how to address this topic. Others report concern that their care would be negatively impacted by discussion of cost. Despite this, the majority of patients report a desire to talk to their physicians about the impact of medical costs on their lives. Given the prevalence of cost distress and the subsequent negative impact on patient outcomes, it seems prudent to establish a protocol to screen for the presence of significant cost distress. The guide below can be implemented to identify patients who may warrant further discussion regarding cost distress with their provider.

If the patient responds "Yes" to any question, he or she would benefit from a dedicated cost conversation with the doctor or a member of the health care team.

Before asking these questions, frame the conversation using the following language:

"Our goal is for you to get the care you need with fewer problems and lower costs, and this involves us asking new types of questions to ALL of our patients."

- Do you feel financially stressed due to your current health care needs?
- Are you worried about how your health care bills will be paid?
- Are you concerned about your current financial situation due to your health care needs?
- Would you like to discuss the cost of your health care with your health team at today's visit?

Evidence has highlighted specific patient factors that might put individuals at higher risk of cost distress, including younger age, applying for copayment assistance, race, and socioeconomic factors.<sup>3</sup> However, prior studies are limited by selection bias, and it is imperative to screen all patients for cost distress given the negative impact on patient-centered outcomes. This way, all patients will be given the opportunity to discuss any potential impacts of the cost of their health care. Implementation of the above questions, which were adapted from the COST Measure, <sup>10,11</sup> could be an important step to ally with patients on patient-centered and costaware care. After screening with the above criteria, care providers can implement the cost conversation strategies below.



# **Cost Conversation Guide**

As detailed above, while health care providers are interested in discussing costs with patients, few feel comfortable initiating this discussion. However, cost distress has been associated with myriad negative

patient outcomes, including mortality. Following an initial screening protocol (above), providers can implement conversation strategies for approaching these discussions to optimize patient-centered care.

# **Before the Encounter:**

Know your available resources	<ul> <li>Discuss available financial assistance options within your care center (including case management and social work assistance)</li> </ul>
	<ul> <li>Learn about available pharmaceutical programs available for commonly prescribed medications within your practice</li> </ul>

#### **Start of Encounter:**

Set up/framing	• "Our goal is for you to get the best care with fewer problems and lower costs."
	<ul><li>"This may involve us asking new types of questions."</li></ul>
	<ul> <li>"I'd like to discuss any worries or concerns you have about the cost of your health care."</li> </ul>
Ally with patient/reassure	"Our goal is for you to get the best available care."
	• "In some cases, financial stress negatively impacts our patients."
	• "I'd like us to work together on these issues."
	<ul> <li>"We will continue to treat your medical conditions the best way possible, and this will not be impacted by this discussion."</li> </ul>



# **Assessment and Plan:**

Understand concerns/screen for financial cost distress	<ul> <li>"Do you have any concerns about how your health care will be paid for?"</li> <li>"Are you worried about how your care will be paid for?"</li> <li>"Are you worried about your current financial situation due to your health?"</li> <li>"Do you feel financially stressed due to your health?"</li> <li>"How can we help you with these problems?"</li> </ul>
Identify areas of cost distress	<ul> <li>"Other patients I've worked with have dealt with the financial stress of health care in a variety of ways, including cutting back on medicines, cancelling appointments with doctors, and cutting back on home expenses (like leisure activities, food, and clothing). Have you made any of these changes due to financial stresses from your health?"</li> </ul>
Discuss options and share evidence	<ul> <li>"Let's discuss some different options to help decrease the financial stresses of your health care, and the pros and cons of each."</li> <li>"Pharmaceutical companies often have assistance programs to help patients like you. Would you be interested in learning more about that?"</li> <li>"There are other medications that are equally effective, and might be less expensive."</li> <li>"I think we should discuss this issue at each visit to make sure we are on the same page."</li> <li>"I am going to bring in another member of my team who can help us brainstorm for possible solutions."</li> <li>"Which option seems like the best fit for you?"</li> <li>"What additional information do you need to make your decision?"</li> <li>"Would it be helpful to talk to someone else on my team about your options?"</li> </ul>
Follow-up	<ul> <li>"Let's schedule a time to follow up on this problem, either in person or by telephone."</li> <li>"I am going to have someone from my team reach out to you in a few days to check in."</li> </ul>
Confirm patient understanding using "teach-back"	"Would you describe our care plan so we can be sure we understand each other?"



The strategy above provides some guidance for initiating a cost conversation with your patients. The following table provides some additional guidance on the "Do's"

and "Don'ts" for communication regarding cost distress with patients.

# Do's and Don'ts of Communication Regarding Cost Conversations

Do	Don't
Ask your patients about potential cost distress	Assume that your patients does or does not suffer from cost distress
Reassure your patient that the discussion will not negatively impact their medical treatment	Fail to implement a follow-up plan with your patient regarding the discussion
Normalize the issue of cost distress for patients	Identify a management option without including the patient in the decision
Ally with your patient and your health care team to address cost distress	Tackle the problem of cost distress on your own (without the assistance of local clinic and/or pharmaceutical resources and other members of your health care team)

### Conclusion

Cost distress is an important facet of patient-centered care, and providers should discuss financial concerns with their patients. The strategies above will help to (1) identify/diagnose cost distress, and (2) enable cost conversations between health care providers and patients.

#### References

- 1. Zafar SY, Abernethy AP. Financial Toxicity, Part I: A New Name for a Growing Problem. Oncology (Williston Park, NY). 2013;27(2):80-149.
- Yousuf Zafar S. Financial Toxicity of Cancer Care: It's Time to Intervene. JNCI: Journal of the National Cancer Institute. 2016;108(5):djv370-djv370. doi:10.1093/jnci/djv370
- 3. Zafar SY, Peppercorn JM, Schrag D, et al. The Financial Toxicity of Cancer Treatment: A Pilot Study Assessing Out-of-Pocket Expenses and the Insured Cancer Patient's Experience. The Oncologist. 2013;18(4):381-390. doi:10.1634/theoncologist.2012-0279
- Nipp RD, Zullig LL, Samsa G, et al. Identifying cancer patients who alter care or lifestyle due to treatment-related financial distress. Psycho-Oncology. 2015;25(6):719-725. doi:10.1002/pon.3911
- 5. Cohen RA. Financial Burden of Medical Care: Early Release of Estimates From the National Health Interview Survey, January–June 2011. 2011:9.
- Neumann PJ, Palmer JA, Nadler E, Fang C, Ubel P. Cancer Therapy Costs Influence Treatment: A National Survey Of Oncologists. Health Affairs. 2010;29(1):196-202. doi:10.1377/hlthaff.2009.0077
- Schrag D, Hanger M. Medical Oncologists' Views on Communicating With Patients About Chemotherapy Costs: A Pilot Survey. JCO. 2007;25(2):233-237. doi:10.1200/JCO.2006.09.2437
- Bestvina CM, Zullig LL, Rushing C, et al. Patient-Oncologist Cost Communication, Financial Distress, and Medication Adherence. JOP. 2014;10(3):162-167. doi:10.1200/JOP.2014.001406
- 9. Alexander GC, Casalino LP, Meltzer DO. Patient-physician communication about out-of-pocket costs. JAMA. 2003;290(7):953-8.
- Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity patient-reported outcome in cancer: The COST measure. Cancer. 2014;120(20):3245-3253. doi:10.1002/cncr.28814
- 11. Souza JA, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). Cancer. 2016;123(3): 476-484. doi:10.1002/cncr.30369