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“Don’t Tell Me, I Don’t Want to Know”:

Understanding People’s Reluctance to Obtain Medical Diagnostic Information

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Abstract

Prominent theories of health-preventive behavior predict increasing information-seeking as a function of increasing disease severity, yet diagnostic screens for serious diseases are notoriously underutilized. We suggest that in addition to severity, disease treatability impacts people's willingness to submit to medical tests. In two studies, participants were relatively likely to seek a diagnostic test for a disease they believed to be serious and treatable (Study 1) and to avoid a test for a disease they believed to be serious but untreatable (Study 2). Implications for health behavior models and persuasive health communication are discussed.

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People frequently must decide whether to obtain diagnostic information about their skills, character, and prospects. Such information allows them to identify and correct deficiencies that can be consequential. For this reason, people often seek accurate information, even if it reveals their shortcomings (e.g., Festinger, 1954; Trope, 1980). At the same time, however, people are often motivated to protect their psychological well-being in the face of potentially unpalatable feedback by avoiding, denying, or discrediting it (e.g., Alicke, 1985; Brown, 1990; Croyle & Ditto, 1990; Dawson, Gilovich, & Regan, 2002).

These two strategies—seeking accurate feedback and seeking only positive feedback—are often mutually exclusive. Under what conditions does each dominate? Research suggests two significant factors that influence the pursuit of self-relevant feedback: the *importance* of an assessed quality and its *modifiability*, or the degree to which it may be changed. In the domain of academic ability, for example, Dunning (1995) found that individuals tended to seek diagnostic feedback about a characteristic that was important to them, but only when that characteristic was said to be modifiable. When participants believed they could improve upon a characteristic they considered important, they sought information even when led to believe that the feedback would be potentially unpleasant. However, when participants were led to believe that the characteristic was not modifiable—that is, that they could not improve—they tended actively to avoid potentially negative feedback, whether or not the characteristic was seen as important.

The roles of importance and modifiability in people’s decisions to seek diagnostic feedback have significant implications for the health domain. People frequently are reluctant to obtain diagnostic medical tests for disorders including HIV/AIDS (Lyter, Valdiserri, Kingsley, Amoroso, & Rinaldo, 1987), cancer (Eaker, Adami, & Sparen,

2001; Weitzman, Zapka, Estabrook, & Goins, 2001), Huntington's disease (Kaufert, 2000), and Alzheimer's disease (Welkenhuysen, Evers-Kiebooms, & Van den Berghe, 1997), even at the potential cost of their own physical well-being. Clearly, the decision to pursue or eschew a diagnostic test is influenced by a host of cognitive and motivational factors, including the level of perceived risk for the disease (Shiloh & Saxe, 1989); the desire for certainty and accuracy about one's own health (Brashers, Goldsmith, & Heieh, 2002; Brouwers & Sorrentino, 1993; Croyle, Dutson, Tran, & Sun, 1995); the ways in which the suspected disease and suggested diagnostic behavior are framed (Banks et al., 1995; Cioffi, 1991, 1994; Detweiler, Bedell, Salovey, Pronin, & Rothman, 1999); self-presentation issues (Leary, Tchividjian, & Kraxberger, 1994; Grace & Shepperd, 2002; Kowalski & Brown, 1994); rational computation of emotional gains and losses (Yaniv, 2002); and even actual risks associated with the test procedure itself.

We propose that disease treatability, or the degree to which the course of a disease may be changed, is an additional factor in the decision to obtain (or avoid) a diagnostic medical test. Specifically, we suggest that people will tend to seek diagnostic information about serious diseases more so than about inconsequential ones when those diseases are perceived to be treatable. The potential gains of diagnosing and pursuing treatment for a medical condition, and the potential losses associated with a failure to do so, loom largest for serious diseases. This tendency, however, may be checked if the disease in question is not treatable. If people perceive themselves to have no control, they may not seek information about their own health status even if at risk for a serious disease, and may go out of their way to avoid such information. In short, disease severity and treatability may interact to influence people's preferences and decisions about whether to gain information about their own health status by taking medical tests.

