

Cure Me Even If It Kills Me: Preferences for Invasive Cancer Treatment

Angela Fagerlin, PhD, Brian J. Zikmund-Fisher, PhD, Peter A. Ubel, MD

Purpose. When making medical decisions, people often care not only about what happens but also about whether the outcome was a result of actions voluntarily taken or a result of inaction. This study assessed the proportion of people choosing nonoptimal treatments (treatments which reduced survival chances) when presented with hypothetical cancer scenarios which varied by outcome cause. **Methods.** A randomized survey experiment tested preferences for curing an existent cancer with 2 possible treatments (medication or surgery) and 2 effects of treatment (beneficial or harmful). Participants were 112 prospective jurors in the Philadelphia County Courthouse and 218 visitors to the Detroit-Wayne County Metropolitan Airport. **Results.** When treatment was beneficial, 27% of participants rejected medication, whereas only 10% rejected surgery with identical outcomes ($\chi^2 = 5.87, P < 0.02$). When treatment was harmful, participants offered surgery

were significantly more inclined to take action (65% v. 38%, $\chi^2 = 11.40, P = 0.001$), even though doing so reduced overall survival chances. **Conclusions.** Faced with hypothetical cancer diagnoses, many people say they would pursue treatment even if doing so would increase their chance of death. This tendency toward active treatment is notably stronger when the treatment offered is surgery instead of medication. Our study suggests that few people can imagine standing by and doing nothing after being diagnosed with cancer, and it should serve to remind clinicians that, for many patients, the best treatment alternative may not only depend on the medical outcomes they can expect to experience but also on whether those outcomes are achieved actively or passively. **Key words:** MeSH; omission bias; decision-making; survey; cancer. (*Med Decis Making* 2005;25:614-619)

Imagine a group of patients who have a 10% chance of dying of a low-grade malignancy during the next 5 years. Also imagine that these patients are told that a

treatment exists that would cure their cancer but that also carries a 5% chance of leading to another fatal cancer during the same time period. What course of treatment should these patients embark on? If people want to have the best chance of survival, they ought to undergo the treatment. But many people care about more than mere survival. As most clinicians already recognize, people also care about quality of life. Their treatment choices are also influenced, on occasion, by financial considerations. But what if quality of life and financial concerns are not relevant in a particular decision? Is there any other reason people would choose not to receive this treatment?

Another issue that often plays a significant role in people's health care decision making is their perception of responsibility. People do not care only about what happens to them (i.e., the outcomes of their treatments). They also care about whether those outcomes occur as a direct result of actions they take versus as a result of inaction. For instance, many people are reluctant to take a vaccine (e.g., a flu shot) to prevent an illness if the vaccine has a 5% chance of death, even

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Address correspondence and reprint requests to Angela Fagerlin, PhD, Division of General Medicine, Department of Internal Medicine, 300 North Ingalls Building, Room 7C27, Ann Arbor, MI 48109-0429; e-mail: fagerlin@med.umich.edu.

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when the risks of not vaccinating are substantially higher.¹⁻³ In these cases, people reject a beneficial treatment because of an *omission bias*: they perceive bad outcomes caused by omissions, or failures to act, as being somehow better than equally severe outcomes caused by direct actions.⁴ Such greater acceptance of the harms of omission could lead patients diagnosed with cancer to feel that it is better to let nature take its course than to experience a treatment complication, out of a sense that harms of omission are easier to tolerate than harms of commission (this would follow people's behavior in vaccine decisions).

But most clinicians caring for cancer patients probably recognize an opposite reaction, in which patients seem to desire treatments even if the cure might be worse than the disease. For example, many breast cancer patients choose mastectomy to cure their cancer, even when a less invasive lumpectomy would be just as successful at ridding their cancer. Similarly, many prostate cancer patients choose to risk severe side effects from a radical prostatectomy even though other equally effective treatments have fewer side effects.

What leads cancer patients to choose treatments that may lead to potentially devastating side effects over other, less invasive yet equally effective approaches? One reason may be that people feel a strong need to "get the cancer out" of their bodies. Surgical removal of all potentially cancerous tissues may satisfy this desire more effectively than does less invasive treatment alternatives (e.g., radiation or chemotherapy) because people feel more confident that they did not miss anything. The desire to believe that the cancer has been totally removed may cause a sense of peace that outweighs the experienced side effects. Cancer diagnoses, rather than leading people to reject beneficial treatments, may actually cause people to seek to do something about their cancers even when they would be better off doing nothing.

