



The DISCO App: A pilot test of a multi-level intervention to reduce the financial burden of cancer through improved cost communication[☆]



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ABSTRACT

Objective: Financial toxicity affects 30–50% of people with cancer in the US. Although experts recommend patients and physicians discuss treatment cost, cost discussions occur infrequently. We pilot-tested the feasibility, acceptability and influence on outcomes of the Discussions of COst (DISCO) App, a multi-level communication intervention designed to improve cost discussions and related outcomes.

Methods: While waiting to see their physician, patients ($n = 32$) used the DISCO App on a tablet. Physicians were given a cost discussion tip sheet. Clinic visits were video recorded and patients completed pre- and post-intervention measures of self-efficacy for managing costs, self-efficacy for interacting with physicians, cost-related distress, and perceptions of the DISCO App. Coders observed the recordings to determine the presence of cost discussions, initiators, and topics.

Results: Most patients reported needing ≤ 15 min to use the DISCO App, and that it made it easier to ask cost-related questions. Findings showed increased self-efficacy for managing treatment costs ($p = .02$) and for interacting with physicians ($p = .001$). All visits included a cost discussion.

Conclusions: Prompting patients to discuss costs may improve cost treatment discussions and related outcomes.

Innovation: An app-based and tailorable treatment-cost communication intervention is feasible, acceptable, and demonstrates promise in prompting cost discussions and improving outcomes.

Trial registration: Clinical Trials.gov registration number: NCT03676920 (September 19, 2018).

1. Introduction

Financial toxicity, the severe material and psychological burden of the cost of cancer treatment, affects an estimated 30–50% of patients with cancer in the United States, including people with health insurance [1]. As the cost of care increasingly shifts to patients, more patients must use up their savings, incur debt and file for bankruptcy [2–7]. On average, cancer patients are responsible for \$16,000 annually for direct and indirect out-of-pocket treatment costs [8]. Patients may also suffer great psychological harm, including significant, even catastrophic, levels of cost-related distress [9–13].

Cancer treatment cost and financial toxicity can influence treatment decisions, treatment adherence, and health outcomes, including an increased

risk of mortality [1,14–20]. Treatment costs factor into patients' decisions about treatment [21–24], including whether to participate in clinical trials [22,25]. For example, patients with lower incomes are more likely to choose treatments with lower costs even if those treatments have lower survival and higher toxicity [23]. To offset cost, patients may deviate from recommended treatment (including treatment for side effects) [15,26,27] and/or forgo treatment altogether [24]. A study of 254 patients being treated with either chemotherapy or hormonal therapy found that 20% took less than, partially filled, or avoided filling the prescribed medication due to the out-of-pocket costs [15]. Another study of 164 patients with solid tumors found that 45% were non-adherent to treatment due to cost [28]. A study of 1556 cancer survivors found that those who reported financial problems were more likely to delay

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(18.3% vs. 7.4%) or forgo treatment (13.8% vs. 5.0%) than respondents without financial problems [29].

Addressing financial toxicity requires policy changes at the national, state, and hospital levels. In the meantime, however, patient-physician treatment cost discussions early in diagnosis and treatment may help alleviate financial toxicity [10,14,30-33] by improving patients' knowledge of and how to manage potential costs, and by connecting patients with vital economic support early in the treatment process [34]. Most patients (80%) and oncologists (80%) want to discuss treatment costs [35,36], and professional organizations such as the American Society of Clinical Oncology (ASCO) encourage oncologists to discuss treatment cost with patients. However, observational research has found that these discussions are infrequent [36,37]. In our previous observational study of video-recorded treatment discussions between patients with cancer and their oncologists ($n = 103$), we found that cost discussions occurred in only 45% of treatment discussions [38]. When cost was discussed, it was mostly patient-initiated (63%) and focused more on indirect costs (e.g., time off work) than on direct costs (e.g., copayments) [39]. Without a cost discussion early in treatment decision making, patients are unlikely to be referred for guidance or assistance in a timely manner, thereby missing out on early financial and psychological support, which are critical steps in reducing longer-term financial toxicity [15,34,40] and improving treatment adherence [10,28,41].

Question prompt lists (QPL) are simple communication tools that have been shown to prompt discussion about specific topics during clinical interactions. QPLs are composed of a list of questions provided to patients to encourage them to prepare for visits by considering questions they would like to ask their healthcare provider [42-44]. QPLs have been shown to improve communication quality (e.g., patient active participation in interactions [45], patient-oncologist information exchange [46], topics discussed [47]), patient psychological and cognitive outcomes (e.g., satisfaction, anxiety; information recall) [42], and patient role in treatment decisions and trust in their oncologist [42,44,48].

