

Financial Toxicity in the Clinical Encounter: A Paired Survey of Patient and Clinician Perceptions

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Abstract

Objective: To compare the agreement between patient and clinician perceptions of care-related financial issues.

Patients and Methods: We surveyed patient-clinician dyads immediately after an outpatient medical encounter between September 2019 and May 2021. They were asked to separately rate (1-10) patient's level of difficulty in paying medical bills and the importance of discussing cost issues with that patient during clinical encounters. We calculated agreement between patient-clinician ratings using the intraclass correlation coefficient and used random effects regression models to identify patient predictors of paired score differences in difficulty and importance of ratings.

Results: 58 pairs of patients (n=58) and clinicians (n=40) completed the survey. Patient-clinician agreement was poor for both measures, but higher for difficulty in paying medical bills (intraclass correlation coefficient=0.375; 95% CI, 0.13-0.57) than for the importance of discussing cost (−0.051; 95% CI, −0.31 to 0.21). Agreement on difficulty in paying medical bills was not lower in encounters with conversations about the cost of care. In adjusted models, poor patient-clinician agreement on difficulty in paying medical bills was associated with lower patient socioeconomic status and education level, whereas poor agreement on patient-perceived importance of discussing cost was significant for patients who were White, married, reported 1 or more long-term conditions, and had higher education and income levels.

Conclusion: Even in encounters where cost conversations occurred, there was poor patient-clinician agreement on ratings of the patient's difficulty in paying medical bills and perceived importance of discussing cost issues. Clinicians need more training and support in detecting the level of financial burden and tailoring cost conversations to the needs of individual patients.

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Over the past decade, Americans have experienced substantial increases in out-of-pocket spending on health care, resulting in financial hardship. As health care costs increase, insurers have shifted some of the cost burden to patients through higher deductibles, rising copayments and coinsurance, resulting in higher out-of-pocket expenses.¹ In 2015, 1 in 4 Americans with health insurance spent >\$1000 in out-

of-pocket costs, when compared with 1 in 6 in 2005.² In addition to the increasing out-of-pocket health care costs, nonmedical basic needs such as housing, utilities, food, and transportation add to the financial burden and can affect patients' well-being.³ This increase in the shifting of costs to patients has likely led to the cost of care becoming a topic that is influencing patients' preferences and decision-making during a clinical encounter.

As a result, the cost of care has been identified as an important component of medical decision-making.

This importance of cost of care for patients highlights the need to examine whether clinicians can, in real practice, identify the patients for whom cost is important or who have financial concerns. We acknowledge that costs may be important to all patients but given the limited resources in today's time-constrained practice environment, it may not be feasible to discuss costs with everyone. Hence, we have chosen to focus on patients for whom costs are relatively more important than others. The correct identification of those patients could help tailor conversations to explore how cost, along with other variables, influences which treatment or diagnostic option makes intellectual, emotional, and practical sense to them.² On the contrary, not correctly identifying these patients may result in plans of care that may worsen patients' financial distress and subsequently lead to nonadherence and poor outcomes. To this end, we surveyed clinician and patient dyads after a medical encounter to explore the degree of agreement between clinicians' perceptions of and patient's self-reported difficulty in paying for health care and perceived importance of cost in discussing medical care. In addition, we examined patient-level and encounter-level factors associated with higher or lower agreement between clinicians and patients.

