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Original Research

Costs matter: The impact of disclosing treatment costs and provider profit on patients' decisions

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ABSTRACT

Background: Treatment costs and profits are rarely considered when making treatment decisions despite trends to shift costs directly onto patients. We sought to understand whether out-of-pocket costs and provider profit disclosures impacted patients' care preferences, and how patients preferred to incorporate these issues in their decision making.

Methods: We surveyed previous breast cancer patients and unaffected individuals about their preferences for four treatment scenarios (screening with MRI, peg-filgrastim to prevent infection related to chemotherapy, cold cap to reduce hair loss due to chemotherapy, and alternate chemotherapy for adjuvant therapy) that offered varying degrees of clinical benefit. Participants rated their level of interest in each treatment before any disclosure, after disclosure of out-of-pocket costs, and after disclosure of provider profit.

Results: Of 216 participants, 33% had a history of cancer. While interest in all treatment options was high initially (68–92% across the four scenarios), it dropped significantly after disclosure of out-of-pocket costs and provider profit. For three scenarios (MRI, peg-filgrastim, cold cap) interest declined to less than 30%. For the chemotherapy drug scenario, where the alternate treatment offered the most clinical benefit, interest was reduced to a lesser extent.

Conclusion: Patients expressed significantly less interest in four distinct cancer treatments after disclosure of out-of-pocket costs and provider profit. Discussions about these issues are desired in the clinical encounter. As the economic burden of cancer care shifts to patients, communication about costs and provider profit may be needed to ensure that patients are fully informed when making treatment decisions.

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1. Introduction

Global spending on cancer care has risen dramatically in recent years; spending on cancer medications alone has increased from \$75 billion in 2010 to \$100 billion in 2014 [1]. When considering both direct costs of prevention and treatment as well as indirect costs related to disability, the global burden of cancer care reaches

\$1.16 trillion [2]. In the United States, where care costs have risen particularly quickly [3], these costs are increasingly being shifted to patients through higher copays and deductibles. A study comparing financial burden across different non-elderly patient groups found that 13.4% of patients with cancer had high financial burden (health-related spending in excess of 20% of income) compared with 9.7% of patients with chronic conditions and 4.4% of those without chronic conditions [4]. Racial and ethnic minority patients can be more vulnerable to financial burdens associated with a cancer diagnosis, with one study showing 15% of black women and 17% of English-speaking Latinas reporting medical debt four years after breast cancer diagnosis compared with 9% of white women [5].

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Table 1
Cancer Care Scenario Descriptions.

Scenario	Description
Cancer screening: MRI <i>Out-of-pocket cost: \$2000 Provider profit: \$1000</i>	Imagine that you have been told that you may be at increased risk for developing cancer. Your doctor has presented two options: 1) yearly visits and exams, 2) yearly visits and exams plus MRI. The MRI may increase the chance that your doctor will find a cancer, but some patients will experience unnecessary biopsies or surgeries. For people in your situation, MRI has not been proven to help patients live longer or have better quality of life.
Treatment to reduce toxicity of chemotherapy: Peg-filgrastim <i>Out-of-pocket cost: \$5000 Provider profit: \$3000</i>	Imagine you are receiving chemotherapy and your doctor presents information about peg-filgrastim. Peg-filgrastim is an injection given the day after chemotherapy treatment and may reduce the chance you would develop a rare but serious infection. Patients who develop an infection are usually treated with antibiotics and may be hospitalized. About 10% of patients benefit from peg-filgrastim.
Treatment to improve quality of life: Cold cap <i>Out-of-pocket cost: \$2500 Provider profit: \$1000</i>	Imagine you are going to begin chemotherapy, which will likely cause you to temporarily lose all of your hair. Your doctor presents information about a device called a cold cap. The cold cap will reduce your hair loss associated with chemotherapy by 50%. Patients who use the cold cap keep enough hair that they do not need to wear a wig. The device is worn during the chemotherapy treatment and can be uncomfortable. The cold cap has no impact on how effective the chemotherapy is as a treatment for cancer.
Treatment to reduce cancer recurrence: Chemotherapy <i>Out-of-pocket cost: \$500 Provider profit: \$200</i>	Imagine that you have completed surgery for cancer treatment and your doctor now explains that you have two options for medication: Drug A or Drug B. The medications will reduce the chance that the cancer will come back in the future and will help you live longer. Patients who receive Drug A will be just as likely to be alive in 5 years and will have similar side effects as patients who receive Drug B. However, patients who receive Drug A will be 1–2% more likely to be free of cancer after 5 years.

Because the vast majority of physicians in the United States work in fee-for-service environments [6], ordering additional tests or more expensive treatments may be directly or indirectly incentivized. Policies around reimbursement can have a direct impact on physicians' prescription practices. One study found that when Medicare payment rates for certain chemotherapy drugs were reduced in 2005, there was a subsequent increase in the administration of more expensive chemotherapy drugs for lung cancer patients as oncologists tried to recoup lost payment [7]. Further, many oncologists switched from administering chemotherapy drugs with lower reimbursement rates towards similar drugs with higher reimbursement rates. In addition to incurring costs for patients, drug administrations and imaging procedures can generate profits for providers or clinics [7,8] that can raise the perception of a conflict of interest.

Our goal was to examine how patients' preferences for cancer care are affected by the disclosure of information about out-of-pocket costs to patients and profits to the provider or clinic. We presented four hypothetical cancer care scenarios with varying degrees of clinical benefit to participants and measured their interest in each option before and after disclosure of potential costs and profits. Few studies have assessed the impact of cost disclosure on patients' preferences, and we are not aware of studies that have assessed the impact of provider profit disclosure. We expect the results of this study to inform cost transparency initiatives as well as to stimulate discussion around the value of cost and profit information in shared decision making.

2. Methods

2.1. Study design

We surveyed previous breast cancer patients and unaffected individuals about their preferences in four hypothetical cancer care scenarios that related to screening, reducing toxicity, reducing recurrence, and improving quality of life. Participants were asked to rate their interest sequentially in each care option: 1) before any disclosures, 2) after disclosure of out-of-pocket costs, and 3) after disclosure of provider profits. Interest was assessed on a 5-point Likert scale from "very disinterested" to "very interested," and then grouped into a binary of interested ("very" or "somewhat"

interested) or not interested ("very" or "somewhat" disinterested or "neutral"). After responding to each of the four scenarios, participants were asked multiple choice and open-ended questions about how they preferred to learn about costs and profits. This research protocol was reviewed and approved by the institutional review board of the participating institution.

2.2. Cancer care scenarios

The four cancer care scenarios were selected to examine how different treatments, care settings, and degrees of clinical benefit might be associated with a change in interest. Each hypothetical cancer care scenario was presented with a short paragraph introducing the care decision followed by the three successive interest questions, and an open-ended question asking participants to explain why they made the choices they did. Participants were instructed to consider only the information in the provided passage when making their decisions. Table 1 describes the scenarios and lists the key differences between the options presented in each scenario. Content in the scenario descriptions, including estimates of outcome benefits, are based on published literature [9–13].

2.3. Study population

Participants were recruited through two research databases at a large academic medical center. Previous breast cancer patients were eligible for this study if they stated that they would be interested in being contacted for future research, had not been diagnosed with cancer in the last six months, and were not currently undergoing cancer treatment (not including long-term medication, such as hormone therapy). Unaffected participants were recruited through a local research registry. Participants from this database included men and women aged 18 and older. Potential participants from the two research databases were sent an email explaining the study and participation requirements. A second email was sent two weeks later to individuals who had not responded after the initial inquiry. Electronic informed consent was obtained from all participants.

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