However, most current QPLs are limited in two ways: they do not adequately address treatment costs, and most are paper-based and static. Although a few previous QPLs and similar interventions have been tailorable, tailorable QPLs have been not previously been used in the context of treatment cost communication or financial toxicity [49]. An electronic, cost-focused QPL

in the form of an application or “app” provided to patients in the clinic prior to meeting with their physician may overcome these limitations.

Building on our experience with testing QPLs in oncology outpatient clinics [45,50], we designed and built a novel multi-level communication intervention, including the DIScussion of COst Application for patients (DISCO App; Fig. 1) [51] and an accompanying treatment cost tip sheet for physicians (Fig. 2).

The purpose of this study was to pilot-test the intervention in an oncology clinic setting to determine its feasibility, acceptability, and influence on outcomes of interest, including: patient-physician treatment cost discussions during treatment discussions, patients' self-efficacy for managing treatment costs, patients' self-efficacy for interacting with physicians, and patients' treatment cost-related distress.

2. Methods

2.1. Intervention

We designed a multi-level communication intervention to prompt treatment cost discussions between patients and physicians. Although the intervention was focused primarily on patients, research has suggested that physician attitudes and behavior may present barriers to cost discussions because physicians may be uncomfortable or unable to respond appropriately to patient questions about treatment cost [52,53]. To address this, at baseline, we provided physicians a treatment cost discussion “tip sheet.” The tip sheet emphasizes physicians' role in cost discussions (as recommended by ASCO) and suggests ways to overcome identified barriers to cost discussions [36,37,52,53]. The tip sheet also acknowledges the complexities of treatment costs by including statements such as “if a patient asks about cost and you do not know the answer, you can simply say: ‘I'm glad you brought this up, because it's important for me to know what concerns you have about your treatment. I'm not an expert in this area, but if you have questions about costs, I can arrange for you to meet with a social worker who can help after we're done here.’”

For patients, the DISCO App (Fig. 1) [51] is displayed on an iPad provided just prior to their second interaction with their physician, in which they discuss and finalize treatment plans. The DISCO App opens and the