The potential for a disease's treatability<sup>1</sup> to influence testing decisions has been reported elsewhere, most notably in qualitative studies of carrier and predictive genetic testing (for a discussion, see Lerman, Croyle, Tercyak, & Hamann, 2002). As several

researchers have pointed out, however, studies in this domain have tended to lack experimental controls, and to rely on self-reports from a few self-selected samples of participants as the basis for their conclusions (Lerman, et al., 2002; Croyle, Smith, Botkin, Baty, & Nash, 1997; Weinstein, 1993).

Moreover, the proposed interaction between severity and treatability has received little empirical attention, and is not well-represented in current theories of health-protective behavior. For example, two of the most prominent theoretical models in this domain, the Health Belief Model (Becker, 1974; Janz & Becker, 1984) and protection motivation theory (Prentice-Dunn & Rogers, 1986), each propose a strictly additive relationship between disease severity and the potential benefits of diagnostic testing.<sup>2</sup> According to these models, both severity and treatability independently add to an individual's desire for information about his or her health status. Severity is thought to be positively related to preventive behavior even as the perceived benefits of the behavior fall to zero. We instead suggest a multiplicative relationship between severity and treatability. Information-seeking is more likely to be positively related to disease severity when the disease is treatable than when it is untreatable. Indeed, our account suggests that increasing the perceived severity of an untreatable disease might lead individuals to *cancel* any intention of receiving medical feedback, a possibility not predicted by the two theoretical perspectives noted above.

In two studies, participants decided whether or not they wanted information about their health status vis-à-vis a hypothetical (Study 1) or putatively real (Study 2) disorder. We manipulated the ostensible severity and treatability of the disorders, expecting these variables to interact to influence information-seeking.

#### Study 1: TAA Enzyme Deficiency

##### *Method*

Ninety-four Williams College students were asked to imagine that they were at an elevated risk for “TAA enzyme deficiency . . . a [fictitious] condition in which a

pancreatic enzyme known as thioamineacetylase or ‘TAA’ is absent from the body” (Croyle & Ditto, 1990). Participants were randomly assigned to one of four conditions in a 2 (severity: mild vs. severe)  $\times$  2 (treatability: treatable vs. untreatable) factorial design. Those in the mild condition read that TAA enzyme deficiency involves “no adverse symptoms,” whereas those in the severe condition read that it is quite serious, “placing people at a substantially elevated risk for severe pancreatic disorders in adult life.” Those in the untreatable condition read that “it is practically impossible to alter” one’s level of TAA, whereas those in the treatable condition read that people have “a great deal of control over the amount of TAA they possess.”

Participants then indicated the extent to which they would be interested in taking a diagnostic test for the disorder and in learning more about it, on scales from 0 (*not at all*) to 10 (*extremely*). Two final questions separately assessed participants’ perceptions of the severity and treatability of TAA enzyme deficiency, on the same 0 to 10 scale.

### *Results and Discussion*

Participants saw the disorder as more serious in the severe condition ( $M = 6.7$ ) than in the mild condition ( $M = 1.8$ ) and more controllable in the treatable condition ( $M = 8.2$ ) than in the untreatable condition ( $M = 1.4$ ). Both effects were highly significant in a 2  $\times$  2 ANOVA,  $F_s(1, 90) > 165$ , both  $p_s < .0001$ . This analysis revealed no significant interaction.

Participants’ responses to other questionnaire items revealed support for our hypothesis (see Table 1). First, we examined their reported interest in submitting to a diagnostic test for the hypothetical disorder. A 2 (severity)  $\times$  2 (treatability) analysis of variance (ANOVA) revealed a main effect for severity,  $F(1, 90) = 11.56$ ,  $p = .001$ , indicating that participants were more interested in the test when the disorder was severe than when it was mild. This effect was qualified, however, by the predicted interaction,  $F(1, 90) = 7.20$ ,  $p < .01$ . Planned contrasts revealed, as expected, that interest in the test

was related to severity in the treatable condition,  $t(90) = 4.30$ ,  $p < .0001$ , but not in the untreatable condition,  $t < 1$ .

