



How Do You DISCO?



Leveraging the Discussions of Cost App to reduce financial toxicity and improve treatment cost communication

The *Discussions of Cost* (DISCO) application (app) is a scalable and individualizable patient-focused intervention designed to prepare patients for their treatment-related costs and help reduce the burden of these costs. Newly introduced at the Karmanos Cancer Institute in Detroit, Mich., the app was built in partnership with cancer survivors and clinicians in response to the mounting evidence that patients with cancer are unprepared when treatment costs arise, resulting in what is termed as “financial toxicity” or the severe burden of treatment-related costs. Up to 50 percent of patients with cancer experience financial toxicity.¹⁻⁵ Some of these patients forego treatment due to cost. Many experts argue that treatment cost discussions between oncologists and patients early in their treatment can help mitigate financial toxicity by facilitating patient access to financial assistance and other resources. Unfortunately, research has shown that such discussions are rare, engagement around treatment costs is an unmet patient need, and opportunities to connect patients with support and resources are being routinely missed. In response to these findings, we developed the DISCO App to educate patients with cancer about their potential treatment-related costs and prompt them to discuss these costs with their oncologist(s) using questions tailored to their specific situation.

Patients with lower incomes are more likely to choose treatments with lower costs even if those treatments have lower survival and higher toxicity.²⁴ To offset costs, patients may deviate from treatment, including prescriptions for side effects,^{3,28,29} and/or forgo treatment altogether.²⁵

What is Financial Toxicity?

Financial toxicity—the severe material and psychological burden brought on by the costs of cancer treatment—affects an estimated 30 percent to 50 percent of patients.¹⁻⁵ As cancer treatment costs escalate⁶ and the cost burden increasingly shifts to patients,⁷⁻¹⁰ more patients are experiencing severe economic consequences.

Across cancer types, patients are, on average, responsible for \$16,000 in out-of-pocket direct and indirect treatment-related costs annually.¹¹ People with cancer are 2.6 times as likely as people without cancer to file for bankruptcy.^{12,13} Recent studies on survivors of breast cancer found that 24 percent used all of their savings over 6 months to pay for their treatment,¹⁴ and 62 percent of survivors of colorectal cancer incurred debt to pay for treatment, with an average liability of \$26,860.¹⁵ Financial toxicity can also result from indirect costs, such as loss of income. Breast cancer survivors reported losing an average of 42 workdays per year, which translated to an average of \$8,236 in lost wages.¹⁶ Treatment costs can also have deleterious psychological effects, with almost half of survivors reporting significant, even catastrophic, levels of cost-related distress.¹⁷⁻¹⁹ The consequences of financial toxicity can be both short term (during diagnosis and treatment) and long term (into survivorship).^{1,19,20}

Influence on Treatment Adherence and Patient Outcomes

Cancer treatment costs and related material and psychological burden influence treatment recommendations,²¹ treatment decisions,²²⁻²⁵ adherence,^{1,3,20,25} and mortality.²⁶ A majority of oncologists report that anti-cancer drug costs (56 percent) and patient out-of-pocket costs (84 percent) influence their treatment recommendations.²¹ Costs also influence patients' treatment decisions,²²⁻²⁵ including whether to participate in clinical trials.^{23,27} Patients with lower incomes are more likely to choose treatments with lower costs even if those treatments have lower survival and higher toxicity.²⁴ To offset costs, patients may deviate from treatment, including prescriptions for side effects,^{3,28,29} and/or forgo treatment altogether.²⁵ A study of 254 patients being treated with either chemotherapy or hormonal therapy found that 20 percent of patients took less than the prescribed amount of their medication, partially filled, or avoided filling prescriptions due to their out-of-pocket costs.³ Another study of patients being treated for solid tumors found that 45 percent of patients were non-adherent to treatment due to its costs.²⁰ A study of 1,556 cancer survivors found that those who reported financial problems were more likely to delay (18.3 percent vs. 7.4 percent) or forgo treatment (13.8 percent vs. 5 percent) compared to respondents without financial problems.³⁰ In a study of more than 22,000 patients with early-stage breast cancer, higher co-payments were associated with greater non-adherence to treatment by Medicare and non-Medicare patients. Indirect costs (e.g., travel costs and time) also reduce the likelihood of receiving or completing treatment.³¹ Severe financial distress resulting from cancer treatment may itself be a mortality risk factor.²⁶

