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Recommended Citation

Hamel LM, Penner LA, Eggly S, Chapman R, Klamerus JF, Simon MS, Stanton SC, Albrecht TL. Do Patients and Oncologists Discuss the Cost of Cancer Treatment? An Observational Study of Clinical Interactions Between African American Patients and Their Oncologists. *J Oncol Pract.* 2017 Mar;13(3):e249-e258.

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Disclosures provided by the authors are available with this article at jop.ascopubs.org.



DOI: [10.1200/JOP.2016.015859](https://doi.org/10.1200/JOP.2016.015859); published online ahead of print at jop.ascopubs.org on December 13, 2016.

Do Patients and Oncologists Discuss the Cost of Cancer Treatment? An Observational Study of Clinical Interactions Between African American Patients and Their Oncologists

Lauren M. Hamel, Louis A. Penner, Susan Eggly, Robert Chapman, Justin F. Klamerus, Michael S. Simon, Sarah C.E. Stanton, and Terrance L. Albrecht

QUESTION ASKED: Do African American patients with cancer and medical oncologists discuss cancer treatment costs, and if so, who initiates the discussion and what cost topics are discussed?

SUMMARY ANSWER: Treatment cost discussions occurred in 45% of clinical interactions between African American patients with cancer and their medical oncologists. Patients initiated 63% of discussions; oncologists initiated 36%. (One discussion was initiated by a patient's companion.) The most frequent topics were concern about time off from work for treatment (initiated by patients) and insurance (initiated by oncologists). Younger patients and patients with more perceived social support satisfaction were more likely to discuss cost. Patient age interacted with amount of social support to affect frequency of cost discussions. Younger patients with more social support had more cost discussions; older patients with more social support had fewer cost discussions.

WHAT WE DID: A total of 103 African American patients with cancer and 18 non-African American medical oncologists met for the first time to discuss treatment of breast, lung, and colorectal cancer, and we video-recorded that interaction. Patients and oncologists provided information on their sociodemographic characteristics and patients' perceived amount of social support and satisfaction with that social support. Trained coders observed the video recordings for the presence and duration of treatment cost

discussions. The coders then determined the initiator, topic, oncologist response to the patient's concerns, and the patient's reaction to the oncologist's response.

WHAT WE FOUND: Our findings of who initiates cost discussions and what cost topics are discussed in treatment discussions with African American patients with cancer and their medical oncologists may provide additional understanding of what cost issues are important to this underserved patient population. Importantly, most cost discussions focused on the impact of the diagnosis on patients' opportunity costs rather than on direct treatment costs. This finding has an important implication for ASCO's Value Framework, which does not include these kinds of cost considerations and focuses exclusively on direct treatment costs.

BIAS, CONFOUNDING FACTOR(S), REAL-LIFE IMPLICATIONS: All the patients were African American and more than 90% were female, which may limit the generalizability of the findings. This was a secondary analysis of a larger study that was not focused on patient-oncologist cost discussions. Thus, we were not able to ask patients what they wanted to know about treatment cost before the interaction or assess patient level of understanding of cost discussions after the interaction. The study has important implications for how oncologists discuss cost with economically disadvantaged minority patients and professional guidelines for cost discussions with patients with cancer. **JOP**

Do Patients and Oncologists Discuss the Cost of Cancer Treatment? An Observational Study of Clinical Interactions Between African American Patients and Their Oncologists

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Abstract

Purpose

Financial toxicity negatively affects patients with cancer, especially racial/ethnic minorities. Patient-oncologist discussions about treatment-related costs may reduce financial toxicity by factoring costs into treatment decisions. This study investigated the frequency and nature of cost discussions during clinical interactions between African American patients and oncologists and examined whether cost discussions were affected by patient sociodemographic characteristics and social support, a known buffer to perceived financial stress.

