



Published in final edited form as:

*Patient Educ Couns.* 2017 October ; 100(10): 1928–1933. doi:10.1016/j.pec.2017.05.029.

## Spontaneous mental associations with the words “side effect”: Implications for informed and shared decision making

Sonya Izadi, BA<sup>1</sup>, Thorsten Pachur, PhD<sup>2</sup>, Courtney Wheeler, MPH<sup>1</sup>, Jaclyn McGuire, MPH<sup>1</sup>,  
and Erika A. Waters, PhD, MPH<sup>1</sup>

<sup>1</sup>Surgery, Washington University School of Medicine, St. Louis, USA

<sup>2</sup>Center for Adaptive Behavior and Cognition, Max Planck Institute for Human Development,  
Berlin, Germany

### Abstract

**Objective**—To gain insight into patients’ medical decisions by exploring the content of laypeople’s spontaneous mental associations with the term “side effect.”

**Methods**—An online cross-sectional survey asked 144 women aged 40–74, “What are the first three things you think of when you hear the words ‘side effect?’” Data were analyzed using content analysis, chi-square, and Fisher’s exact tests.

**Results**—17 codes emerged and were grouped into 4 themes and a Miscellaneous category: Health Problems (70.8% of participants), Decision-Relevant Evaluations (52.8%), Negative Affect (30.6%), Practical Considerations (18.1%) and Miscellaneous (9.7%). The 4 most frequently identified codes were: Evaluating Risks (36.1%), Health Problems-Specific Symptoms (35.4%), Health Problems-General Terms (32.6%), and Negative Affect-Strong (19.4%). Code and theme frequencies were generally similar across demographic groups ( $p > 0.05$ ).

**Conclusion**—The term “side effect” spontaneously elicited comments related to identifying health problems and expressing negative emotions. This might explain why the mere possibility of side effects triggers negative affect for people making medical decisions. Some respondents also mentioned decision-relevant evaluations and practical considerations in response to side effects.

**Practice Implications**—Addressing commonly-held associations and acknowledging negative affects provoked by side effects are first steps healthcare providers can take towards improving informed and shared patient decision making.

### Keywords

health beliefs; perceptions; attitudes; side effects; medical decision making

---

Corresponding author at Erika A. Waters, Associate Professor, Division of Public Health Sciences, Washington University in St. Louis, 660 S. Euclid Ave., Campus Box 8100, Saint Louis, Missouri, 63110, USA, Tel: +1-314-747-5705, waterse@wudosis.wustl.edu.

### Conflict of Interest

The authors declare they have no conflict of interest.

## 1. INTRODUCTION

Modern medical practice places a strong emphasis on the premise that an informed medical decision is based not only on an objective evaluation of the probability and severity of the benefits and side effects of treatment, but also on an individual patient's preferences, values, and subjective perceptions of risk and severity.(1–4) One particularly relevant concern seems to be side effects of medical treatments. Sometimes patients reject a potentially-beneficial treatment because of the mere possibility that side effects may occur.(5) For example, concerns about side effects have been implicated in decisions to forego taking tamoxifen to reduce breast cancer risk among high-risk women,(6) to refuse influenza vaccinations among healthcare personnel,(7) and to decline taking pre-exposure prophylaxis for HIV transmission among men who have sex with men.(8) Some patients are willing to undergo treatment regardless of side effects because, for them, the risk of *not* taking a medication is most salient,(9–11) but side effects have been cited as a reason why some patients are reluctant to begin therapy and/or are not adhering to their medication regimens. This has occurred in diverse clinical contexts, including undergoing biologic therapy for rheumatoid arthritis,(12) adhering to antipsychotic(13) and antidepressant(14) medications, and initiating adjuvant chemotherapy for breast cancer.(15)

Several studies indicate that side effects may discourage treatment uptake because they elicit negative emotional responses,(16, 17) not because side effects make it difficult for patients to calculate the relative risks and benefits of treatment.(18–20) Emotional responses to side effects, in turn, have been shown to decrease people's use of information about the probability of occurrence of the side effects.(21) Patients' evaluations of treatment options may thus be based less on a deliberative calculation of risks and benefits and more on a spontaneous and affectively-based judgment about the medication quality. These spontaneous reactions, in turn, could act as a frame through which subsequent beliefs about the medication are formed and decisions made. Such an influence of spontaneous and non-deliberative information processing and medication belief formation would be consistent with an extensive body of theoretical literature related to decision making, marketing, stereotyping, and persuasion,(22–25) and an empirical literature related to engaging in healthy behaviors, seeking medical care, making medical decisions, and attitudes about genetics.(26–30) However, very little research has examined the content of people's spontaneous beliefs and negative affective responses related to medication side effects.