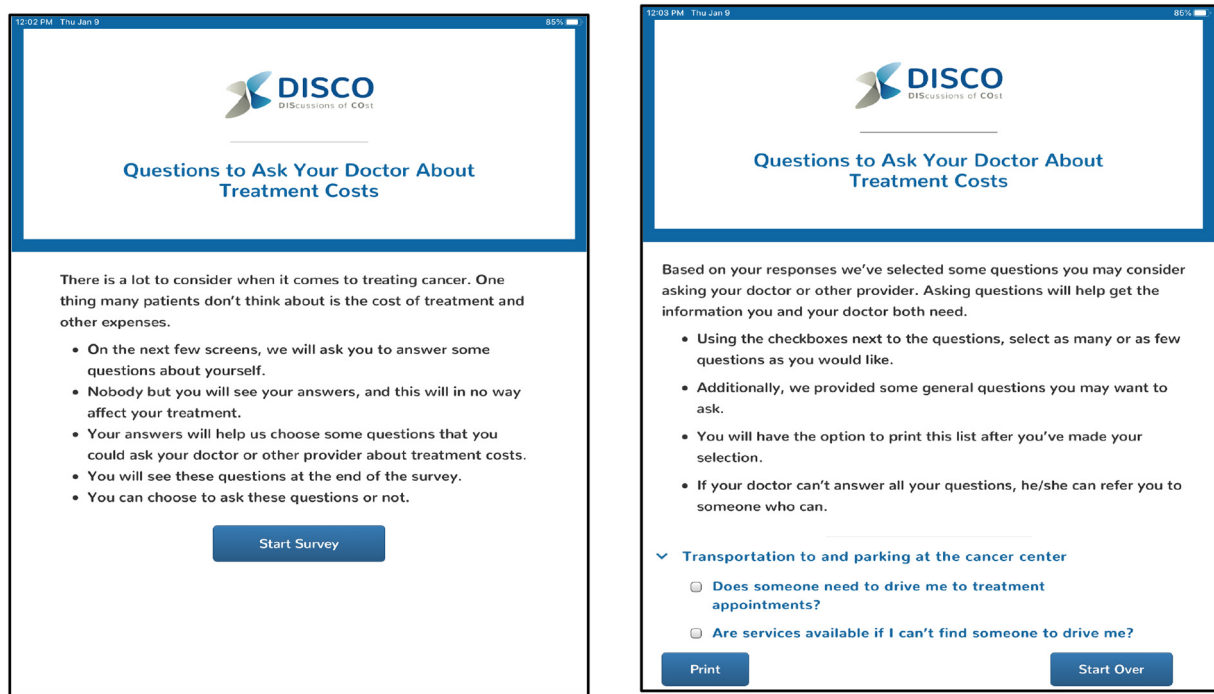


Fig. 1. DISCO App QPL Introduction Screens.

DISCO
Discussions of Cost
Tip Sheet for Oncologists

Reasons to Discuss Treatment Cost with Patients

- Discussing cost concerns, especially early on in treatment, can help patients and oncologists make better treatment decisions and help identify which patients could benefit from referral to a social worker or financial navigator.
- Most patients want to discuss cost with their treating physicians and are comfortable being referred to a social worker or a financial navigator, who are often better equipped and positioned to assist patients with more in-depth financial issues.
- Major oncology professional organizations, including ASCO and NCCN, encourage oncologists to include cost in their treatment discussions with patients.

Barriers and Responses

- **Barrier:** *Oncologists may not know how to address patients' cost concerns.*
Response: Oncologists do not need to have all the answers. Many cost-related issues cannot be addressed in a single discussion. The best thing to do is to acknowledge your patients' questions and concerns and then refer them to a social worker or a financial navigator if they need more help.
- **Barrier:** *Cost discussions take too long during treatment discussions.*
Response: Karmanos research shows that cost discussions typically last less than a minute. For patients needing more information, a referral to a social worker or a financial navigator can be made. Discussing cost now, may save you time in the future.

Barriers and Responses

- **Barrier:** *Patients may feel uncomfortable discussing cost.*
Response: 80% of patients surveyed want to discuss treatment cost, at least initially, with their physician. Then, they are amenable to discussing cost with other providers.
- **Barrier:** *Patients may be concerned that a less expensive treatment may be less effective.*
Response: As an oncologist, you are in the unique position to inform patients of the effectiveness of different treatment options and weigh that against toxicity and cost. See the ASCO Value of Cancer Treatment Options Framework for more information.

Communication Tips

- **Patient:** *"I am worried I can't afford what my insurance won't cover."*
Response: "I'm glad you brought this up because it's important for me to know what concerns you may have about your treatment. If you have questions about your insurance or other costs, I can refer you to someone who can help after we're done here."
- **Patient:** *"Will I be able to work during my treatment?"*
Response: "Many of my patients work during treatment, but some prefer not to. A lot will depend on how you feel once the treatment gets started. Then, we can try to work your treatment schedule around your job."
- **Patient:** *"Do I need someone to drive me to treatment? Do I need to pay for parking?"*
Response: "It may be helpful to have someone available to drive you to appointments. If you have concerns about transportation or parking costs, our social work team may be able to provide you with information to help."

As an oncologist, you are your patients' best advocate for all aspects of their treatment, including helping them understand treatment costs.

Karmanos
CANCER INSTITUTE
Wayne State University

Fig. 2. Physician Tip Sheet.

QPL is introduced with text that explains that the DISCO App includes a short survey, which will lead to some cost-related questions the patient can consider asking the physician. This section asks patients to enter their demographic information and their financial circumstances. Specifically, patients respond to 17 questions, such as “How much do you know about your insurance coverage?”; “Are you currently employed?”; “Is there anyone who helps you when you're sick or need help of any kind?”. Based on patient responses, an individually-tailored QPL with up to 18 cost-related questions in 7 categories is generated (Table 1). For example, patients who indicate they are employed will be prompted to ask: “Can I schedule my treatment around my job?”; patients who indicate transportation concerns will be prompted to ask: “Are services available if I can't find someone to drive me?” Patients who indicate they are unfamiliar with their insurance coverage will be prompted to ask: “Is there someone I can talk to about my insurance and treatment cost questions?” All patients, regardless of their responses, are provided with four general questions about their diagnosis and have the option of adding in any of their own questions. Once they have completed the questions and received their individualized QPL, they can take the iPad or a printed question list into the meeting with the physician.