Methods

Video recorded patient-oncologist clinical interactions (n = 103) from outpatient clinics of two urban cancer hospitals (including a National Cancer Institute–designated comprehensive cancer center) were analyzed. Coders studied the videos for the presence and duration of cost discussions and then determined the initiator, topic, oncologist response to the patient's concerns, and the patient's reaction to the oncologist's response.

Results

Cost discussions occurred in 45% of clinical interactions. Patients initiated 63% of discussions; oncologists initiated 36%. The most frequent topics were concern about time off from work for treatment (initiated by patients) and insurance (initiated by oncologists). Younger patients and patients with more perceived social support satisfaction were more likely to discuss cost. Patient age interacted with amount of social support to affect frequency of cost discussions within interactions. Younger patients with more social support had more cost discussions; older patients with more social support had fewer cost discussions.

Conclusion

Cost discussions occurred in fewer than one half of the interactions and most commonly focused on the impact of the diagnosis on patients' opportunity costs rather than treatment costs. Implications for ASCO's Value Framework and design of interventions to improve cost discussions are discussed.



DOI: [10.1200/JOP.2016.015859](https://doi.org/10.1200/JOP.2016.015859);
published online ahead of print at
jop.ascopubs.org on December 13,
2016.

INTRODUCTION

Financial toxicity, the increased financial burden from cancer treatment and its influence on patient well-being, treatment decisions, and health outcomes, negatively affects many patients with cancer.¹⁻⁵ As the cost of cancer care escalates⁶ and the burden of cost shifts to the patient,⁷⁻¹⁰ more patients are incurring debt,¹¹ filing for bankruptcy,¹² deviating from cancer treatment plans,¹ and forgoing treatment.¹³ Recent evidence also suggests that severe financial distress as a result of cancer treatment may itself be a mortality risk factor.¹⁴

The encouragement of patients and physicians to discuss treatment costs may help to alleviate financial toxicity and facilitate more-informed treatment decisions.^{5,15-20} Such discussions are an opportunity for patients to voice cost concerns and for physicians to provide information about costs (if available) and to allow cost to factor into treatment decisions.^{2,5,15,17} In fact, clinicians increasingly have been encouraged to discuss treatment costs with patients as economic concerns grow.^{5,17,21}

The data on patient-physician treatment cost discussions are inconsistent. Some studies show that patients want to discuss treatment costs with their physicians,²² and most physicians report that they frequently discuss cost with their patients.²³ However, other research has found that physicians often are hesitant about initiating cost discussions²⁴⁻²⁶ and rarely fully engage with patients to resolve their financial concerns.²⁷ Several studies suggest that discussions of treatment costs in patient-physician clinical interactions are rare.^{15,24-26,28,29}

Given the potential importance of cost-related discussions in cancer care, this study systematically assessed the extent and nature of actual cost discussions that occur between a sample of African American patients and their oncologists. This study focused on African Americans because, on average, African Americans are more likely than whites to have low annual household incomes³⁰ and, thus, may be at greater risk to incur economic hardship as a result of a cancer diagnosis.³¹⁻³⁵ In addition, most African American patients with cancer experience racially discordant clinical interactions (ie, non-African American physician with African American patient),³⁶ and a significant body of research has found that relative to racially concordant interactions, patient-physician communication in racially discordant interactions is of poorer quality.³⁷⁻⁴³

A secondary purpose of this study was to explore how certain patient characteristics affect cost discussions. Research

has found that financial toxicity is an emotional stressor.^{3,4} Thus, patient perceptions of social support were examined because social support has been found to be a buffer to financial stress.^{44,45} Patients reported the amount of social support they received and their satisfaction with that social support. These aspects of social support are distinct and often have a variety of effects on how people react to environmental stressors.^{46,47} Given the likely association of patient age, education, and annual household income with patient finances, the influence of these sociodemographic characteristics on cost discussions was also examined. To answer the questions of interest in this study, real-time video-recorded patient-oncologist clinical interactions were analyzed for frequency and content of cost discussions.