The goal of this study is to improve understanding of laypeople's beliefs about side effects by eliciting the spontaneous mental associations that the words "side effects" evoke (31, 32) and then categorizing the contents of these associations into broad "themes" and narrower "codes." (33) Several studies suggest that side effect concerns may be more prevalent and/or influential among women than men.(5, 7, 19, 20) Therefore, we included only women in our study to reduce response variability due to sex. Decreasing sex-related variability made identification of distinct categories of side effect beliefs more feasible. By elucidating what specific spontaneous beliefs about side effects exist and how frequently they occur relative to each other, this study will offer healthcare providers insight they can apply to patient consultations and may contribute to the development of patient decision support tools.

## 2. METHODS

### 2.1. Design

All procedures and study materials were approved by the Washington University IRB. This article presents a secondary analysis of data collected for a study examining how individuals conceptualize side effects and how these conceptualizations may influence aversion to medications that have side effects.(17)

### 2.2 Participants

Participants were recruited from among 10,239 women enrolled in a participant registry and biorepository who consented to being recontacted for future research. Women were recruited into this registry by clinic staff immediately following their mammographic screening. All women were age 40–74 to be consistent with the American Cancer Society’s breast cancer screening recommendations at the time the data were collected in 2012. Other inclusion criteria were: reporting white or African American ancestry, having no cancer history, having a working computer at home, and using the Internet three or more times weekly. The latter two criteria were added after pilot testing revealed that some participants with very limited computer literacy were unable to independently complete the survey. Individuals with a history of cancer were excluded because treatment for cancer is typically quite different from treatment for other conditions in intensity, duration, frequency, and administration, as well as its risks and benefits. A random sample of 1,400 women in the registry who met these criteria were contacted for participation. Of these, 270 were screened, 151 consented and 149 completed the survey. This article uses data from the 144 women with at least one valid response to the item of interest for this analysis.

### 2.3 Approach

Participants completed an online survey at home. A research assistant sent up to two reminder emails. Participants who completed the survey were entered to win one of six \$75 gift cards.

The survey first asked participants if they think thought they had ever experienced a side effect (“Yes,” “No,” or “Not Sure”) and if so, to rate its severity (“Not at all serious,” “A little bit serious,” “Somewhat serious,” or “Very serious”). Participants were then asked, “What are the first three things you think of when you hear the words ‘side effect?’” Three open text fields were presented for participants to provide responses. This question was used to document participants’ spontaneous associations to the words “side effect.” The remainder of the survey presented participants with several questions about different specific side effects. Full details of the methodology and results of those data have been published previously.(17)

### 2.4 Analysis

We conducted qualitative content analyses(33) on the open-ended responses, which ranged in length from 1–18 words. We examined the manifest content (i.e., stated meaning) of participant responses, with the intent of producing results that would be relevant to practitioners. E.A.W. and S.I. independently reviewed all responses. Using an iterative

strategy, similar responses were grouped into codes and similar codes were grouped into themes. E.A.W., S.I., C.W., and J.M. met weekly to discuss the codes. Formal inter-rater reliability was not assessed, but agreement was reached by consensus. Each response was assigned 1–2 codes. Sample words or phrases that demonstrated common and potentially unique perceptions within each code were identified. T.P. provided feedback on the code definitions and acted as an additional reviewer when coding discrepancies or questions arose. Responses were explored for any differences in frequency of codes by age, race/ethnicity, education, side effect history, and side effect history severity, using chi-squares and Fisher's exact tests as appropriate. All authors participated in the final interpretation of results.

### 3. RESULTS

Of 144 women, 111 (77.1%) were white, 77 (53.5%) had a Bachelor's or postgraduate degree, and 117 (81.3%) had experienced a side effect in the past (See Table 1). There were 424 responses to the question "What are the first three things you think of when you hear the words 'side effect'?" Most participants provided three responses (n=138, 95.8%), although a few gave only one (n=2, 1.4%) or two (n=4, 2.8%) responses. Seventeen unique codes emerged and were combined into four unique themes: Health Problems, Negative Affect, Decision-Relevant Evaluations, and Practical Considerations. All responses that did not relate to these themes were grouped into a Miscellaneous category. Table 2 provides definitions of themes and corresponding codes. Table 3 provides the proportion of participants who had one or more responses for each theme and code.