2.2. Participants and setting

Data were collected in two outpatient community clinics affiliated with Wayne State University (WSU)/Karmanos Cancer Institute (KCI) located in Southeast, Michigan from August 2018 to December 2019.

Patients were eligible to participate if they were recently diagnosed with breast, lung, prostate, or colorectal cancer and were scheduled to see a participating radiation oncologist for an initial treatment discussion. We focused on these cancers due to their prevalence in the United States [54]. Radiation oncologists were eligible if they routinely treated patients for breast, lung, prostate, or colorectal cancer. We focused on radiation oncology because radiation treatment is disruptive, expensive, and includes both direct and indirect costs of treatment [55,56]. Given that this was a pilot test of an intervention, we recruited a small convenience sample, which is a common strategy for this type of clinic-based intervention pilot [57].

2.3. Procedure and measures

Upon consent into the study, physicians completed a one-time baseline questionnaire where they provided information on their sex and race/ethnicity, and then received the physician treatment cost discussion tip sheet. After patients were consented, they completed a baseline questionnaire that assessed sociodemographic characteristics and other personal attributes.

Patients arrived up to one hour before their scheduled appointment to complete self-report measures on an iPad through an electronic survey service (Qualtrics). After completing pre-interaction measures, a member of the research staff showed patients the DISCO App on an iPad and provided a brief explanation on how to use it. The iPad was connected to a printer on-site, allowing patients to print their individually-tailored QPL created from the DISCO App for note-taking.

Table 1
The DISCO App's Prompted Questions by Question Type.

| |
|--|
| Cost of appointments and treatments |
| 1. How much will I have to pay for my treatment? |
| 2. Is there a less expensive drug, like a generic, that will be equally effective? |
| 3. How many visits will I have? I may have to pay each time I come to the cancer center (co-pay, parking, etc.). |
| 4. What happens if I can't pay for some of my treatment costs? |
| Help with understanding my treatment costs and what my insurance covers |
| 5. Do I need additional or supplemental insurance coverage? |
| 6. Do I have a co-pay every time I come to the cancer center? |
| 7. Is there someone I can talk to about my questions about my insurance and treatment costs? |
| Transportation to and parking at the cancer center |
| 8. Does someone need to drive me to treatment appointments? |
| 9. Are services available if I can't find someone to drive me? |
| 10. How much does parking cost? |
| Living far from the cancer center |
| 11. Is it possible for me to receive my treatment closer to where I live? |
| 12. Are there free or reduced-cost hotels nearby for me and my family? |
| Working during treatment |
| 13. Can I keep working during treatment? If not, when can I go back to work? |
| 14. Can I schedule my treatment around my job? |
| 15. Do I need to file Family and Medical Leave Act (FMLA) paperwork? If so, how? |
| Assistance programs |
| 16. Are assistance programs available to help me with treatment costs or other expenses or needs? |
| 17. If I need a wig or other supplies, is there somewhere I can get them free or at a reduced cost? |
| Family and living responsibilities |
| 18. Can I schedule my treatment around my family's schedule? |
| General questions about cancer and treatment (all patients will get these) |
| 19. What is my diagnosis and stage? |
| 20. Is it possible to cure my cancer? |
| 21. What is my treatment plan? |
| 22. Are there clinical trials I can participate in? If so, will this cost more or less than standard treatment? |

Each examination room was equipped with unobtrusive digital audio and video devices that recorded the examination room during the clinical interaction. This recording system has been used by the study team for more than 15 years [28,41], and research has strongly suggested that video recording has little impact on participants' verbal or nonverbal behaviors [42] and provides enhanced validity compared with audio recording alone [43].

After the patient-physician treatment discussion, patients completed post-discussion self-report measures. The study was approved by WSU/KCI institutional review board. All patients and physicians provided consent as participants, which included specific permission to be video recorded.

2.4. Feasibility

To assess the feasibility of the DISCO App, patients reported how long it took them to use the DISCO App and research staff collected a copy of the printed question list to determine how many questions patients selected from the DISCO App to be printed for a discussion with their physician. The procedures would be considered feasible if the majority of patients were able to complete using the DISCO App in less than 15 min, and managed the DISCO App with little or no assistance. We also tracked whether any participant refused to be video recorded and/or left the study early.

2.5. Acceptability

To assess the acceptability of the DISCO App, after the clinical interactions, patients completed measures of their perceptions of the DISCO App ("the questions in the DISCO App were easy to understand"; "the DISCO App made it easier to ask my doctor cost-related questions"; "some of the questions in the DISCO App were useful to me as I was talking with my doctor"; "some of the questions in the DISCO App made me uncomfortable") on a Likert scale (1 = strongly disagree to 5 = strongly agree). The DISCO App

would be considered acceptable if the average response to the measures was at the mid-point or above.