METHODS

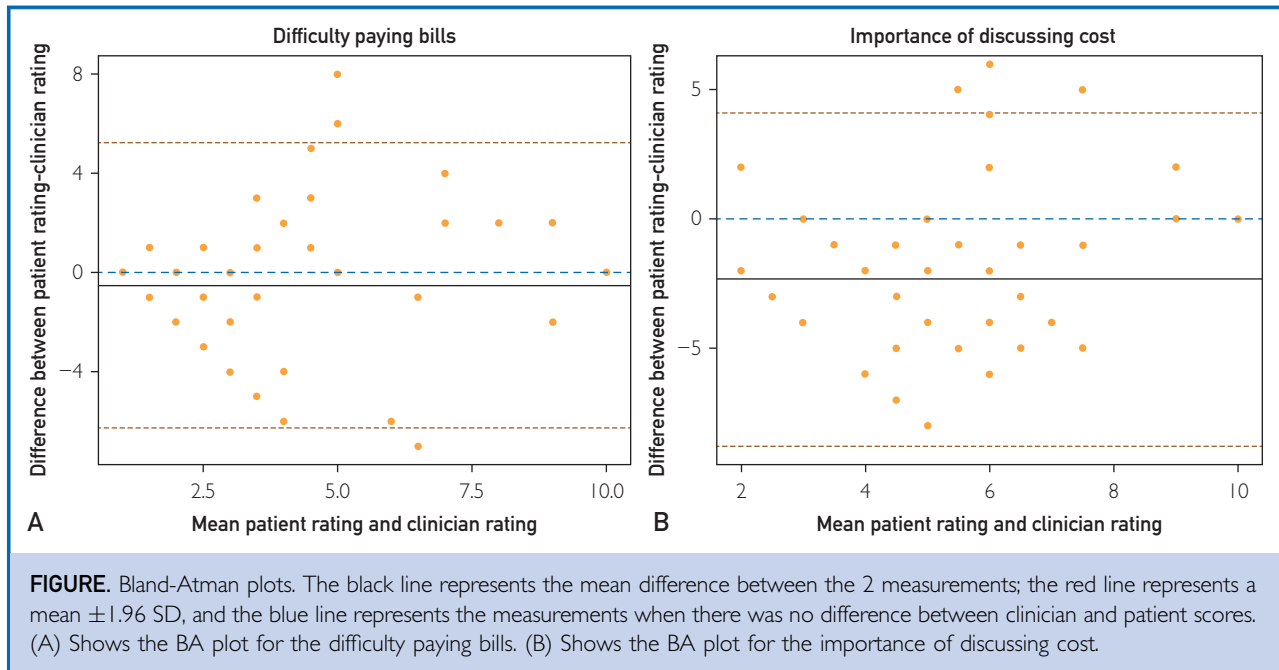
Study Participants

We conducted a cross-sectional study of clinicians and patients at Mayo Clinic in Rochester, MN, between September 2019 and May 2021. Eligible patients were adults (18 years and older) scheduled to have an outpatient medical encounter for any health condition with their clinician and reported no evidence of cognitive impairment or need for an interpreter during the medical encounter. We excluded patients scheduled for medical visits where no conversation about their conditions occurred (eg, procedures). A convenience sample of patients was identified from calendar screenings of future medical appointments by a convenience sample of internists. This

study was approved by the Mayo Clinic Institutional Review Board. All clinicians and patient participants provided a written informed consent to participate before completing the survey. Patients and clinicians did not receive any remuneration for being part of the study.

Survey Development

We developed 2 survey instruments for clinicians and patients, respectively. The clinician survey included 4 items that assessed the following: 1) clinician medical specialty, 2) perceived difficulty this patient may face in paying subsequent health care bills (Likert scale 1-10, 1 being no difficulty, 10 being the most difficult), 3) perceived importance this patient attributes to cost when discussing medical care (Likert scale 1-10, 1 being no difficulty, 10 being the most difficult), and 4) whether they had a conversation about medical costs with this patient during the encounter (Yes/No). The patient survey included: the items on the clinician survey related to financial concerns (difficulty and importance of costs in their medical care), demographic characteristic information (current age, race, ethnicity, marital status, education level, and comorbid medical conditions), and the number of previous visits with the clinician. Sex was not included in the survey because it was considered by the institutional review board as identifiable information; the informed consent did not include this variable. We also extracted data regarding the patient's self-reported level of financial resource strain from the social determinants of health forms embedded in the Mayo Clinic electronic health record (EHR). All Mayo Clinic patients were asked to complete the social determinants of health form before each outpatient appointment at Mayo Clinic. The financial resource strain is coded in different colors (green, yellow, red, and gray) on the basis of the patient's response to the question, "How hard is it for you to pay for the basics like goods, housing, medical care, and heating?" Green was associated with response "not hard at all"; yellow with responses "Not very hard or Somewhat hard"; red with response "very hard"; and gray when the patient refused, or the response was not available.



Data Collection

We surveyed patients and clinicians immediately after the index medical encounter. First, a member of the research team approached the patient in the examination room after the clinician had exited and invited the patient to complete a post-visit survey. If the patient agreed to participate, they were given a paper version of the patient survey and instructed to complete it at their earliest convenience (ie, in the examination room or waiting area, if possible). After a patient agreed to participate, their clinician was approached immediately post-visit by a different member of the research team and asked to complete a paper version of the clinician survey in reference to their visit with that patient. We used a wash-out window of at least 2 weeks to re-enroll clinicians who had previously participated in the study to minimize influences from previous study participation on interaction with newly enrolled patients (eg, higher tendency to engage in cost-related issues with patients). Patients and clinicians returned the surveys through the mail or to the front desk staff. The survey data were entered into a REDCap 10.6.14 database, where each patient and clinician was assigned a unique study number; clinician study numbers were linked to the

patients' study numbers. Only the study personnel had access to this data.