An examination of participants' reported interest in learning more about TAA Enzyme Deficiency revealed a similar pattern. Again, a  $2 \times 2$  ANOVA revealed a main effect for severity,  $F(1, 90) = 7.72$ ,  $p < .01$ , indicating that participants were more interested in seeking information when the disorder was severe than when it was mild. Although the interaction between severity and treatability fell short of significance,  $F(1, 90) = 2.05$ ,  $p < .16$ , planned contrasts again revealed that information-seeking was related to severity in the treatable condition,  $t(90) = 2.98$ ,  $p < .005$ , but not in the untreatable condition,  $t < 1$ .

Of course, this exercise was hypothetical. Thus, participants' responses may or may not align with how they would have behaved if their health were actually in question (Sherman, 1980). We therefore designed Study 2 to examine our hypothesis in a more realistic context.

### Study 2: *Alopecia Areata* and You

Participants in Study 2 believed themselves to be facing a choice about a diagnostic test for a genuine condition known as *alopecia areata*, which was presented as either responsive or resistant to treatment and, orthogonally, as either mild or severe. For ethical reasons, the disorder was described in all conditions as medically benign but, in the severe condition, cosmetically distressing, in that it caused total and early hair loss. A pilot study confirmed that this prospect was sufficiently alarming to our student population to qualify as a serious outcome without threatening their perceived physical well-being.

Study 2 included both self-reported and behavioral measures of information-seeking, and reflected the multiple channels that may be used to communicate health information (e.g., written materials, support groups, and health care professionals; Brashers et al., 2002). We expected the positive relationship between disease severity

and information seeking to be attenuated or even reversed when the disease in question was said to be unavoidable and untreatable.

### *Method*

Seventy Cornell University undergraduates participated in exchange for \$7.00 each. The study was represented as a multi-campus effort to identify individuals likely to carry a genetic mutation related to a condition called *alopecia areata*, a disease that can cause hair loss. Participants randomly assigned to the mild condition were told that *alopecia* can “slow the rate of new hair production slightly,” but that most people with the condition do not realize they have it. They viewed a photograph of a person alleged to have *alopecia*; in fact, the photo depicted a healthy individual with a normal head of hair. Participants in the severe condition were told that *alopecia* can “dramatically slow the rate of new hair production” and that most affected individuals experience extensive hair loss beginning in their late 20s. These participants viewed a photograph depicting an actual *alopecia* sufferer with significant hair loss. In all conditions, *alopecia* was said to present no threat to overall physical well-being.

Orthogonal to this manipulation, we varied treatability. Participants in the treatable condition were told that *alopecia* is influenced by a combination of genetic and environmental factors and thus can be prevented or, if already present, treated. Those in the untreatable condition were told that as a genetically determined condition, *alopecia* is unresponsive to treatment; therefore, people with the genetic marker for *alopecia* inevitably experience it. In both cases, we explained that the mutation tends to “skip” generations, so that the presence or absence of the condition in one’s relatives was not a reliable indicator of one’s own status.

The experimenter explained that although a reliable genetic test for *alopecia* exists, it was inconvenient for use in this screening. Instead, we would estimate participants’ susceptibility using hair analysis and an on-line health survey. Participants completed the survey on a laptop computer while the experimenter examined a strand of

their hair under a microscope to render a (bogus) “hair shaft integrity rating,” which, in principle, would be entered into the computer and integrated into the risk computation. In reality, regardless of their answers to the survey, all participants received feedback placing them in a “moderate-to-high” probability category. Specifically, they viewed a results screen reporting their “probability factor” as 17 to 20%, making them eligible to receive a free and more accurate genetic test.