2.6. Self-report measures of outcomes of interest

To assess the influence of the intervention on outcomes of interest, patients completed pre- and post-interaction measures of financial toxicity and cost discussion-related outcomes including self-efficacy for managing treatment costs (e.g., how confident are you in your ability to find out how to pay for direct costs that arise with treatment?; 5 = very confident, 1 = not at all confident) [58]; self-efficacy for interacting with physicians (e.g., how confident are you in your ability to know what questions to ask a doctor?; 5 = very confident, 1 = not at all confident) [59], and cost-related distress (e.g., I am concerned about my ability to afford to pay for my cancer treatment; 5 = strongly agree, 1 = strongly disagree).

2.7. Physician and patient interaction coding

To further assess the influence of the intervention, we analyzed video-recorded patient-physician treatment cost discussions using methods from our previous research [38]. Patient-physician cost discussions were broadly defined as verbal discussion of topics related to a monetary expense for the patient for cancer treatment. This includes direct costs such as appointment copayments and indirect costs such as loss of income due to time off work.

Two trained coders observed all video-recorded interactions to identify the presence of cost discussions using a validated coding system, and, when these occurred, the initiator (patient or physician) and the cost topics raised, from a list identified from previous research, including insurance/copayment, out-of-pocket costs, time off from work, transportation/parking, lodging, social work/financial navigation, and scheduling treatment around patient's schedule [38].

Interrater reliability was assessed using 20% of the sample of video-recorded interactions. First, the coders identified the presence of cost discussions and reliability was determined using percent agreement, which was 87.5%. Second, the coders labeled each cost discussion's initiator and topic. Reliability for this phase was determined by Cohen's kappa ($K = 1.0$). Because the high K value suggested high intercoder reliability, the remaining video-recorded interactions were coded by one coder each.

2.8. Data analysis

Data included patient and physician self-report sociodemographics, patient perceptions of the DISCO App, patient self-reported outcome variables, and coder ratings of the video-recorded clinical interactions. We used descriptive statistics to describe the patient and physician participant sociodemographic characteristics, feasibility, acceptability and outcomes of interest. To describe feasibility, we determined how long patients reported using the DISCO App and how many questions patients selected from list the DISCO App created for them. We also determined how many patient and physician participants agreed to have their visits video recorded and if any patients dropped out of the study. To assess acceptability, we determined patients' perceptions of the DISCO App. To assess influence on outcomes of interest, we determined presence, initiator, and topics of any cost discussions that occurred during the video-recorded interactions. We used two-tailed paired samples t -tests to determine any pre- to post-intervention changes in patient self-report outcomes of self-efficacy for managing treatment costs, self-efficacy for interacting with physicians, and cost-related distress. For all analyses α was set at $p < .05$ (two-tailed).

3. Results

Thirty-two recently-diagnosed patients of two of the three participating physicians agreed to participate and are included in the final sample. Most ($n = 30, 94\%$) interactions were video recorded (in two cases technical difficulties prevented recording) and lasted for an average of 25.7 min ($SD =$

5.1 min). The sociodemographic characteristics of patients and physicians are reported in Table 2. Most patients had breast cancer (84%).

3.1. Feasibility

All participants agreed to have their interactions video recorded and completed all procedures for the study. Most patients (84%) reported needing 15 min or less to use the DISCO App, while 13% needed 16 to 30 min, and 3% needed 31 to 45 min. All patients finished using the DISCO App without assistance during the time they were in the exam room and waiting to see their physician. On average, patients selected 6.5 questions from the individualized question prompt list to print, with a range of 1–18 selected questions. We emphasize that the list of questions was individually-tailored so not every patient was presented with all 18 possible questions.