The *Health Problems* theme includes responses that refer to undesirable health consequences of taking a medication with side effects. It was by far the largest theme; 71% of participants provided a response that fell within this category. The codes within this theme included *Specific Symptoms*, which was listed by 35% of participants. This code encompassed symptoms caused by the medication, such as "allergic reactions," "nausea," and "dizziness." Conversely, the *General Health Problems* code (33%) used vague terms to describe health problems arising from medication, such as "adverse effect," "consequence" and "reaction." The *Worsening Health* code (12%) represented the idea that side effects would result in new health problems or exacerbate existing problems. For example, one participant indicated that a side effect would "fix one thing...and totally tear up something else." The *Permanent Effects* (10%) code identified long-lasting health effects, such as "death," a "permanent effect," and "damage to body organs."

The *Negative Affect* theme, mentioned by 31% of participants, describes responses that reflect any degree of negative emotions or feelings. Responses coded as *Strong Negative Affect* (19%) conveyed explicitly strong negative emotions, such as the mention of "danger," "scared," "threatening," or "terrible." The *Mild Negative Affect* code (16%) indicated mildly or moderately negative associations, such as "unpleasant," "possible annoyance," "troubling," "discomfort," or "undesirable."

Responses that fell within the *Decision-Relevant Evaluations* theme seemed to indicate active thinking through the key issues surrounding medication decision making. 53% of

participants provided a response that represented this theme. Spontaneous associations coded as *Risk* were mentioned by 36% of participants and included statements related to appraising the risks and benefits of taking a medication. Exemplar quotes include: “Do the benefits outweigh the side effects?”, “Is it worth the risk?”, and “end result may be worth putting up with the side effects.” Participants also used probabilistic language, such as “odds of getting the side effect,” “may or may not happen,” “possible,” and “what is the likelihood I will experience the side effect?” Participants commented about the *Severity* of the side effects (18%), asking “how serious are the side effects,” “are the side effects too bad,” “are the side effects dangerous,” and “It can be minor (itch, rash, etc.).” A few participants wondered about *Alternative Options* (2%) in statements such as, “Isn’t there something less lethal” and “Is there another option.” However, more participants noted that side effects are *Rare* (9%) (e.g., “Doesn’t effect [sic] everyone,” “rare event”) and *To Be Expected* (4%) (e.g., “No med is 100% safe,” “There is a risk with any medication”). They also engaged in *Questioning* (7%) (e.g., “How will this affect me,” “What are the side effects”). Participants drew diverse conclusions about the implications of side effects for the *Efficacy* of the medication (5%). Whereas some participants viewed side effects as a sign that the “drug is potent,” others thought the medication was “not going to be effective” or a sign of “medical failure.”

The *Practical Considerations* theme encompasses all actions or thoughts related to avoiding the undesirable outcomes of side effects or the experience of side effects altogether. This theme included the code *Unable to Take* (11%), which demonstrated a belief that side effects would prevent use of the medication (e.g., “Shouldn’t take the drug”) due to “tolerability” or “contraindication[s]” with other medications. *Responsive Actions* (8%) described how participants might avoid or cope with side effects (e.g., “call my physician,” “need to monitor,” and “read instructions on the pharmacy handout”).

All responses that did not pertain to the other themes were categorized as *Miscellaneous*. Some examples include comments such as, “lawyers and court,” “I think of Viagra because of all the ads,” and “There are so many side effects listed”. One word responses that did not provide enough context to meaningfully code also fell under this category. These included words such as, “why,” “what,” and “how.”

A participant-level analysis of the contents of the 424 responses showed that spontaneous reactions to the term “side effect” were relatively similar across demographic characteristics,  $p > 0.05$ , with only one exception. Younger (vs. older) participants more often gave responses that fit the *Decision-Relevant Evaluations* theme,  $X^2(1, n=144) = 4.13, p=0.04$ . Non-Hispanic white (vs. non-white) participants gave responses more frequently coded with *Negative Affect-Mild*,  $X^2(1, n=144) = 8.14, p=0.004$ .

An exploratory analysis was performed to determine whether responses varied by the severity of the side effect that participants had previously experienced. Since 81% of participants had experienced a side effect in their lifetime, analyzing response codes by history of side effect would not be meaningful. We performed logistic regressions using side effect severity as a predictor and the presence/absence of a code as the outcome. The only

significant relationship was for *Specific Symptoms*: the more severe a side effect experience was, the higher the odds of identifying specific symptoms (OR=1.86, 95% CI 1.23–2.83).