Afterward, participants were left alone to report their desire to (a) receive a call from a physician; (b) receive information from a support group; (c) discuss the disorder with their doctor (all *yes* or *no*); and, most importantly, (d) receive a definitive genetic test for the *alopecia* mutation (*yes, maybe—contact me in 30 days, or no*). To bolster the cover story that the session was a screening to identify possible subjects for a future study of *alopecia*, participants also indicated whether they would be interested in participating in the study, if eligible (*yes, maybe, or no*). An additional form described as a check of experimenter consistency comprised our manipulation and suspicion checks. Participants were asked to what degree *alopecia* was distressing, preventable, and treatable, on scales ranging from 1 (*not at all*) to 7 (*extremely*), and to describe their understanding of the purpose of the study and anything they found unusual or distressing.

A stack of business cards with contact information for the National *Alopecia Areata* Foundation and an array of brochures entitled “*Alopecia Areata* and You” were displayed within reach. Our behavioral measures of information-seeking were whether or not participants examined these materials during the time they were alone, determined by a visual check of the precise arrangement of materials and confirmed during debriefing.

When the experimenter returned, she asked participants to report their probability of experiencing *alopecia areata* later in life and recorded their response. This served both as a check of perceived risk and as a transition into a process debriefing (Ross, Lepper, & Hubbard, 1975), during which participants received veridical information about *alopecia areata* and assurances that the information they had received regarding their health status

had been false and randomly determined. During the debriefing, the experimenter assessed participants' level of suspicion on a 5-point scale, with 5 indicating disbelief in the cover story. Later, an assistant used a similar scale to judge independently the degree of suspicion expressed in the written responses.

### *Results*

The written and verbal responses of eight participants (six from the mild condition and two from the severe condition) were rated 4 or 5 on both suspicion scales. These ratings met our planned criteria for suspicion and data from these participants were omitted.

*Manipulation checks.* The results of our manipulation checks are summarized in Table 2. As expected, a 2 (severity)  $\times$  2 (treatability) ANOVA revealed that participants in the treatable condition believed *alopecia* to be both more preventable ( $M = 4.79$ ) and more treatable ( $M = 4.63$ ) than did participants in the untreatable condition ( $M_s = 1.89$  and  $2.43$ , respectively), both  $F_s(1, 56) > 32.00$ ,  $p_s < .0001$ . There was no independent effect of our severity manipulation on perceptions of disease preventability or treatability, both  $F_s(1, 56) < 1.5$ , *ns*, and, for perceptions of treatability, no significant interaction,  $F(1, 56) < 2.05$ , *ns*. We did observe a significant severity  $\times$  treatability interaction with regard to participants' perceptions of the degree to which *alopecia* may be prevented, such that the difference between the treatable and untreatable conditions was larger in the serious condition than in the mild condition,  $F(1, 56) = 7.42$ ,  $p < .01$ . An examination of the means suggests that the differing perceptions of preventability were similarly patterned but more extreme in the serious than in the mild condition.

We used reported distress as a check of the severity manipulation. A 2 (severity)  $\times$  2 (treatability) ANOVA revealed that participants were more distressed in the severe condition ( $M = 5.51$ ) than in the mild condition ( $M = 3.31$ ),  $F(1, 58) = 47.53$ ,  $p < .0001$ , and were somewhat more distressed in the untreatable condition ( $M = 4.78$ ) than in the

treatable condition ( $M = 4.05$ ),  $F(1, 58) = 5.15$ ,  $p < .03$ . The interaction term did not approach significance.

Critically, a similar ANOVA conducted on the perceived probability of experiencing the disease revealed no differences, with participants in each of the four conditions perceiving their risk to be, on average, between 14% (in the severe/untreatable condition) and 16.5% (in the mild/treatable condition); all  $F$ s for main effects and interaction  $< 1$ . Thus, participants in all conditions appear to have believed the feedback about their risk for *alopecia areata* to an equal degree.