3.2. Acceptability

Patients reported that the questions in the DISCO App were easy to understand (M = 4.5; SD = 0.8); the DISCO App made it easier to ask their doctor cost-related questions (M = 3.8; SD = 0.8); and that some of the questions in the DISCO App were useful to them as they were talking with the doctor (M = 3.8; SD = 0.7). They also reported that the questions

Table 2
Patient and physicians sociodemographics.

| Patients ¹ | Total n = 32 |
|--|--------------------------|
| Age | M = 61.48 (SD = 8.08) |
| Female | 31 (97%) |
| Race/Ethnicity | |
| Caucasian or White/Non Hispanic | 32 (100%) |
| Education | |
| < High School | 1 (3%) |
| Graduated High School | 9 (28%) |
| Some College | 9 (28%) |
| Graduated College | 11 (34%) |
| Post-graduate degree | 1 (3%) |
| Marital Status | |
| Married/Partnered | 20 (63%) |
| Divorced/Widowed/Separated | 9 (28%) |
| Single | 1 (3%) |
| Annual Household Income | |
| 0 - \$19,999 | 4 (13%) |
| \$20,000 - \$39,999 | 6 (19%) |
| \$40,000 - \$59,999 | 14 (44%) |
| \$60,000 - \$79,999 | 8 (25%) |
| Employment | |
| Employed | 12 (38%) |
| Unemployed but looking for employment | 1 (3%) |
| Retired | 14 (44%) |
| Disabled/unemployed for another reason | 5 (16%) |
| Insurance | |
| Medicaid | 8 (25%) |
| Medicare/Supplement | 9 (28%) |
| Private insurance from employer | 13 (41%) |
| Private insurance the patient pays for | 2 (6%) |
| Primary Tumor Site | |
| Breast | 27 (84%) |
| Lung | 5 (16%) |
| Interaction Length (in Minutes) | M = 25.7 SD = 5.1 |
| Physicians (n = 3) | |
| Male | 3(100%) |
| Race/Ethnicity | |
| Caucasian or White | 2 (50%) |
| Asian or Pacific Islander | 1 (50%) |
| Number of participating patients seen | |
| MD 1 | 25 (78%) |
| MD 2 | 7 (22%) |

¹ Some data are missing because of omissions in patients' responses (education and marital status are not available for one and two patients, respectively).

in the DISCO App did not make them feel uncomfortable (M = 4.1; SD = 1.1; this was a reverse-coded item).

3.3. Influence on outcomes of interest

3.3.1. Observed cost discussions

Cost discussions occurred in all 30 of the video-recorded interactions. The number of cost discussions per interaction ranged from 1 to 6, for a total of 97 individual cost discussions across all interactions. Patients and physicians were equally likely to initiate the first cost discussion during a clinical interaction, and the topic most-frequently discussed first was insurance. Physicians were more likely to initiate any subsequent cost discussions. The most frequent patient-initiated topics were insurance followed by time off from work. The most frequent physician-initiated topics were social work/financial navigation followed by insurance (Table 3).

3.3.2. Financial toxicity-related outcomes

We also examined whether the DISCO App influenced other financial toxicity- and cost discussion-related outcomes reported by patients before and after they used the DISCO App and subsequently met with their physician. There were significant pre- (M = 16.17, SD = 6.76) to post- (M = 18.69, SD = 5.07) intervention increases in patients' self-efficacy for managing treatment costs ($t(31) = 2.38, p = .02$) and in patients' self-efficacy for interacting with physicians (M = 40.78, SD = 6.69; M = 43.84, SD = 5.77; $t(31) = 3.86, p < .001$). There was also a non-significant decrease in pre- (M = 3.23, SD = 0.63) to post- (M = 3.09, SD = 0.77) DISCO App use in treatment cost-related distress ($t(31) = 1.28, p = .21$).

As a post-hoc sensitivity test, we conducted Levene's Test of Equality of Variances to determine if there was a physician effect on outcomes. Tests for self-efficacy for managing treatment costs ($p = .15$), self-efficacy for interacting with physicians ($p = .95$), and cost-related distress ($p = .72$) all showed equal variances in outcomes when we included physician.