METHODS

Participants and Setting

Data were from a larger parent study that tested a communication intervention in the outpatient clinics of two urban cancer hospitals.⁴⁸⁻⁵⁰ The two hospitals provide the largest proportion of cancer care for the residents of Detroit, Michigan, a city with a majority African American population. Data were collected between March 2012 and December 2014. The current study was a secondary analysis conducted after the parent study was completed.

Participants were African American patients with cancer and their non-African American medical oncologists. The oncologists and patients were meeting for the first time to discuss treatment options for breast, lung, or colorectal cancer. One clinical interaction for each patient was video recorded. The parent study focused on patient-oncologist communication; thus, patients and physicians did not know that cost discussions would subsequently be assessed.

Procedure and Measures

Upon recruitment into the parent study, patients and oncologists completed a baseline questionnaire that assessed demographic characteristics and other personal attributes. Patients provided information on their sociodemographic characteristics and perceived social support.⁴⁶ Patients were presented with five social support domains, including dependability (eg, Whom can you really count on to be dependable when you need help?), help with relaxing, unconditional acceptance, unconditional care, and consolation. Patients reported the number of persons who provided

them with social support in each domain and their level of satisfaction with the support received (1 = very dissatisfied to 4 = very satisfied). Responses were summed across items for each type of support and then averaged across the five domains to yield two scores for each patient. Higher scores indicate more perceived social support and greater satisfaction. Oncologists provided information on their sex, race/ethnicity, age, and number of years in practice since their fellowship.

As part of the larger study, patients were randomly assigned to three study arms: control group (usual care); those who received a question prompt list that contained questions patients might ask their oncologist; and those who received the question prompt list and met with a coach who reviewed the questions with them. Approximately 1 week later, patients and their oncologist met to discuss treatment options.⁴⁸ Patients from all arms were included in this study, and each study arm was controlled for in all analyses.

Each examination room was equipped with unobtrusive digital audio and video devices that recorded all occupants of the examination room during the clinical interaction. This recording system has been used by the study team for more than 15 years,^{51,52} and research has strongly suggested that video recording has little impact on participants' verbal or nonverbal behaviors⁵³ and provides enhanced validity compared with audio recording alone.⁵⁴

The study was approved by the institutional review boards of the affiliated university and both hospitals. All patients, companions (if present), and oncologists provided consent as participants, which included specific permission to be video recorded.

Oncologist and Patient Interaction Coding

The first and senior authors watched 10 video-recorded clinical interactions from the data for examples of cost discussions to develop a coding system that identified and described cost discussions. Cost discussions were defined broadly²⁴ as verbal expressions of any perceived monetary expense for the patient for cancer treatment. Topic categories for cost included out-of-pocket expenses for treatment, insurance coverage, transportation and parking for treatment, time off from work for treatment and recovery, and loss of employment.

Two trained research assistant coders then observed all the video-recorded interactions, (including those used to develop the coding system). The coders assessed the frequency and duration of cost discussions according to the aforementioned topic categories for cost by using observational coding software

(Studiocode [www.studiocodegroup.com]; Vosaic, Lincoln, NE). Cost discussions were marked as beginning with the first mention of cost and ending with the first mention of either a noncost topic or a new cost topic. Both individual cost discussions and total clinical interaction time (total time the oncologist and patient were in the examination room together) were assessed to the nearest second. For each cost discussion, coders identified the initiator, topic, oncologist's response to the patient's concern, and how the patient reacted to the oncologist's response.

Interrater reliability was assessed in two stages. First, the coders were trained to assess the presence and duration of the cost discussion; reliability was assessed by percentage of agreement (presence, 88.3%; duration, 83.8%). Second, the coders were trained to label discussion elements (initiator, topic, oncologist response, and patient reaction). Reliability was determined by Cohen κ ($\kappa = 0.84$; an average κ was taken across the coded elements). Because the high κ value suggested high intercoder reliability, each coder independently coded approximately 40% of the interactions. The remaining interactions were coded by both coders to assess continued intercoder reliability, which remained high.