Statistical Analyses

Patient and clinician responses were computed using mean \pm SD for continuous variables and frequencies with percentages for categorical variables. Total agreement between patient and clinician scores was assessed using the intraclass correlation coefficient. The level of agreement was defined as poor for <0.20 ; weak for 0.21 - 0.40 ; moderate for 0.41 - 0.60 ; strong for 0.61 - 0.80 ; and very strong for >0.81 . Bland-Altman plots were generated to visualize trends in agreement across the range of mean between patient and clinician ratings.⁴ To assess patient predictors of differences in patient-perceived and clinician-perceived difficulty in paying for upcoming health care bills and importance of cost when discussing medical care, we used random effects models accounting for clustering within clinicians to estimate the mean difference between paired scores (patient—clinician score) and generate 95% CIs. All statistical analyses were conducted in SAS Version 9.4 (SAS Institute Inc) and R (R Core Team 2020; R Foundation).

RESULTS

In total, 58 patient-clinician pairs were enrolled in the study and completed the survey (Appendix Figure 1). The 58 patients were mostly White (97%) and reported ≥ 1 long-term medical conditions, the highest proportion of which were heart conditions (28%) and diabetes (24%). In addition, most patient participants reported some college or associated degree of education (62%), being married or living with someone in a marriage-like relationship (78%), and an annual income between \$40,000 and \$99,999 (40%). Forty clinicians participated in our study (clinicians could see multiple included patients), spanning 5 different departments (community internal medicine, family medicine, endocrinology, cardiology, and pain services) (Table 1).

The mean \pm SD patient score rating difficulty in paying upcoming health care bills was 3.22 ± 2.75 , whereas for clinicians, the score for perceived patient difficulty in paying bills was 3.82 ± 2.49 . For the importance of considering cost when discussing medical care, the mean \pm SD patient score was 4.38 ± 2.83 when compared with a clinician's perceived patient importance score of 6.57 ± 2.15 . Intraclass correlation coefficient for difficulty in paying bills was higher at 0.375; (95% CI, 0.13-0.57) than that for the importance of discussing cost: -0.051 ; (95% CI, -0.31 to 0.21). Bland-Altman plots (Figure) indicate that clinicians generally rated the importance of discussing costs higher than their patients but rated similarly to patients when assessing the difficulty of paying upcoming health care bills. Patients whose financial status was red (mean difference of -5.89 ; 95% CI, -11.49 to -0.28 ; $P=.04$) and those whose highest level of education was high school or less (-2.02 ; 95% CI, -3.80 to -0.25 ; $P=.03$) were perceived as significantly more likely to have difficulty in paying upcoming bills by their clinicians, as compared with the patients' own ratings (Table 2). For the importance of cost when discussing medical costs, race (White) (-2.37 ; 95% CI, -3.41 to -1.32 ; $P=.04$); any comorbidities, (-2.35 ; 95% CI, -3.43 to -1.26 ; $P \leq .01$); marital status (married)

TABLE 1. Patient Characteristics

Characteristic	n	%
Race		
White	56	96.6
Non-White	1	1.7
Missing	1	1.7
Medical conditions		
Diabetes	14	24.1
Cardiovascular disease	16	27.6
Depression	7	12.1
Other	19	32.7
Missing	2	3.4
Comorbidity		
Any	35	60.3
None	21	36.2
Missing	2	3.4
Marital status		
Married or living with someone in a marriage-like relationship	45	77.6
Never married, divorced, or widowed	12	20.7
Missing	1	1.7
Highest level of education		
Some high school or less or high school graduate	11	19
Some college or associate degree or 4-year college graduate	36	62.1
Graduate or professional school degree	9	15.5
Missing	2	3.4
Annual household income		
$\leq \$39,999$	13	22.4
\$40,000-\$99,999	23	39.7
$> \$100,000$	20	34.5
Missing	2	3.4
Financial status		
Green	41	70.7
Other	17	29.3
Number of previous encounters with clinician		
1		
> 1		
Missing		
Medical specialty of clinician seen		
Endocrinology	15	25.9
Cardiology	6	10.3
Family medicine	4	6.9
Community and internal medicine	29	50
Other	4	6.9
Agreement on whether cost conversation occurred during encounter		
Yes	46	79.3
No	12	20.7