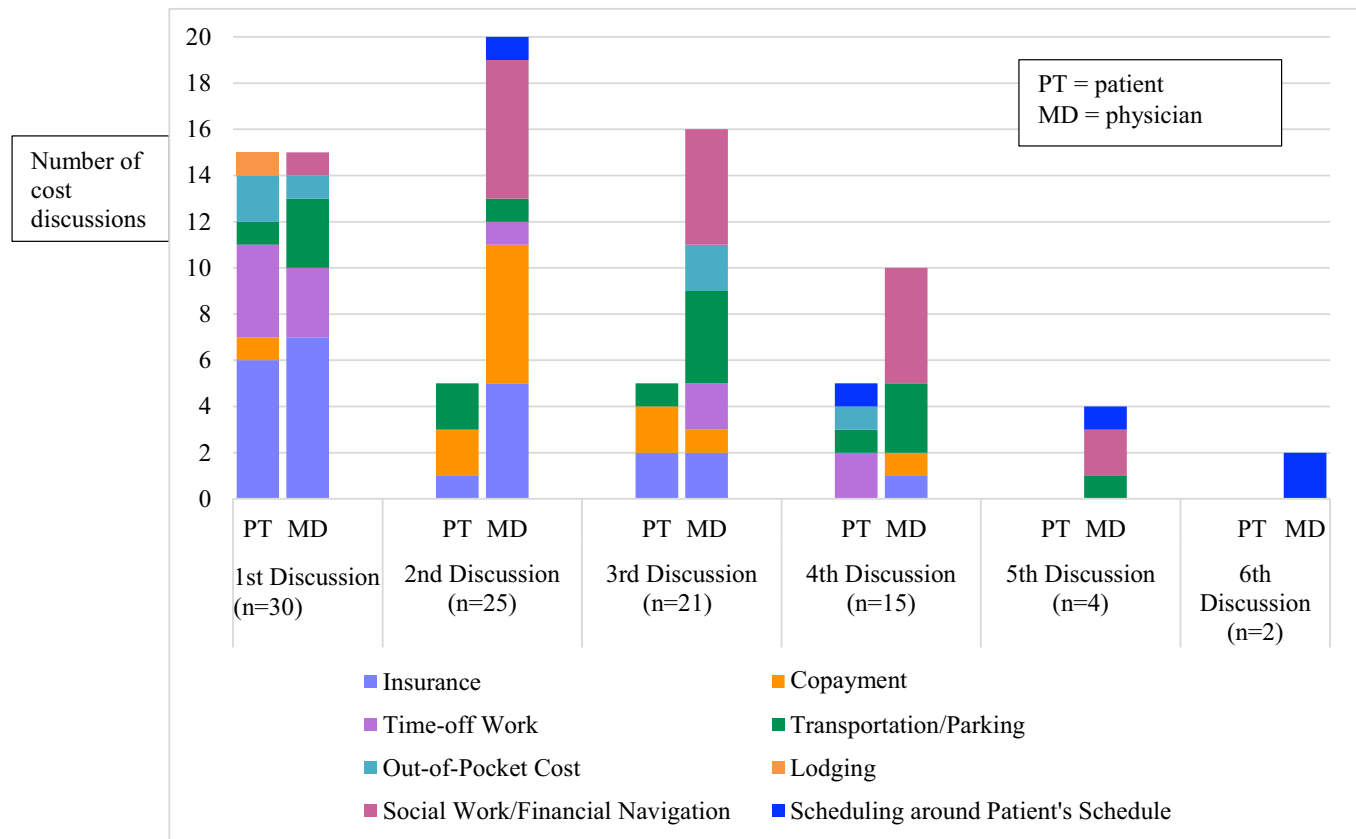
4. Discussion and conclusion

4.1. Discussion

To our knowledge, this study is one of the first to investigate an intervention to prompt patient-physician treatment cost discussions, and to begin to determine if we see the improvements in financial toxicity-related outcomes for patients. In this pilot test, this multi-level intervention appears feasible in a clinic setting and acceptable to patients. Moreover, it appears to influence short-term outcomes, including prompting treatment cost discussions and increasing patient self-efficacy for interacting with physicians and managing costs, which is promising, as improving these may lead to improving longer-term outcomes like the experience of financial toxicity and treatment adherence. It is difficult to discern which of the two parts of the intervention was the most effective, but multi-level interventions are likely to be more effective given the dyadic nature of clinical communication [60,61].

Treatment cost discussions have been identified as one way to help mitigate the deleterious experience of financial toxicity due to cancer treatment by helping to connect patients to important resources earlier on in treatment, and by increasing patients' self-efficacy in managing their treatment costs [10,14,30-34]. In a previous observational study we conducted also using video-recorded treatment discussions, we observed that only 45% of interactions had a treatment cost discussion [38]. Here, we observed that 100% of video-recorded treatment visits had at least one treatment cost discussion, and 70% of treatment discussions had at least three treatment cost discussions. Interestingly, once an initial cost discussion occurred physicians were more likely to initiate subsequent cost discussions in a given interaction. Perhaps this demonstrates that when physicians are prompted by a patient that cost is a concern, they are more likely to continue the discussion. Surprisingly, we observed that physicians would sometimes ask patients for their list of questions and responded to their questions that way, rather than waiting for patients to verbalize their

Table 3
Observed treatment cost discussion by initiator and topic.



questions. This was not part of our planned analyses, but we made note of this as observational data were collected. Additional work is needed to better understand how the presence of the question list produced by the DISCO App influences both the content and quality of cost discussions, and patients' satisfaction with those discussions.