Health insurance, whether public or private, does not protect patients against financial toxicity.¹⁴ The American Cancer Society conducted a national poll of more than 1,000 adults who reported that they or a member of their household had cancer or a history of cancer.⁴ Regardless of insurance, 20 percent of respondents had difficulty paying for basic necessities, 15 percent used up all or most of their savings, and 11 percent incurred thousands of dollars in debt due to treatment expenses. This survey found that

26 percent of respondents who were insured during their cancer diagnosis and treatment experienced problems with their insurance coverage.⁴ A study of 10,000 patients with Medicare or private insurance found that higher co-payments were related to prematurely stopping oral chemotherapy.³²

Inequities in the Burden of Financial Toxicity

The burden of financial toxicity is a health equity issue, disproportionately affecting patients who are of racially and/or ethnically marginalized groups,^{15,33-36} have lower incomes,^{13,15,18,34} and/or are 65 years of age and older.^{13,26,34} Compared to White patients with cancer, Black patients with cancer are twice as likely to deviate from treatment, have utilities turned off, and move out of their homes because they cannot afford to pay for their treatment and living expenses.³³ Black survivors are more likely to report treatment-related debt (15 percent) than White survivors (9 percent). Lower-income Black patients with breast cancer spend a greater proportion of their income (27 percent to 31 percent) on treatment-related expenses compared to lower-income White patients (9 percent to 13 percent).³⁴ Across all races, survivors of cancer are 1.4 times as likely to be unemployed—often due to extended time off for treatment/recovery—as people without cancer, and survivors from racially or ethnically marginalized groups are twice as likely to be unemployed than White cancer survivors.³⁷ The disproportionate burden of financial toxicity experienced by historically marginalized groups remains even when controlling for employment status and insurance status at diagnosis.^{34,35} Younger patients (less than 65 years old) are also at greater risk for financial toxicity and bankruptcy than older patients, mainly due to insurance status (i.e., Medicare).²⁶

Treatment Cost Discussions May Help Reduce Financial Toxicity

Including costs as a topic when patients and oncologists discuss treatment plans could help prepare patients to manage their treatment-related costs. A major contributor to the burden of financial toxicity is that patients are often not aware of the potential costs they may incur during treatment and survivorship and how to manage those costs.^{2,38-41} Treatment cost discussions between oncologists and patients could improve patients' knowledge of what costs to anticipate^{2,38,40-42} and connect patients with vital financial resources.⁴³ Most patients want to discuss costs with their physicians.⁴⁴⁻⁴⁶ However, a rich body of research shows that cost discussions occur infrequently.⁴⁷⁻⁴⁹ For example, a study of video-recorded treatment discussions ($n = 103$) found that speaking on costs occurred in only 45 percent of these discussions. When costs were discussed, it was usually initiated by patients (63 percent) and focused more on potential indirect costs (e.g., time off work) than on direct costs (e.g., co-payments).⁴⁷

In an attempt to increase patient awareness and communication about cancer-related costs, the American Society of Clinical Oncology (ASCO) developed tools, including ASCO Answers: Managing the Cost of Cancer Care,⁵⁰ the ASCO Value Framework,² and Patient-Clinician Communication: ASCO Consensus Guideline.⁵¹ These materials are intended to educate patients on

the types of treatment-related costs they may incur, to encourage physicians to discuss patient cost concerns directly, and to refer patients to a social worker or financial navigator if needed. Unfortunately, ASCO's current materials are static and text-heavy and do not provide patients with specific actions they can take to manage their costs. Though these tools encourage discussions, the guidelines are overly general and do not provide patients and physicians with specific strategies to initiate such discussions.