(−2.87; 95% CI, −4.11 to −1.63; $P \leq .01$); higher level of education (graduate or professional school degree) (−3.35; 95% CI, −5.60 to −0.80; $P \leq .01$); and higher income (+ \$40,000 or more) (−3.07; 95% CI, −4.50 to −1.63; $P = .002$) were all associated with higher clinician ratings of the patient's perceived importance compared with the patient's own rating of importance (Table 3). Clinician and patient dyads that agreed they had a cost conversation during the medical encounter reported a statistically significant difference in mean score for the importance of discussing medical costs in the encounter (−2.40; 95% CI, −3.56 to −1.23; $P \leq .01$), but not for the difficulty of paying upcoming health care costs (−0.86; 95% CI, −1.90 to 0.18; $P = .10$).

Discussion

Comparisons of clinician and patient ratings on a post encounter survey reported weak agreement between clinicians and patients on perceptions of patient difficulty affording care and the importance to patients of discussing costs in medical encounters, even when cost conversations did occur during that encounter. Compared with patients' own ratings, the clinicians were more likely to overestimate the patient's level of difficulty in paying upcoming medical bills for patients with a lower educational level and higher financial stress (as documented in the EHR). In addition, clinicians were more likely to overestimate the importance of cost discussions with their patients who were White, married, had higher levels of income and education, less financial stress, and reported at least 1 long-term medical condition.

Our findings of poor agreement on perceptions of patients' difficulty suggest that clinicians, at least in this sample, cannot accurately identify patients' financial distress in medical encounters. Furthermore, the current point-of-care information available to clinicians (eg, EHR-based information about social determinants of health) may not accurately capture health care-related financial concerns. For instance, the EHR-based financial distress measure used in our study does not distinguish between financial distress related to paying for basic goods and services

(eg, food or housing) or if it is specifically related to medical care.

However, conversations about the cost of medical treatment—when they did occur—did not appear to clarify the actual magnitude of the financial burden. On average, patient-perceived importance of discussing costs in the encounter was rated lower by patients than clinicians and significantly more so with patients of higher socioeconomic means. These findings speak about the quality and value of cost conversations. We had previously conducted 3 studies showing that cost conversations have a minimal but favorable effect on decision-making but not on cost-reducing outcomes in clinical encounters, particularly when they occur in encounters aided by a shared decision-making tool.⁵ Further cost conversations were associated with patients' consideration of treatment cost burden but not the final treatment choice.⁶ We also found that using shared decision-making tools that raise cost as an issue increased the occurrence of cost conversations but were less likely to address cost issues or offer potential solutions to patients' cost concerns.⁷ Given these findings, it is possible that patients scored the importance of cost conversations lower than clinicians because of past experiences with cost conversations that did not result in solutions to problems of affording care. Furthermore, clinicians may have more information and exposure than patients about the overall effect on out-of-pocket costs, therefore, assigning cost conversations a higher rating for importance than patients. Another possible explanation is that patients may not want to bring financial concerns to their clinicians owing to concerns or a perceived negative effect on their clinical decisions. For example, patients may perceive that bringing up cost issues in the encounters may lead clinicians to recommend cost-responsive treatment rather than the right treatment.

This is one of the only studies that focuses on assessing the agreement between patients and clinicians in determining the magnitude and importance of addressing patient financial burden, such as by examining patient characteristics associated with such agreement or lack thereof. Our findings indicate that certain patient demographic characteristic factors (White race, being married, higher levels of

income, and education) and certain long-term conditions (eg, diabetes, cardiovascular disease, and depression) are associated with larger discrepancies in perceptions of importance between patients and clinicians. These findings resonate with those of other cost studies: higher patient cost burden is associated with the desire to discuss costs in encounters,⁸⁻¹¹ whereas patients' higher socioeconomic status is associated with lower desire for such discussions.^{9,12} Thus, our findings validate indications from other studies that a certain demographic characteristic profile of patients is associated with lower motivation to want to engage in discussion on affordability of care. Discerning the broad profile of a patient who is likely to desire and would benefit from cost conversations is important in the context of limited clinical encounter time, while tailoring the conversation to the individual patient would achieve the overall objective of discussing costs.