*Diagnostic testing.* Responses to the remaining dependent measures are reported in Table 3. The most direct measure of information-seeking was participants' responses to the offer of genetic testing. In all conditions but one, the majority opted for the test. The clear anomaly was the severe/untreatable condition, in which the majority chose to forego testing. To test the significance of this pattern, we conducted a 2 (severity)  $\times$  2 (treatability) ANOVA with response options coded 1 (*no*) to 3 (*yes*), with *maybe* coded 2. This analysis yielded a marginally significant main effect for severity,  $F(1, 58) = 3.39$ ,  $p < .08$ , a significant main effect for treatability,  $F(1, 58) = 12.13$ ,  $p < .001$ , and a significant interaction,  $F(1, 58) = 4.14$ ,  $p < .05$ . A contrast analysis confirmed that participants in the severe/untreatable condition were significantly less likely than others to request the lab test,  $t(58) = 4.31$ ,  $p < .001$ .

To examine the role of distress in the decision to seek or forego the diagnostic test, we repeated the 2 (severity)  $\times$  2 (treatability) analysis, this time including reported distress as a covariate. The analysis of covariance (ANCOVA) revealed that distress did not exert an independent effect on participants' testing decisions,  $F < 1$ , although including it in the analysis reduced the marginal effect of severity to nonsignificance,  $F(1, 57) = 1.70$ , *ns*. Treatability and the severity  $\times$  treatability interaction remained significant,  $F$ s(1, 57) = 10.81 and 4.05, respectively;  $p$ s  $< .05$ .

Similarly, a  $2 \times 2$  ANCOVA with perceived risk included as a covariate yielded no effect for risk itself,  $F < 1$ , but a marginally significant main effect for severity,  $F(1, 57) = 3.50, p < .07$ , a significant main effect for treatability,  $F(1, 57) = 12.08, p < .001$ , and a significant severity  $\times$  treatability interaction,  $F(1, 57) = 4.10, p < .05$ . Taken together, these results suggest that the decision to seek medical testing was due neither to variation in risk perceptions, nor to differing levels of distress.

*Participating in future study.* Responses to this question were coded using the same three-point scale described above, and revealed a similar pattern. A 2 (severity)  $\times$  2 (treatability) ANOVA yielded a significant main effect for treatability,  $F(1, 56) = 7.97, p < .007$ , and a marginally significant interaction,  $F(1, 56) = 3.61, p < .07$ . As before, a contrast revealed those in the serious/untreatable condition to be significantly less inclined to participate in a future study than participants in the other three conditions,  $t(56) = 3.37, p < .001$ . Once again, ANCOVAs including either distress or perceived risk were virtually identical to the analysis presented above and yielded no effect for either covariate, both  $F_s(1, 55) < 1$ . Although these results are suggestive, it is unclear whether all participants construed participation in a future study of *alopecia* as a means of obtaining more information about the disease, and to what degree this consideration dominated others (e.g., lack of information about the future study, implication of a large time commitment, and so on). For this reason, we remain cautious in our interpretation of responses to this question.

*Information from other sources.* All remaining dependent measures were analyzed using logistic regression with predictor variables *treatability* (dummy coded -1 = treatable, 1 = untreatable), *severity* (dummy coded -1 = mild, 1 = serious), and the interaction term.

The three measures of interest in receiving information from health care practitioners and *alopecia* sufferers failed to distinguish among participants in any of the conditions. Roughly equal proportions in all conditions planned to speak to, or requested

a call from, a doctor, or sought the name of a support group. Likewise, although more participants in the mild/treatable condition than in any other took a business card, this unexpected pattern did not approach significance, for all terms, Wald  $X^2(1, N = 62) < 1$ , *ns*.