Improving an Effective Clinical Communication Intervention

Question prompt lists are communication tools designed to enhance patients' active participation in interactions with their physicians. These tools list questions that patients might consider asking their healthcare provider during a clinical interaction⁵²⁻⁵⁶ and are shown to improve a patient's:

- Active participation in interactions⁵⁷
- Psychological outcomes (e.g., anxiety)⁵⁸
- Cognitive outcomes (e.g., information recall)⁵²
- Report of their role in treatment decisions⁵³
- Trust in their oncologist.^{52,54,55}

Question prompt lists have also successfully increased patients' active participation, particularly among Black patients with cancer as they discuss treatment with their oncologists.⁵⁷ However, most are limited in two ways: 1) question prompt lists do not adequately address treatment-related costs and 2) most are paper-based and static. Although a few question prompt lists and similar interventions are tailorable, these tools have not been used in the context of treatment-related cost communication or financial toxicity.⁵⁹ A cost-focused question prompt list in the form of an application or "app" provided to patients in the clinic prior to meeting with their physician may overcome these limitations.

Dr. Hamel brought the idea of an app-based question prompt list to her mentor and collaborator, Dr. Eggle. Drs. Hamel and Eggle are both experts in communication science, with a focus on improving patient-clinician communication to reduce health disparities. Dr. Eggle has led the design and testing of several paper-based question prompt lists in diverse patient populations and clinical settings. Using their expertise, together they sketched out a basic idea and plan for an app-based tool devoted to cancer treatment-related costs.

The study team is based at Wayne State University and the Karmanos Cancer Institute, a National Cancer Institute-designated comprehensive cancer center located in Detroit, Mich. To continue to develop and test the DISCO App, Dr. Hamel leveraged her professional network, institutional funds, and resources. Specifically, Dr. Hamel had established partnerships with:

- Karmanos Cancer Institute's Detroit Healthlink Cancer Action Councils⁶⁰
- Oncologists and social workers from Karmanos Cancer Institute and the Dana-Farber Cancer Institute
- The University of Michigan's Tech Transfer Program
- CrossComm, a mobile application development firm that builds custom apps.

The Cancer Action Councils are racially diverse groups of community members and include many cancer survivors. Several individual council members met one-on-one with Dr. Hamel to go through the wireframe of the DISCO App. This was a critical stage in the app's development because it helped ensure that the tool was acceptable and useful for the people who need it most—patients. Subsequently, Dr. Hamel had several one-on-one meetings with practicing oncologists, social workers, financial navigators, and administrators. This stage helped ensure that the app meet the needs and requirements of the health system in which it would ultimately be implemented. With feedback on content and format from Cancer Action Council members, oncologists, and social workers, Dr. Hamel worked with the University of Michigan's Tech Transfer Program and CrossComm to build the DISCO App.

Preliminary Version of the DISCO App

The first working version of the DISCO App included a treatment-cost focused question prompt list, which provided individually tailored questions to patients. The question prompt list is introduced with the following text, "There is a lot to consider when it comes to treating cancer. One thing many patients don't think about is the cost of treatment and other expenses." The text continues to explain that the DISCO App includes a short survey, which will lead to some cost-related questions the patient can consider asking their oncologist. This section asks patients to enter their demographic information and their financial characteristics. Specifically, patients respond to 17 questions (e.g., 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 patients' responses, the app then generates an individually tailored question prompt list with up to 18 cost-related questions within 7 categories (Table 1, page 26). 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 that 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 are provided with four diagnosis questions (e.g., What is my diagnosis?), have the option of adding in any of their own questions, and can then either take the iPad or a printed question list into the meeting with their oncologist.

To test acceptability and readability of this version of the DISCO App, Dr. Hamel recruited an expert panel of 12 members, including cancer survivors, oncologists, and social workers.⁶¹ The majority ($n = 10$) of panel members found the DISCO App acceptable and likely useful for patients to prompt treatment-related cost discussions between oncologists and patients and for patients to gain important treatment-related information.