In the current study, we assessed the proportion of people who would choose nonoptimal treatments (treatments which reduce their overall survival chances) when presented with hypothetical scenarios describing the need to cure already existent cancers. We explored the relative frequency of people's willingness to forgo treatment even though treatment would improve their likelihood of survival and, conversely, people's desires to undergo treatment even when treatments would reduce their chance of survival. In addition, we tested whether willingness to undergo treatment varied across different therapeutic approaches. Specifically, we predicted that—much the way many breast and prostate cancer patients opt for aggressive surgical treatments despite compelling evidence

that less invasive approaches are equally effective—willingness to accept harmful treatments would be increased (and denial of helpful treatments would be decreased) when people are told that a surgical treatment is available for their cancer.

METHODS

Participants

Participants were prospective jurors in the Philadelphia County Courthouse and visitors to the Detroit-Wayne County Metropolitan Airport. In Philadelphia County, prospective jurors are selected from voter registration and drivers license records. Surveys were distributed to interested jurors after the announcement that those who filled out a survey would receive a candy bar. In the airport, individuals were approached at gates and offered a candy bar for participation. Institutional review board approval was obtained prior to conducting the study.

Questionnaire Design

Participants read a short scenario describing a generic cancer diagnosis and then chose 1 of 2 treatment options, either watchful waiting or an active treatment option (medication or surgery). Thus, the primary outcome of interest was participants' preference for treatment. We randomly varied the treatment choices. For half the participants, the treatment involved surgery to remove the cancer, while for the remaining participants, the treatment was medication. We also varied the likelihood of death that would result from the active treatment versus watchful waiting. In half of the scenarios, we tested people's willingness to reject a beneficial treatment in order to avoid feeling "blame" for a bad outcome. In these scenarios, the treatment reduced 5-year mortality from 10% to 5%. By contrast, in the remaining scenarios, treatments increased mortality from 5% to 10%, allowing us to test people's willingness to accept harmful treatments. We randomized subjects across 4 scenarios using a 2 × 2, fully factorial design with 2 treatments (medication or surgery) and 2 effects of treatment (beneficial or harmful), so that each person made a hypothetical treatment choice for only 1 of the 4 scenarios (see Tables 1 and 2 for examples of 2 of the scenarios). One exception to the randomization was a subset of subjects in the medication scenarios ($n = 112$). These data were collected as part of a pilot study before we ran the randomized experiment. However, participants' preferences did not differ significantly from those collected as part of the randomized experi-

Table 1 Medication Scenario in which Treatment Provided Benefits over Watchful Waiting**Scenario**

Imagine that you have been diagnosed with a slow-growing cancer. Right now, the cancer is not causing you to feel sick. For most people, the cancer will grow so slowly it will never cause them any trouble. For others, the cancer will grow to the point that it makes them sick. Untreated, *ten percent* (10 out of 100) will die of the cancer. Your doctor tells you that you have two treatment options: watchful waiting or medication.

Watchful waiting means you will not do any treatment right away, but your doctor will follow your cancer closely and treat any symptoms that you have if it begins to spread. Although it would be too late to be cured, you would be comfortable and free of pain. There are no side effects to watchful waiting, but *ten percent* (10 out of 100) of the people who choose this treatment will develop symptoms and die from their cancer within five years.

On the other hand, the *medication* would cure your cancer permanently. You would take this medication every day for 3 months. The only side effect of this new medication is during the treatment you will feel more tired than usual and will experience stomach upset occasionally. However, it has a *five percent* (5 out of 100) risk of causing a second deadly cancer. If you got this second cancer, you would die within five years.

Our Question

Imagine that both of these treatments are completely covered by your health insurance. Which would you choose?

- I would *not* take the pill and accept the 10% chance of dying from this cancer
- I would take the pill and accept the 5% chance of dying from a different cancer

Please explain your answer:

ment, and all significant results are maintained when the pilot subjects are dropped from analyses.

Data Analysis

We used analysis of variance (for continuous variables) and χ^2 tests (for categorical variables) to analyze differences in demographic characteristics across questionnaire versions and site of data collection. We compared treatment choices across questionnaire versions with χ^2 tests.