Implications for Research and Practice

These findings have implications for clinical practice. Care teams should gauge the pulse of patients' financial distress before the appointment, transmitting this information to clinicians in advance. This information could be elicited from several potential sources, including patient-reported outcomes, such as self-reported adherence to therapy, responses on validated scales such as COST,³ administrative or pharmacy records on adherence, routinely collected information on social determinants of health, and other information from the EHR. Although this information paints a broad patient profile, it forms an important baseline for clinicians to personalize, contextualize, and clarify with the individual patient through careful bidirectional cost conversations, eliciting and integrating the patient's preferences, care goals, and lifestyle factors with cost considerations.

Patients can be guided and educated in setting the agenda of cost conversations during routine clinic visits. This can be done through education or interventional nudges to go beyond discussing just financial burden, but situating such discussion in the context of quality of life, safety, lifestyle, and other burdens of alternative treatments.¹³ In particular, clinicians need guidance and resources to

TABLE 2. Patient Predictors for Mean Difference in Score: Difficulty in Paying for Upcoming Health Care Bills^a

Patient predictors	Estimate (95% CI)	P value
Age (10 y)	-0.13 (-0.62 to 0.35)	.57
Race ^b		
White	0.78 (-4.98 to 6.55)	.78
Non-White	-0.64 (-1.57 to 0.28)	.17
Medical conditions		
Diabetes	-0.20 (-1.87 to 1.48)	.81
Cardiovascular disease ^c	-0.82 (-2.14 to 0.50)	.21
Depression	-1.55 (-3.31 to 0.20)	.08
Other	-0.50 (-1.61 to 0.60)	.36
Comorbidity		
Any	-0.67 (-1.62 to 0.28)	.16
None	0.26 (-3.96 to 4.48)	.90
Marital status		
Married	-0.40 (-1.43 to 0.63)	.43
Living with someone in a marriage-like relationship	-2.70 (-5.69 to 0.29)	.08
Divorced	1.16 (-4.75 to 7.08)	.69
Widowed	-0.75 (-4.19 to 2.70)	.66
Never married	-0.63 (-2.77 to 1.52)	.55
Highest level of education		
Some high school or less or high school graduate	-2.02 (-3.80 to -0.25)	.03
Some college or associate degree or 4-year college graduate	-0.52 (-1.57 to 0.54)	.33
Graduate or professional school degree	0.44 (-1.5 to 2.47)	.66
Annual household income		
≤ \$39,999	-0.77 (-2.51 to 0.97)	.37
\$40,000 to \$99,999	-0.70 (-1.99 to 0.59)	.27
>\$100,000	-0.49 (-1.97 to 1.00)	.51
Financial status		
Green	-0.98 (-1.98 to 0.01)	.05
Gray	1.76 (-0.82 to 4.34)	.17
Yellow	0.50 (-3.56 to 4.56)	.80
Red	-5.89 (-11.49 to -0.28)	.04
Number of previous encounters with clinician	-0.34 (-0.83 to 0.15)	.17
Agreement on whether cost conversation occurred during encounter		
Yes	-0.86 (-1.90 to 0.18)	.10
No	-0.10 (-1.98 to 1.78)	.92

^aRandom effects model, clustered at the clinician level; patient score—clinician score.

^bEthnicity not included because there were no Hispanic/Latino patients.

^cAtrial fibrillation, heart failure, dyslipidemia, and high blood pressure.

identify financial burdens and improve the quality of cost conversations.^{14,15} Patient affordability is typically a delicate issue that is brushed aside in medical encounters owing to its sensitive nature and time constraints.¹⁶ Clinicians should be equipped with the right

TABLE 3. Patient Predictors for Mean Difference in Score Between Patients and Their Clinicians on Patient-Perceived Importance of Cost When Discussing Medical Care^a