We also see improvements in some self-reported financial toxicity-related patient outcomes, including self-efficacy in managing treatment costs. Of course, our pilot study design does not allow us to conclude with certainty that the DISCO App or cost discussions prompted from it led to those improvements, but these data are encouraging enough to warrant further investigation into the longer-term effects of the DISCO App and treatment cost discussions for patients.

ASCO's Value of Cancer Treatment Options Framework [14] and its Patient-Clinician Communication Guideline [62] both encourage physicians to discuss treatment costs with their patients. Despite these guidelines, however, research has shown that cost discussions infrequently occur, and that physician engagement around cost concerns is an unmet patient need [63]. Many of the cost discussions we observed in the recorded data did not focus on treatment cost as ASCO defines it. ASCO's tools focus exclusively on direct out-of-pocket costs for patients such as copayments or insurance costs [62]. In this study, both patients and physicians initiated discussions about indirect costs for patients (e.g., taking time off from work, transportation to treatment appointments), which can often be just as detrimental to patients as the direct cost of treating cancer [64-67]. We emphasize this here knowing that the distinction between direct and indirect treatment costs may not be experienced by patients, but that this may be evidence that physicians are well positioned to address the indirect cost of care, even if the precise direct cost of treatments remain elusive.

Concern that cost discussions may add time to clinic interactions has been identified as a barrier to discussing cost [68,69]. Recorded interactions in our study lasted an average of 25.7 min, and we did not have a

comparison group to determine if the intervention added time to the treatment discussions. However, data from our own program of research testing similar paper-based QPLs indicated that QPLs do not add a significant amount of time to cancer treatment discussions [45].

Lack of knowledge of the cost of treatment has also been identified as a barrier to providers discussing treatment cost with patients [53]. Our findings, albeit from a small pilot, demonstrate that while both patients and physicians may initiate treatment cost-related discussions, physicians are more likely to follow up with additional topics and discussions. Perhaps this suggests that once a physician knows treatment cost is important to a patient and that the patient is open to discussing cost, the physician is more likely to follow up. Research has shown that, despite the guidelines from ASCO, treatment cost discussions do not occur regularly, perhaps these guidelines coupled with an individualized prompt from an intervention like the DISCO App just prior to meeting with physicians may help these discussions occur with more regularity for patients.

Findings must be considered within the limitations of the study. This was a descriptive, one-arm pilot test using pre-post patient-reported measures and recorded data to assess the DISCO App's feasibility, acceptability, and influence on short-term outcomes. Most patient participants were women with breast cancer, and we did not track patient refusal as a part of our protocol, raising questions about selection bias and limiting the generalizability of the findings [67,70]. Further study with a randomized controlled trial design is needed to assess short and longer-term outcomes, and this research is needed in a diverse patient population with regard to racial/ethnic background, gender, and cancer type.

4.2. Innovation

The DISCO App is innovative because it is among the first of its kind to adapt the QPL, an effective paper-based communication intervention, into an electronic, individually-tailorable, and highly scalable multi-level

communication intervention. Designing a communication intervention in an electronic format is especially innovative as we aim to enhance scalability to diverse patient populations and begin to integrate into electronic medical records and patient portals. Additionally, our study is innovative in its methods which included evaluation of outcomes using rigorous, systematic analysis of video-recorded interactions of patient-physician treatment discussions. This work is contributing to our understanding of the mechanisms through which treatment cost discussions and other aspects of clinical communication improve short- and longer-term patient outcomes related to financial toxicity.

4.3. Conclusion

In conclusion, we found the DISCO App to be feasible and acceptable in a clinic setting and potentially effective at prompting treatment cost discussions between patients and physicians and improving other patient outcomes related to financial toxicity. We note here that these findings provided preliminary evidence supporting a larger test of the DISCO App. The effectiveness of an enhanced version of the DISCO App on short- and longer-term patient outcomes, including patient-physician treatment cost discussions, is currently being tested in a randomized controlled trial with a diverse patient population (RSG-20-026-01-CPHPS, Hamel, PI) [71].

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Declaration of Competing Interest

None.

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