However, seven panel members were concerned that oncologists may be unprepared to answer some questions. To address this, a panel member suggested including a tool that would help prepare

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

Cost of appointments and treatments
<ol style="list-style-type: none"> 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
<ol style="list-style-type: none"> 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
<ol style="list-style-type: none"> 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
<ol style="list-style-type: none"> 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
<ol style="list-style-type: none"> 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 paperwork? If so, how?
Assistance programs
<ol style="list-style-type: none"> 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
<ol style="list-style-type: none"> 18. Can I schedule my treatment around my family's schedule?
General questions about cancer and treatment (all patients will get these)
<ol style="list-style-type: none"> 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?

oncologists for such discussions. The resulting tip sheet emphasizes oncologists' role in cost discussions (as encouraged by ASCO) and provides ways to overcome identified barriers to cost discussions.⁶²⁻⁶⁵ The tip sheet acknowledges the complexities of treatment costs by including statements like, "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.'" The tip sheet is designed as a two-sided, tri-fold document that fits in physicians' white lab coats (Figure 1, page 28).

Clinic-Based Pilot Test

After revising the DISCO App based on feedback from the expert panel, the app was pilot tested for feasibility and preliminary effectiveness in two Karmanos Cancer Institute outpatient clinics. Oncologists ($n = 3$) and patients ($n = 32$) newly diagnosed with breast (94 percent) or lung (6 percent) cancer agreed to participate. Physicians received the tip sheet when they consented to participate

in the study. Patients who agreed to participate were invited to use the DISCO App on an iPad and print their question prompt lists while they waited to see their oncologist. Clinic visits were video recorded for later analysis. Patients completed pre- and post-interaction surveys.

Analysis of patient surveys showed significant pre- to post-intervention increases in patients' self-efficacy for managing treatment-related costs ($p = 0.01$) and for interacting with their oncologists ($p = 0.001$). There was also a promising trend toward decreased patient distress. Patients reported that the DISCO App was easy to understand (mean = 4.5 out of 5) and useful as they talked with their doctor (mean = 4); 84 percent of patients reported needing less than 15 minutes to use the DISCO App, and all patients were able to use the DISCO App in the time that they were waiting for their oncologist. On average, patients selected 6.5 out of the 18 possible questions to print.

Most interactions (94 percent) were video recorded; in two cases, technical difficulties prevented recording. Analysis by trained observers showed that all ($n = 30$, 100 percent) of the video-recorded interactions included a cost discussion, and 23 (77 percent) included multiple cost topics. The most frequently discussed topics were insurance, time off from work, and social work and/or financial navigator referrals, which suggested an immediate and direct benefit of the DISCO App. Taken together, findings from this pilot test suggest that the DISCO App is feasible, acceptable, and effective for improving outcomes.^{66,67}

Current Version of the DISCO App

The DISCO App was later revised, based on further feedback from researchers and clinicians (Figure 2, page 29). The current version of the DISCO App includes a brief treatment cost educational video in addition to the original individually tailorable question prompt list. The DISCO App now opens with an introduction screen. Patients watch a 3-minute educational video featuring a communication scientist, medical oncologist, and a patient using the app. The video summarizes the types of treatment costs patients may incur (e.g., co-payments, transportation and/or parking costs, time away from work) and ways to manage those costs (e.g., talk with an oncologist or social worker, contact pharmaceutical companies, seek clarification from insurance providers). The video ends by emphasizing to patients that the best way to start managing treatment-related costs is to discuss them with their oncologist, who can answer their questions or refer them to someone who can assist. After the video, patients are presented with instructions on how to use the question prompt list and are asked to enter their demographic information and their financial characteristics. The DISCO App then uses those responses to produce an individually tailored list of cost-related questions, just as it did in the original version of the app. Thus, the DISCO App provides patients with specific information about the types of out-of-pocket and indirect costs they may incur while undergoing cancer treatment, specific actions they can take to begin addressing those costs, and a list of cost-focused questions they can take with them to their clinic visit to ask their oncologist. This information and individualized prompting are something few patients with cancer currently receive, on any topic.