The exception to this pattern of null findings was participants' interest in informational brochures. Logistic regression analysis of the proportion in each condition who examined a brochure revealed a pattern consistent both with our hypothesis and with our primary findings, reported earlier. Specifically, this analysis revealed a marginally significant main effect for severity, Wald  $X^2(1, N = 62) = 3.15, p < .08$  ( $b = 1.38, SE = .78$ ), a significant main effect for treatability, Wald  $X^2(1, N = 62) = 6.26, p < .02$ , ( $b = 1.97, SE = .79$ ), and a marginally significant interaction, Wald  $X^2(1, N = 62) = 2.82, p = .09$  ( $b = -1.86, SE = 1.11$ ). Participants assigned to the treatable condition were more likely to take a brochure when the disease was said to be severe than when it was said to be mild, an effect that was reversed among those assigned to the untreatable condition. Thus, not only did participants who thought themselves at risk for a severe, untreatable disease tend to decline a genetic test for *alopecia*, they avoided even reading privately about it.

### *Summary and Discussion*

Severity and treatability interacted to affect participants' desire for more information about *alopecia* and themselves. When participants were told that *alopecia* was both severe and untreatable, they tended to avoid opportunities to obtain information. Relative to those in the other conditions, they were less likely to request a conclusive genetic test, less likely to volunteer to participate in a future study about the disease, and avoided looking at an informational brochure about the disease.

On the other hand, we found no such pattern for several other measures. What can account for these divergent findings? Upon reflection, differences for some of the measures may have been anticipated. In particular, the failure of most participants to

request contact from an unfamiliar doctor or peer support group likely reflects privacy concerns more so than self-protection motives. We believe the key difference between the remaining measures that showed an information-avoidance pattern and those that did not was whether they required immediate action, and thus provided immediate information, or whether they instead allowed for some future censoring of information. Reading a brochure or submitting to a genetic test commits one in the “here and now” to learning potentially disturbing facts, and it was precisely these actions that participants in the severe, untreatable condition tended to avoid. Other dependent measures allowed for some uncertainty (taking a business card, for example, permits but does not require one to seek potentially disturbing information in the future, as does claiming nonspecific plans to speak to one’s own doctor). We observed no avoidant behavior on these measures.

Although speculative, this interpretation recalls a phenomenon observed in a number of surveys conducted before predictive testing for Huntington’s disease was widely available. Lerman and colleagues (2002) report that whereas 56% to 81% of at-risk individuals in these studies expressed interest in Huntington’s testing “if such a test were available,” only 10% to 20% actually availed themselves when faced with the real option. From a safe temporal distance, at-risk individuals appear motivated to seek accurate, definitive information about their own health status; when that information becomes immediately available, however, self-protection motives may play a larger role and these individuals may be less likely to seek out medical diagnostic tests. Data from the current study suggest that our participants similarly struggled with the mutually exclusive goals of seeking and avoiding information. As an apparent solution, they took actions that could be defended (to themselves and others) as proactive, but that posed minimal risk of revealing threatening information.

### *General Discussion*

The present results demonstrate that severity and treatability jointly influence medical information-seeking. In Study 1, participants anticipated seeking more

information for a serious and treatable disease than for any other kind. Faced with a seemingly real health decision, participants in Study 2 at risk for a serious, untreatable disorder were distinguished by their avoidance of unpalatable information, saying implicitly, “Don’t tell me, I don’t want to know.” Indeed, this study may underestimate information avoidance for real world diseases whose severity eclipses that of the hair loss said to characterize *alopecia*.

We believe these results warrant caution in applying the Health Belief Model (Becker, 1974; Janz & Becker, 1984) and protection motivation theory (Prentice-Dunn & Rogers, 1986) to information-seeking via diagnostic tests. Both models have been used to predict an additive relationship between disease severity and the potential benefits of diagnostic testing (e.g., Maddux & Rogers, 1983; Wackerbarth & Johnson, 2002). According to these studies, severity is positively related to preventive behavior even when the behavior is perceived to be entirely futile. In contrast, participants’ choices in our studies indicated a multiplicative relationship. Preventive behavior (i.e., seeking a diagnostic test) may be positively related to the severity of treatable conditions, but did not appear to be positively related to the severity of immutable ones. Indeed, in Study 2, as severity increased for an untreatable disease, interest in medical information went down, not up. Only if the potential for psychological distress or incidental discomfort are coded as a significant barrier does a linear model predict this pattern of behavior.