Patient predictors	Estimate (95% CI)	P value
Age (10 y)	0.19 (−0.37 to 0.75)	.49
Race ^b		
White	−2.37 (−3.41 to −1.32)	<.001
Non-white	1.56 (−5.02 to 8.14)	.63
Medical conditions		
Diabetes	−2.19 (−4.07 to −0.29)	.03
Cardiovascular disease ^c	−2.85 (−4.31 to −1.39)	<.001
Depression	−3.64 (−5.77 to −1.51)	.002
Other	−1.76 (−2.92 to −0.60)	.004
Comorbidity		
Any	−2.35 (−3.43 to −1.26)	<.001
None	−2.11 (−6.90 to 2.68)	.38
Marital status		
Married	−2.87 (−4.11 to −1.63)	<.001
Living with someone in a marriage-like relationship	−1.32 (−5.22 to 2.59)	.49
Divorced	1.22 (−5.31 to 7.75)	.70
Widowed	−1.28 (−5.11 to 2.56)	.50
Never married	−0.67 (−3.20 to 1.86)	.59
Highest level of education		
Some high school or less or high school graduate	−2.19 (−4.39 to 0.01)	.05
Some college or associate degree or 4-year college graduate	−2.11 (−3.36 to −0.85)	.002
Graduate or professional school degree	−3.35 (−5.90 to −0.80)	.01
Annual household income		
≤\$39,999	−1.03 (−3.02 to 0.96)	.30
\$40,000–\$99,999	−3.07 (−4.50 to −1.63)	<.001
>\$100,000	−2.04 (−3.74 to −0.33)	.02
Financial status		
Green	−3.27 (−4.36 to −2.17)	<.001
Gray	−0.24 (−3.02 to 2.54)	.86
Yellow	2.00 (−2.36 to 6.36)	.35
Number of previous encounters with clinician	−0.28 (−0.83 to 0.27)	.30
Agreement on whether cost conversation occurred during encounter		
Yes	−2.40 (−3.56 to −1.23)	<.001
No	−1.97 (−4.26 to 0.33)	.09

^aRandom effects model, clustered at the clinician level; patient score—clinician score.

^bEthnicity not included because there were no Hispanic/Latino patients.

^cAtrial fibrillation, heart failure, dyslipidemia, and high blood pressure.

communication skills, aware of resources, and encouraged to normalize the practice of discussing treatment costs together with treatment recommendations. This should be followed up with tangible plans to address the financial burden, supported by the clinical

team and other organizational resources.² Finally, future research studies could be conducted to examine whether improved patient-clinician agreement on care-related financial issues translates to improved patient outcomes, such as increased adherence to treatment and improved quality of life. In addition, future studies could examine how other patient and clinician characteristics not included in this study may affect patient-clinician agreement on care-related financial issues.

Limitations

Our study reported several limitations. First, we utilized a small convenience sample; a larger sample would have provided a better estimate of our effect size and likely revealed additional factors associated with discrepancies between clinician and patient ratings. Second, the study was conducted in a tertiary care center that included many insured patients. Therefore, some of these findings may not generalize to patients seen in other settings, such as community and safety net hospitals. Third, patients' actual level of financial burden was derived from past responses to a single-item, EHR-based questionnaire on the social determinants of health and may not have reflected the true level of financial treatment burden experienced at the time our study was conducted. We also did not use validated scales to assess the difficulty and importance of discussing costs with patients and clinicians. Fourth, there may have been a large variation in the quality and value of cost conversations across encounters. We did not observe or record cost conversations to control for or assess the quality of conversations. Fifth, there were wide variations in medical conditions or severity among patients in this study. Perhaps patients with similar medical conditions and levels of medical acuity may have generated different findings. The study also targeted clinicians who were inter-nists. The results of this study may not transfer to other clinician-patient dyads where new therapeutic drugs, devices, or needed medical procedures are being prescribed and discussed or for short-term conditions.^{6,16} Finally, clinicians and patients who consented to participate in the study may differ in important ways from those who did not.

CONCLUSION

Although limited in size and generalizability, this study provides insights into the level of agreement between patients and clinicians on patient's ability to afford health care and the importance of discussing issues related to cost in the clinical encounter. Relative to patients' perceptions of their own difficulties, clinicians are likely to overestimate the difficulty their patients face in affording health care on the basis of gross socioeconomic indicators. On the contrary, patients in certain sociodemographic groups are more likely to downplay the importance of having a cost discussion in clinical encounters relative to clinicians, even when they have experienced a cost discussion. Future work should focus on the development of more sensitive indicators of patients' desire or need to have these conversations, better clinician skills in conducting the discussions, and informed patients who understand the need to discuss costs and the trade-offs to be considered.

POTENTIAL COMPETING INTERESTS

The authors report no competing interests.

SUPPLEMENTAL ONLINE MATERIAL

Supplemental material can be found online at <http://www.mcpiqjournal.org>. Supplemental material attached to journal articles has not been edited, and the authors take responsibility for the accuracy of all data.

Abbreviations and Acronyms: EHR, electronic health record

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