Data Analysis

Data included the video-recorded clinical interactions, patient and oncologist self-reported sociodemographics, and patient-reported amount of social support and social support satisfaction. Bivariate associations between the outcome variables and patient age, education, income, perceived amount of social support and satisfaction with social support, and interaction length were examined to identify possible predictors and covariates to be included in the regression analyses.

The primary analyses of the predictors for the outcome variables used generalized estimating equation (GEE)^{55,56} multiple regressions with robust standard error estimates to account for patients being clustered within oncologist. Patient attributes and other variables that correlated with the outcome variables were included in the GEEs.

The first GEE used absence or presence of a cost discussion as the outcome variable. For the clinical interactions that included cost discussions, two more GEEs were conducted, with frequency of cost discussions and total time spent in discussion about cost as the outcome variables. Study arm to which patients were assigned in the parent study was included as a covariate in all regression analyses. For all analyses, α was set at $P < .05$ (two-tailed).

RESULTS

Of the 273 patients invited to participate in the parent study, 137 (50%) accepted. Patients who declined to participate did so because of limited time or feeling burdened by their cancer. An analysis of zip codes of participants and nonparticipants suggested that they came from areas with similar sociodemographic characteristics.⁵⁰ Twenty-three patients were excluded from this analysis because they were not video recorded as a result of issues with equipment availability.

Eleven patients were excluded from this analysis because their diagnosis did not warrant a discussion of medical treatment (eg, ductal carcinoma in situ). Thus, the final sample was composed of 103 patients.

The sociodemographic characteristics of the 103 African American patients and their non-African American medical oncologists (n = 18) are listed in Table 1. All patients self-identified as African American, and most had breast cancer (87%). Most patients (73%) reported annual household

Table 1. Patient and Oncologist Demographics

Demographic	Total	Cost Discussion	No Cost Discussion
Patients*			
No. of participants	103	46	57
Mean age, years (SD)	58.74 (10.82)	55.24 (10.30)	61.56 (10.47)
Female	95 (92)	41 (89)	54 (95)
Education			
< High school	23 (22)	8 (17)	15 (26)
Graduated high school	12 (12)	5 (11)	7 (12)
Some college	34 (33)	18 (39)	16 (28)
Graduated college	21 (20)	8 (17)	13 (23)
Postgraduate degree	13 (13)	7 (15)	6 (11)
Marital status			
Married or partnered	33 (32)	19 (41)	14 (25)
Divorced, widowed, or separated	38 (37)	16 (35)	22 (39)
Single	30 (29)	10 (22)	20 (35)
Annual household income			
\$0-\$19,999	43 (42)	17 (37)	26 (46)
\$20,000-\$39,999	31 (30)	15 (33)	16 (28)
\$40,000-\$59,999	8 (8)	4 (9)	4 (7)
\$60,000-\$79,999	8 (8)	3 (7)	5 (9)
> \$80,000	7 (7)	4 (9)	3 (5)
Primary tumor site			
Breast	89 (86)	38 (83)	51 (90)
Colorectal	7 (7)	4 (9)	3 (5)
Lung	7 (7)	4 (9)	3 (5)
Mean interaction time, minutes (SD)	31.01 (14.14)	34.57 (13.84)	28.08 (13.82)
Amount of social support score, mean (SD)	4.03 (2.36)	4.67 (2.36)	3.52 (2.24)
Social support satisfaction score, mean (SD)	3.71 (0.61)	3.84 (0.33)	3.59 (0.75)
Oncologists			
No. of participants	18		
Mean age, years (SD)	46.76 (10.60)		
Male	10 (56)		
Race/ethnicity			
White	10 (56)		
Asian or Pacific Islander	4 (22)		
Arab American or Middle Eastern	4 (22)		
Attending	15 (83)		
Years in practice since fellowship, mean (SD)	7.69 (9.83)		

NOTE. Values are No. (%) unless otherwise indicated.

Abbreviation: SD, standard deviation.