Alternatives such as the theory of reasoned action (Ajzen, 1985) and subjective expected utility theory (Edwards, 1954; Yaniv, 2002) more explicitly posit an interaction between severity and the effectiveness of preventive behavior that is consistent with our thesis. The interaction and its effects on information-seeking, however, has remained largely untested (Weinstein, 1993). Our findings help to address this deficiency and help to explain why some people at risk for incurable diseases choose to forego diagnosis. We have implied that defensive motivated reasoning and the perceived (negative) utility of obtaining a diagnostic test for a serious but untreatable disease drive our results. Like all

complex social phenomena, however, the decision to forgo testing likely is a product of multiple psychological mechanisms, and future work should examine these.

A distinction that remains unaddressed in the current studies is that of prevention behaviors, which are adopted to forestall disease, versus diagnostic behaviors, which are adopted to detect the presence of disease. These behaviors are psychologically distinct, and people appear to reason about them differently. For example, individuals tend to be most persuaded by gain-framed appeals to adopt prevention behaviors, but by loss-framed appeals to adopt diagnostic behaviors (Detweiler et al., 1999). Our description of *alopecia* to participants in the treatable condition as both “preventable and treatable” prohibits us from considering the effects of these characteristics separately. Knowing whether at-risk individuals construe a test for an inevitable but manageable disease as a prevention or a diagnostic behavior would help health care professionals to frame persuasive messages so as to be most effective, and should be examined in future studies.

Of course, it is understandable that people, powerless over a distressing situation, sometimes cope by avoiding the threat. Indeed, there is research to suggest this can be a healthy approach (Taylor & Brown, 1988). Yet such behavior may not be optimal. Test results may impart peace of mind (Sonnenberg & Vakil, 2002), and even the distress of unfavorable results can be counterbalanced by the benefits of certainty about one’s health, including the ability to plan for the future (Boudrez & DeBacker, 2001; Lynch, Robins, Morse, & MorKrause, 2001; Roberts, 2000; Turner, 2000). Furthermore, people tend to cope with bad news more successfully than they anticipate (Gilbert, Pinel, Wilson, Blumberg, & Wheatley, 1998), suggesting that the threat of an unfavorable test result may unnecessarily discourage people from obtaining useful information about themselves.

Thus far, we have implied that people render accurate appraisals of the degree to which diseases can (or cannot) be controlled. Although there are some diseases (e.g., Huntington’s) that currently offer little to no hope for effective treatment—and for which

individuals can hardly be faulted for avoiding testing—many others are more manageable than is commonly believed. Some individuals remain unaware, for example, that advances in antiretroviral therapies can render HIV/AIDS a chronic, but manageable disease, rather than a rapid and inexorable “death sentence” (Spielberg, Kurth, Gorbach, & Goldbaum, 2001). These individuals may believe the absence of a cure implies the absence of a treatment and consequently forego testing. Similarly, people may erroneously equate DNA testing for treatable hereditary cancers with testing for incurable neurological diseases (Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere, & Denayer, 2000). In short, people sometimes believe themselves to be in the “untreatable condition” when in fact they are not, an assertion that implies that efforts to redress this misconception may be an effective way to encourage people to submit to medical testing when they are otherwise disinclined to do so. If nothing else, it would help to ensure that even a decision to forego testing is an informed one.