RESULTS

A total of 330 participants completed a questionnaire, 112 from the Philadelphia County Courthouse and 218 from the Detroit-Wayne County International Airport. The average age of participants was 43 years ($s = 15$ years, range = 18–89 years). On average, they had 15 years of education ($s = 3$ years, range = 8–20 years); 56% were female, 16% identified themselves as African American, and 76% indicated that they were European American. Participants' demographic char-

acteristics did not differ across questionnaire versions, (all P s > 0.20). Although the demographic characteristics of the 2 samples (courthouse and airport) differed with regard to gender, race, age, and education (all P s < 0.01), there were few differences in participants' preferences for accepting the treatment (compared to watchful waiting). Therefore, we collapsed data across site of collection.

The top of Table 3 highlights the risks of death from active treatment and watchful waiting.

In the omission scenario (Table 3, column 1), the treatment was more effective than watchful waiting. In these scenarios, we told people that there was a 5% risk of death from treatment and a 10% risk of death from watchful waiting. Whereas only 73% of subjects were willing to take the beneficial medication treatment, 90% were willing to do so when the intervention was surgical. Thus, respondents were much more willing to maximize their overall survival by undergoing surgery than by taking medication to cure the same cancer ($\chi^2 = 5.87$, $P < 0.02$).

In the commission scenario (Table 3, column 2), the treatment was more harmful than watchful waiting. In

Table 2 Surgery Scenario in which Treatment Provided Benefits over Watchful Waiting

Scenario

Imagine that you have been diagnosed with a slow-growing cancer. Right now, the cancer is not causing you to feel sick. For most people, the cancer will grow so slowly it will never cause them any trouble. For others, the cancer will grow to the point that it makes them sick. Untreated, *ten percent* (10 out of 100) will die of the cancer. Your doctor tells you that you have two treatment options: watchful waiting or surgery.

Watchful waiting means you will not do any treatment right away, but your doctor will follow your cancer closely and treat any symptoms that you have if it begins to spread. Although it would be too late to be cured, you would be comfortable and free of pain. There are no side effects to watchful waiting, but *ten percent* (10 out of 100) of the people who choose this treatment will develop symptoms and die from their cancer within five years.

On the other hand, the *surgery* would cure your cancer permanently. Following surgery you will feel more tired than usual and will experience stomach upset occasionally for the three months following your surgery. However, surgery has a *five percent* (5 out of 100) risk of death during the surgery.

Our Question

Imagine that both of these treatments are completely covered by your health insurance. Which would you choose?

- I would *not* take the surgery and accept the 10% chance of dying from this cancer
- I would take the surgery and accept the 5% chance of dying from the surgery

Please explain your answer:

Table 3 Study Parameters and Results

	Omission Scenario	Commission Scenario
Parameters		
% chance of death from watchful waiting	10	5
% chance of death from active treatment	5	10
Results		
% choosing surgery instead of watchful waiting	90 ^a	65 ^b
% choosing medication instead of watchful waiting	73 ^a	38 ^b

a. $\chi^2 = 5.87, P < 0.02$ (χ^2 testing row differences).
 b. $\chi^2 = 11.40, P = 0.001$ (χ^2 testing row differences).

these scenarios, we told people there was a 10% risk of death from treatment and a 5% risk of death from watchful waiting. Once again, respondents presented with the opportunity to rid themselves of their cancer through surgery were significantly more inclined to take action (65% v. 38%; $\chi^2 = 11.40, P = 0.001$), even though doing so in this case reduced their overall chance of survival.

DISCUSSION

People perceive that cancer diagnoses are a call to action. Consequently, when presented with hypotheti-

cal cancer diagnoses, many people say they would pursue treatment even if such an action would increase their mortality rate. Few people can imagine standing by and doing nothing after being diagnosed with cancer. In this study, we found that action (i.e., treatment) is preferred when there is a benefit to the treatment. This, of course, is not surprising. However, motivation for action is so strong that people showed a strong preference for action even when the treatment is more harmful than doing nothing (i.e., watchful waiting). This desire for action was especially strong when the treatment offered was surgery rather than medication. Contrary to previous research, only a small minority of

our respondents chose to risk higher death rates in order to avoid actively causing their own death.

In most theories of rational choice, people are expected to choose the treatment alternative that has the most favorable balance of risks and benefits. In weighing these risks and benefits, most experts contend that it is the outcome that should matter, not the way in which people achieve those outcomes. Our results suggest that this is not how people want to make such decisions, at least for cancer treatment decisions. In related research, Horne and colleagues have found that people's decisions to remain adherent to treatment are closely related to their perceptions of the tradeoffs between the necessity of the treatment and their concerns about adverse effects.⁵⁻⁷ Furthermore, one study found that this difference was higher for oncology-related treatment than for the treatment of other serious medical conditions (i.e., asthma, renal dialysis, cardiac).⁶ These results suggest that people have qualitative reactions to cancer risks (which in Horne and others' research translated into increased "necessity" of treatment), which promote active intervention.