*Some data are missing because of omissions in patients' responses.

incomes of < \$40,000. Ten of the 18 oncologists were male, 56% reported their race as white, 22% reported being Asian or Pacific Islander, and 22% reported being Arab American or Middle Eastern. On average, each oncologist saw six patients (range, 1 to 25 patients).

Occurrence and Nature of Cost Discussions

Cost discussions occurred in 46 (45%) of 103 patient-oncologist clinical interactions. One to six cost discussions occurred per interaction for a total of 88 (mean, 1.91; standard deviation [SD], 1.46). Individual cost discussions lasted an average of 35.72 seconds (SD, 34.85 seconds). Total average time spent in discussion about cost within the entire clinical interaction was 1.14 minutes (SD, 1.18 minutes), which comprised an average of 3.28% (SD, 0.03%) of the interaction length. Twenty-nine patients initiated 55 (63%) of the 88 cost discussions; 11 oncologists initiated 32 (36%) discussions. Companions were present in 59% of interactions, and one companion (1%) initiated one cost discussion (Table 2).

Patient-initiated discussions

In the 55 patient-initiated cost discussions, concern about having to take time off from work for treatment or recovery was the most frequent topic (56%) followed by insurance questions or concerns (16%); transportation and parking costs (11%); concerns about loss of employment as a result of extended time off from work for treatment and recovery (7%); out-of-pocket costs for treatment, such as copayments (6%); and general financial concerns (4%). Oncologists' responses to patient-initiated discussions were to address the issue directly (69%); to refer the patient to another health care provider, such as a social worker (20%); or to not address the issue (11%).

Most patients (78%) were observed to agree or be satisfied with the oncologist's response to patient-initiated discussions (most frequently with a head nod or by saying okay or yes). Patients demonstrated disagreement or dissatisfaction in 6% of discussions (usually observed as a head shake or similar nonverbal behavior). The patient changed the topic in 7% of the discussions, and the oncologist changed topic in 9%. The switch to a cost topic occurred twice.

Table 2. Cost Discussions by Initiator and Topic Within Clinical Interactions

Initiator and Topic	Cost Discussion Clinical Interaction, %						Total, No.
	First	Second	Third	Fourth	Fifth	Sixth	
Patient							
No. of participants	22	14	9	3	4	3	55
Time off from work	68	71	33	33	25	33	
Transportation/ parking	18	7					
Insurance	14	7	11	67	25	33	
Treatment costs		7	11			33	
Job loss		7	33		25		
General concern			11		25		
Oncologist							
No. of participants	24	5	1	1	0	1	32
Time off work	38	60					
Transportation/ parking	8	20					
Insurance	42	20		100		100	
Treatment costs	8		100				
General concern	4						
Companion							
No. of participants	0	1	0	0	0	0	1
Insurance		100					
Total, no. of participants	46	20	10	4	4	4	88

Oncologist-initiated discussions

In the 32 oncologist-initiated cost discussions, insurance was the most frequent topic (41%) followed by time off from work (38%), transportation and parking costs (9%), out-of-pocket costs for treatment (9%), and general financial concerns (3%). If an oncologist initiated a discussion, he or she always addressed the topic.

Coders judged the majority of patients (66%) to be either in agreement or satisfied with the oncologist's response to oncologist-initiated discussions. Patients always provided answers to oncologist-posed questions in the remaining 34% of oncologist-initiated discussions.

Correlates of Cost Discussions

Bivariate associations between the outcome variables (ie, presence of a cost discussion, frequency of a cost discussion within a single clinical interaction, time spent in discussion about cost) and patient age, income, education, and interaction length identified patient demographic characteristics (ie, age, income, education) to be included in the GEE analyses of the cost discussions. The only characteristic associated with the outcome variables was patient age, which was significantly ($P \leq .05$) and negatively correlated with presence of a cost discussion ($r = -0.29$), frequency of cost discussions ($r = -0.26$), and time spent in discussion about cost ($r = -0.22$).