Concerns about utility are but one reason people may decline a medical test. Others may include a resultant implied obligation to undergo treatment, the desire to remain anonymous, questionable insurance coverage for treatment, and the risk of losing health insurance altogether (Myers, Orr, Locker, & Jackson, 1993; Spaulding, 1995). The social stigma attached to diseases like HIV/AIDS undoubtedly looms large in the minds of many who are at risk, amplified by the potential for social exclusion and employment discrimination. Indeed, to some, the very act of seeking testing may be socially awkward and embarrassing, and they may avoid testing out of self-presentation concerns (Leary, Tchividjian, & Kraxberger, 1994; Grace & Shepperd, 2002; Kowalski & Brown, 1994). At the same time, the role of perceived treatability, our focus in the present research, is undeniable. In a study of individuals at risk for HIV/AIDS, Siegal and colleagues note of their respondents:

At first, they believed that nothing could be done to help HIV infected individuals or prevent the disease from running its inexorable course...In this sense,

“ignorance was bliss” under conditions of helplessness...However, the perceptions of these men changed over time. Many came to believe there were effective medical therapies for HIV disease...Some men also recognized that early implementation of these treatments could prolong health and life...Accordingly, they recognized that these treatments provided a means of exerting some control or influence over their future health *and said or implied that this recognition motivated them to take the test* (Siegel, Levine, Brooks, & Kern, 1989, p. 370-371, emphasis added).

By manipulating perceived treatability, our research corroborates Siegel et al.’s (1989) observation. Placed in a larger context of health behavior theory, our findings suggest that researchers and health care professionals may predict when people are prone to avoid testing by examining lay theories of treatability. In these cases, caretakers should discuss treatment options not only with patients who have been positively diagnosed, but also with those who have considered—but not yet consented to—diagnostic testing. Providing accurate accounts of the degree to which a disease can be managed allows individuals to make fully informed testing decisions. Ultimately, people may be more apt to submit to a diagnostic test if convinced not only of its importance, but also of its utility.

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Notes

1. Strictly speaking, our theoretical framework invokes the notion of the perceived treatability of a disease rather than its actual treatability. Although perceived and actual treatability often align, they may not always—a consideration we return to in the General Discussion.

2. Whereas the Health Belief Model may not have been intended to predict individuals' decision to undergo or refrain from diagnostic testing (but rather preventive and restorative behaviors), in practice it has been adapted for this purpose (e.g., Wackerbarth & Johnson, 2002).

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Table 1

*Information-seeking as a Function of the Severity and Treatability of a Fictitious Medical Disorder (Study 1)*

Measure	Treatable		Untreatable	
	Mild (n = 23)	Severe (n = 24)	Mild (n = 23)	Severe (n = 24)
Interest in diagnostic test	7.1	9.4	7.5	7.8
Interest in learning more	6.2	8.3	7.4	8.0

*Note.* Scores could vary from 0 to 10.

Table 2

*Responses to Manipulation Checks (Study 2)*

Measure	Treatable		Untreatable	
	Mild	Severe	Mild	Severe
Perceived preventability <sup>a</sup>	4.2	5.4	2.2	1.6
Perceived treatability <sup>a</sup>	4.3	5.00	2.6	2.3
Reported distress <sup>a</sup>	2.8	5.3	3.8	5.7
Perceived risk <sup>b</sup>	16.5%	14.7%	15.9%	14.0%

<sup>a</sup>Scores could vary from 1 to 7.

<sup>b</sup>All participants had received prior feedback that their *alopecia areata* “probability factor” was 17-20%.

Table 3

*Percent Responding “Yes” or “Maybe” to Measures of Information-seeking as a Function of the Severity and Treatability of a Medical Disorder, Study 2*

Measure	Treatable		Untreatable	
	Mild	Severe	Mild	Severe
Genetic test	73 (27)	82 (12)	64 (21)	19 (50)
Future study	60 (27)	63 (37)	46 (39)	13 (56)
Call from doctor	13	31	23	13
Support group information	13	0	8	8
Speak to own doctor	40	44	46	44
Take business card	40	12	0	25
Read brochure	27	35	24	16

*Note: For the genetic test and future study questions, the first number refers to the percentage responding “yes” and the number in parentheses refers to the percentage responding “maybe.”*