In one of our scenarios, we described a hypothetical medication that would cure people of their cancer but increase their chance of dying by potentially creating a 2nd cancer, which would lead to death during the same time period as the 1st cancer. In this scenario, the only medical outcome of any relevance was death from cancer; therefore medically speaking, the only rational choice would appear to be the alternative that yields the lowest mortality rate (which would be to reject the treatment). Yet, almost 40% of people said they would choose to take the medication. Some wrote comments explaining that they would take their chance on experiencing a 2nd cancer in order to do something about their 1st cancer. They said they could not bear standing by and doing nothing. For instance, one participant wrote, "I would want to try to cure the disease rather than just 'watch and wait' for symptoms to develop. I would feel like I had to try to do things instead of just letting it go." This anecdote likely reflects the respondent's implicit beliefs about cancer treatment.⁷ Our findings suggest that people's treatment decisions may be based not on the effectiveness of the treatments but rather on their beliefs about how cancer *should* be treated.

This desire to take action was even stronger when the hypothetical treatment described was a surgical intervention. In this case, the surgery not only increased people's mortality rate but also led to earlier mortality than watchful waiting because the scenario we presented described the surgery as carrying a potential for immediate death. To some people, this early mortality

was preferable to a slower death from cancer. Two thirds of our respondents, in fact, preferred death on the battlefield of surgery to death from cancer, even if the surgical treatment doubled their risk of dying.

Researchers have long recognized that, when people make decisions, they care not only about the outcomes of their choices (e.g., survival v. mortality) but also about the manner in which they arrive at these outcomes. Bad outcomes that are achieved naturally or passively are felt to be less burdensome than bad outcomes achieved through active choices. To take a noncancer example: losing one's eyesight because of a hereditary disease may feel less awful to people than losing their eyesight because they chose to undergo a risky procedure. Blind is blind of course, but people anticipate that they will feel especially awful about being blind if they feel responsible for becoming blind. But in this study, we have shown that in the context of cancer, people's attitudes toward action and inaction shift, with many people preferring to take action even if it increases their chance of experiencing a bad outcome.

Our study has several limitations. First, we did not control or assess the internal consistency of participants' responses. Thus, there are potential biases that could influence the conclusion. Second, our study did not explore people's actual decisions but instead presented them with hypothetical scenarios, and therefore, it does not reveal how likely people would be willing to reject beneficial treatment or accept harmful treatment in real life. However, such scenarios can tap into beliefs that can be difficult to uncover in more complex, real-world decisions. Using hypothetical scenarios, we can control the information that we present to people as well as other differences that would affect people's preferences. In this way, we can also isolate factors of interest and see what role they play in people's beliefs and preferences. This approach has allowed us to test whether preferences for action increase or decrease when people are presented with surgical treatment alternatives. As we predicted, surgical treatments increased people's desire to take action. We think this result is important because it sheds light on people's actual decisions. For instance, for men with localized prostate cancer, radical prostatectomy, radiation (both external beam and brachytherapy), and watchful waiting have similar survival rates, and yet a significant proportion of men chose to undergo radical prostatectomy even though this treatment has a higher likelihood of resulting in significant side effects (e.g., impotence or incontinence). Our results suggest that men might be willing to suffer these side effects in order to get the cancer out of them.

We expect that the results from our study will resonate with many clinicians, who have encountered cancer patients who seem to desire treatment for treatment's sake. It will also resonate with clinicians who have encountered patients with strong preferences for surgical over nonsurgical interventions, preferences that exist even before these patients learn about the pros and cons of their treatment alternatives. Some people seem to have an intuitive belief that cancers should not simply be treated but should be removed.

Our study should serve to remind clinicians that patients' preferences may not only depend on the medical outcomes they can expect to experience but also whether those outcomes are achieved actively or passively. In writing about omission preferences, most experts have considered such preferences to be biases that should be overcome through policies or persuasion.^{2,3} By the same reasoning, preferences for action can also be strong enough, at times, to be a bias. At a minimum, we think it is important for health care professionals to be aware of the potential for such biases, so they can decide whether to accept patients' preferences at face value or try to convince patients that aggressively treating a tumor may not be in their best interests.

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