Ongoing American Cancer Society-Funded Randomized Controlled Trial

In 2020, the DISCO study team was awarded a five-year research scholar grant from the American Cancer Society to test the effectiveness of the DISCO App on short- and long-term patient outcomes, including patient-physician treatment cost discussions, with a diverse patient population (RSG-20-026-01-CPHPS, Hamel, principal investigator).⁶⁸ White and Black patients from various ages and income levels diagnosed with a solid tumor at a National Cancer Institute-designated comprehensive cancer center in Detroit, Mich., will be randomized to intervention or usual care study arms. All patients will have up to two interactions with their oncologist video recorded and complete measures at baseline; after the recorded interactions; and at 1, 3, 6, and 12 months after the second interaction. If effective, the DISCO App will improve awareness of and discussions of treatment-related costs and alleviate the burden of financial toxicity. It may be especially helpful to groups disproportionately affected by financial toxicity, including Black patients, younger patients, and patients with lower incomes, thus helping to improve health equity.

We expect the intervention may need reinforcement to influence long-term outcomes (e.g., financial toxicity, treatment adherence, and clinic appointment adherence). Thus, we are testing the use of individually tailored emails with information from the DISCO App. Half of the intervention patients will receive an intervention “booster,” comprising an email reminding them of the questions they selected and that treatment costs can be discussed with their oncologist.

Innovation in Action

The DISCO App is innovative because it is among the first of its kind to adapt the question prompt list, an effective paper-based communication intervention, into a digital, individually tailorable, and highly scalable multi-level communication intervention. Designing a communication intervention in a digital format is especially innovative as we aim to enhance scalability to diverse patient populations and begin to integrate into electronic health records (EHRs) and patient portals. Additionally, our study is innovative in its methods, which included evaluation of outcomes using rigorous, systematic analysis of self-reported patient data, and video-recorded interactions of patient-physician treatment discussions. This work is contributing to our understanding of the mechanisms through which treatment-related cost discussions and other aspects of clinical communication improve short- and long-term patient outcomes related to financial toxicity.

Next Steps

The findings from the clinic-based pilot test of the DISCO App's preliminary effectiveness were encouraging, and the current randomized clinical trial is underway. The DISCO App's design, which was based on rigorous testing and strong collaborations among key stakeholders (i.e., behavioral scientists, cancer survivors, advocates, and providers), promises to be effective in the short and long term for a diverse population of patients. However, a multi-level design may increase the effectiveness of the DISCO App. Steps toward this goal include designing an enhanced and

Figure 1. Oncologist Tip Sheet, Front and Back

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.