Perceived amount of social support was significantly and positively correlated with the presence of a cost discussion ($r = 0.24$), frequency of cost discussions ($r = 0.29$), and time spent in discussion about cost ($r = 0.26$). Perceived satisfaction with social support was significantly and positively associated with presence of a cost discussion ($r = 0.21$) and time spent in discussion about cost ($r = 0.26$).

As would be expected, interaction length was significantly and positively correlated with the presence of a cost discussion ($r = 0.23$), frequency of cost discussions ($r = 0.33$), and time spent in discussion about cost ($r = 0.35$).

Thus, the following were included as predictors in the GEE analyses: patient age, amount of social support, and satisfaction with social support. Interaction length was included as a covariate. Although the outcome variables did not significantly differ by study arm, study arm was also included in the models as a covariate because other research⁵⁰ has found that the parent study intervention affected the level of patient participation.

The GEE analysis of the predictors of the presence of a cost discussion revealed that patient age was negatively associated with the probability that cost was discussed ($B = -0.15$;

standard error [SE], 0.07; $P = .05$; odds ratio [OR], 4.0; 95% CI, -0.3 to -0.003), and perceived satisfaction with social support was positively associated with the probability that cost was discussed ($B = 0.08$; SE, 0.03; $P = .009$; OR, 6.9; 95% CI, 0.02 to 0.15). The perceived amount of social support was not associated with the probability that cost was discussed. There were no significant interactions.

For clinical interactions that included a cost discussion, the GEE analysis with frequency of cost discussions as the outcome variable found no significant bivariate associations with age or the two aspects of social support. However, a significant interaction was found between patient age and perceived amount of social support that affected the frequency of cost discussions ($B = -0.55$; SE, 0.11; $P < .001$; OR, 26.8; 95% CI, -0.76 to -0.34 ; Fig 1). Among younger patients (-1 SD), a significant positive association was found between perceived amount of social support and frequency of cost discussions (ie, more perceived support, higher frequency of discussions). However, among older patients ($+1$ SD), a significant negative association was found between perceived amount of social support and frequency of cost discussions (ie, more perceived support, lower frequency of discussions).

The GEE analysis of the predictors of time spent in discussion about cost revealed neither age nor either aspect of social support to be significantly associated.

DISCUSSION

To our knowledge, this study is the first to use video-recorded patient-oncologist clinical interactions to identify and code treatment cost discussions. The discussion of cancer treatment

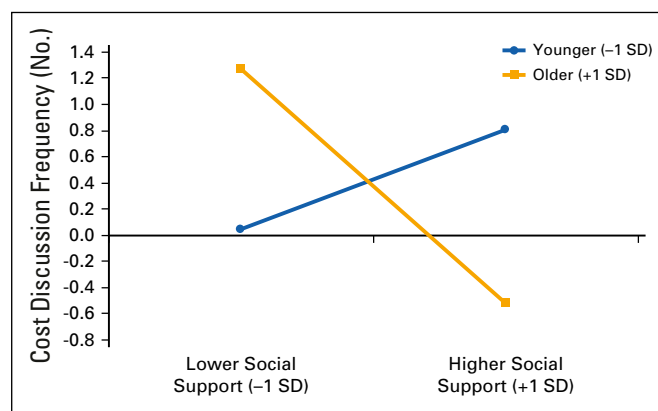


FIG 1. Simple slopes of amount of social support that predicted cost discussion frequency for 1 standard deviation (SD) below the mean age and 1 SD above the mean age.

costs with patients is purported to be a key component of high-quality care¹⁸ and may alleviate financial toxicity.^{5,15-20} Most physicians report that they discuss cost with patients,²³ but a cost discussion occurred in fewer than one half of the clinical interactions observed in this study. Most cost discussions were patient initiated and focused on indirect or opportunity costs of cancer care rather than on the direct costs of treatment. Thus, the treatment-related cost topics that patients discussed were not those considered in the common definition of treatment costs used by the academic and medical communities.^{1,5,17,21}

The Influence of Age and Social Support on Cost Discussions

The reason for the negative association between age and cost discussions is not immediately clear but may involve employment and insurance. The most frequent patient-initiated cost topic was time off from work. Older patients were more likely to be retired and less likely to raise the issue of work in treatment discussions. Furthermore, in the United States, a person is eligible for Medicare at the age of 65 years. Perhaps cost was discussed less in clinical interactions with older patients because of an assumption by the patient or the oncologist that Medicare would cover treatment costs.

Patient-perceived social environment also influenced cost discussions with oncologists. Supportive relationships appear to matter to patients who have limited financial resources and influence their mind-sets when they face the realities of cancer treatment. The majority of patients (73%) reported an annual household income of less than \$40,000; hence, social environment may have created a basis for the salience of treatment-related costs. Perhaps patients were more likely to discuss costs because their family and friends urged them to do so. More research would help to clarify this situation.

For older patients, less perceived amount of social support was associated with more cost discussions, whereas more perceived amount of social support was associated with fewer cost discussions. Perhaps for older patients, a lack of satisfaction with social support prompted them to look to their physician for support with cost issues. Further research will help to elucidate this finding.

Implications for ASCO's Value of Cancer Treatment Options Framework

The topics of discussions observed in this study should be considered in the context of the ASCO Value of Cancer

Treatment Options Framework.^{17,18,21} ASCO's Value Framework weighs clinical benefit and toxicity against cost of treatment and prompts oncologist-patient discussions of treatment value. However, the definition of cost in the framework is limited to a patient's direct expenses (eg, copayments).⁵⁷ Thus many of the cost issues observed in this study would not be taken into account within the framework. This is a particular concern for minority patients who are especially vulnerable to financial toxicity caused by direct^{11,31,33} and indirect financial demands of a cancer diagnosis.³²

Limitations and Future Research

These data and conclusions must be considered within the limitations of the study, which was a secondary analysis of larger study of patient-oncologist communication that was not specifically focused on cost discussions. All the patients were African American and more than 90% were female, which limits the generalizability of the findings. However, we believe that information about cost discussions among this understudied population, which is especially vulnerable to financial toxicity, is important. Future research should assess what patients want to know about treatment cost before the interaction, determine which questions were answered, and assess the patient's level of understanding of cost discussions after the interaction. In addition, cost discussion outcomes were solely based on the coders' observations because corroborative patient self-report data were unavailable. Finally, patient insurance status may play a role in cost discussions, but because of national-level insurance changes during data collection (ie, the Patient Protection and Affordable Care Act), insurance data that could be meaningfully mapped onto the cost outcomes could not be collected.

In conclusion, cost discussions occurred in fewer than one half of cancer treatment clinical interactions with African American patients; they often were patient initiated and focused mainly on taking time off from work. The discussions were not focused on cost per ASCO's Value Framework definition. The findings highlight that African American patients are not a homogenous group^{58,59} because patient age and perceived amount of and satisfaction with social support played a role in the presence and frequency of cost discussions. Interventions to educate patients to ask questions about cost and train providers to sensitively and appropriately initiate cost discussions with all patients are critical steps toward more-informed patients, more-informed treatment decisions, and the potential for less financial toxicity.^{2,17,18,60} JOP

Acknowledgment

Supported by Blue Cross Blue Shield of Michigan Foundation Investigator Initiated Award 2063.ii (L.H., principal investigator); National Institutes of Health, National Cancer Institute grant U54CA153606 (T.A., principal investigator; R.C., co-principal investigator); and National Cancer Institute Center grant P30CA22453 (G.B., principal investigator). Presented at the ASCO Quality Care Symposium, Phoenix, AZ, February 26-27, 2016.

Authors' Disclosures of Potential Conflicts of Interest

Disclosures provided by the authors are available with this article at jop.ascopubs.org.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Do Patients and Oncologists Discuss the Cost of Cancer Treatment? An Observational Study of Clinical Interactions Between African American Patients and Their Oncologists

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or ascopubs.org/journal/jop/site/misc/ifc.xhtml.

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No relationship to disclose

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