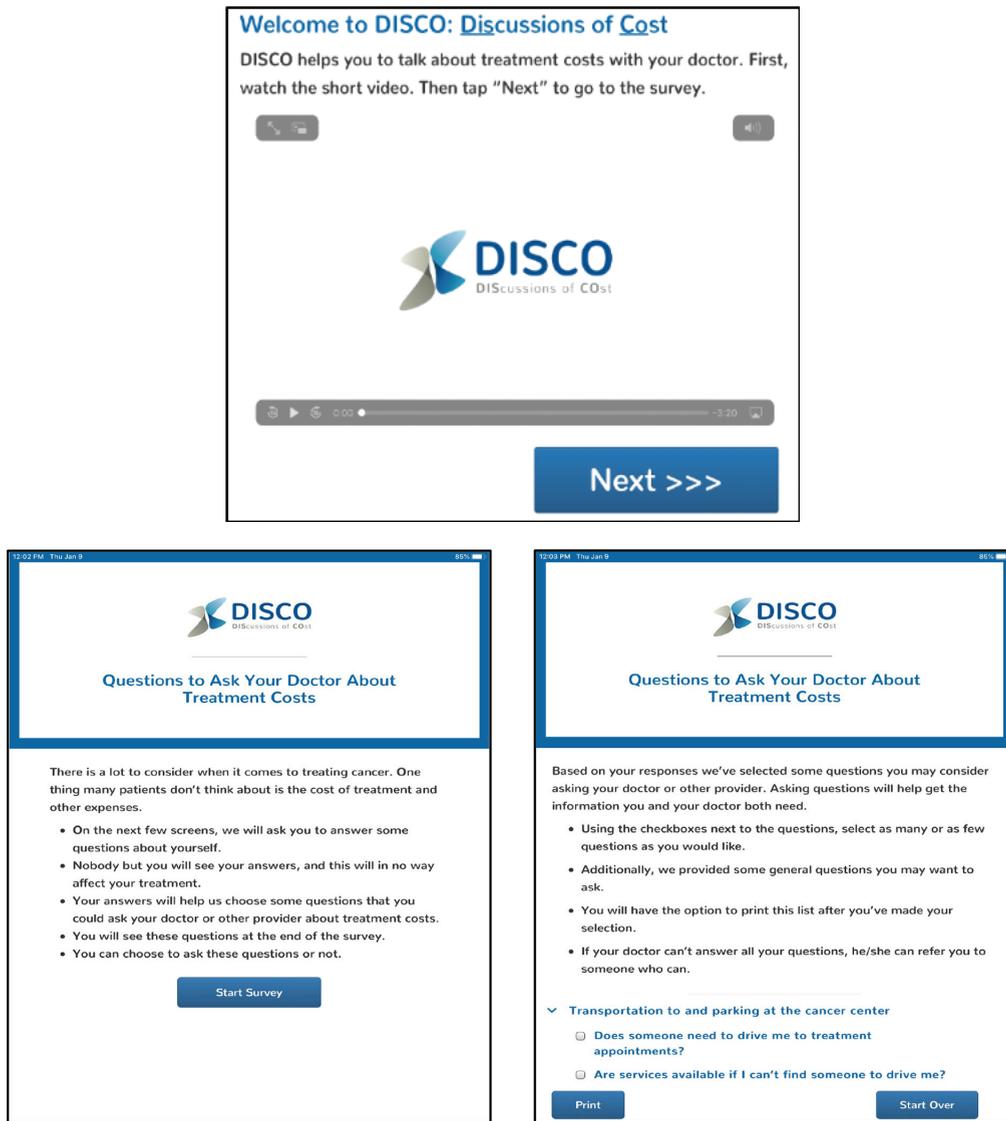
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web-based treatment cost discussion training module for clinicians, such as physicians, nurses, social workers, and other advanced practice providers. Although physicians are the primary source of treatment information, nurses, social workers, and advanced practice providers all need to be prepared to discuss costs because they are also important sources of information for patients. Most patients (80 percent) want to start cost discussions with their physicians, but most (74 percent) are also amenable to discussing costs with other providers subsequently.^{44,45,65} Optimally, a cost discussion with a physician could prompt a referral to another provider who may be better positioned to assist.^{2,41,69,70,43} The physician would be aware of patients' cost concerns, could provide an initial response, and could adapt treatment plans, if possible, while allowing other members of the cancer care team to provide direct assistance. Therefore, this module focuses on preparing the healthcare team to give timely, accurate, and useful information to their patients with cancer.

More improvements include developing the DISCO App for non-English-speaking patients. In Detroit, where the app is being tested, more than 10 percent of the population of the city primarily speaks a language other than English. Thus, it is imperative that we adapt the app for other languages.⁷¹

Another opportunity lies in the integration of the DISCO App into the EHR. This integration would allow providers to document when they discuss treatment-related cost issues with their patients and perhaps provide a foundation for a real-time method of connecting patients with available resources through the cancer center or other associated organizations or groups. Additionally, EHR integration may help facilitate matching cost topics to specific treatments that patients may receive, because physicians enter specific treatment plans for the patient into the EHR. As patient-reported outcomes become more standardized, the DISCO App could be incorporated directly into this type of reporting for new patients with cancer and also potentially be integrated with individual insurance plans. 

Figure 2. DISCO App Educational Video and Question Prompt List Introduction Screens



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