## 4. DISCUSSION AND CONCLUSION

### 4.1. Discussion

The mere possibility of side effects can lead patients to decline otherwise-beneficial therapies. Therefore, understanding the spontaneous associations that people have with the term “side effects” could help enhance patient-provider communication about medication decisions. In the present study, spontaneous associations were heavily focused on aspects related to the process of making an informed and shared medical decision, including identifying health problems resulting from medication, evaluating factors relevant to making medication decisions (especially evaluating the risks and benefits of treatment and the severity of the side effects), and expressing negative affective reactions.(1–4, 34, 35)

Participants’ spontaneous associations of the term “side effect” with specific and general health problems may not be very surprising, because all direct-to-consumer prescription drug advertisements in the US are mandated to list specific health problems that the advertised drug may cause.(36) However, examination of the specific examples of health problems participants mentioned suggests that these spontaneous associations may discourage treatment. For example, our participants listed side effects that prior research(17) identified as being physically challenging, such as fatigue, pain, and nausea. That same research showed that people perceived medications associated with physically challenging side effects as more aversive and were less willing to take them. Participants’ examination of the practical considerations of taking medications with side effects is also consistent with these prior research findings.(17)

Many of the spontaneous associations participants mentioned were laden with negative affect. This was indicated in participant responses by explicitly affective language such as “something uncomfortable.” Negative affect was also indicated by the presence of side effects that elicited strong negative affective reactions in prior research, such as diarrhea and rash.(17) As with the case for physically challenging side effects, such negative affective associations may discourage treatment uptake; previous research has reported that participants were less willing to take medications that had side effects generating negative affective responses.(17)

Affect contributes to many important judgments, as it provides a simpler, quicker signal than quantitative evaluation of the risks and benefits (i.e., trading-off probability and utility).(37) Moreover, in affect-rich decisions, such as considering medication side effects, people tend to neglect probability information.(39) For example, one study of men’s prostate cancer screening decisions reported that, although the men believed the information about prostate cancer screening did not support screening, many ultimately decided, based on emotional responses about cancer or the test, that the benefits of screening exceeded the risks.(40)

The large proportion of affect-laden spontaneous responses that we obtained to the term “side effect” has important practical implications. Probability information, even when

explicitly provided, may not be particularly influential to many individuals considering treatment with potential side effects. Providers should consider this when discussing treatment options with the patient. In addition to reviewing a treatment's benefits and risks, providers should ask patients which side effect symptoms are particularly concerning and how they feel about the treatment, making sure to acknowledge their affective responses without dismissing them. By mentioning these issues during the initial treatment discussion, the patient's concerns can be addressed immediately and directly by the provider when these associations first enter the patient's mind.

It was encouraging to see that over half of participants made statements suggesting that they were making decision-relevant evaluations related to the implications of medication side effects. This indicates that people do take multiple factors into consideration when evaluating a medication. That many of the codes within the larger theme of *Decision-Relevant Evaluation*, such as *Risk* and *Alternative Options*, are included in the "explore and compare treatment options" steps of shared decision making(41) suggests that patients may be ready and willing to discuss these issues with their physicians. That one-quarter of participants also mentioned *Practical Considerations* suggests that the temporal distance between hearing the words "side effect" and subsequent intention formation about medication decisions may be brief.

The content and frequency of themes and codes was highly consistent across participant race, education level, and age. This uniformity may be advantageous for making clinical encounters more straightforward and generalizable to most individuals seeking health services in the U.S. Those codes that did show variation among demographic groups (i.e., negative affect among non-white participants) should be replicated in future research due to the large number of statistical tests conducted.

There were a few demographic-based differences in the proportion of codes that were not statistically reliable but might still be interesting. For instance, study participants over age 50 had a strong negative affective response at nearly twice the frequency as younger participants (21% vs. 11%). This is consistent with research showing that older adults focus relatively more on emotional content when making decisions than younger adults.(42) Research using a larger sample should examine whether age, education, and race/ethnicity are related to spontaneous associations with the term "side effect" and/or other medication beliefs.

## 4.2. Limitations

Our participant sample was demographically homogeneous, as all participants were women and a large majority were white and highly educated. This homogeneity was advantageous for comparing levels of aversion among the 20 side effects in our primary analysis,(17) because it reduced response variability due to factors other than the side effects themselves. However, future research on side effect perceptions should recruit participants who represent the range of demographic factors present in the actual population of interest, including men, people from minority racial and ethnic backgrounds, and those with less formal education. This would increase the generalizability of the results and could ultimately lead to more widespread clinical applications.

It was not possible to compare side effect perceptions between participants who had and had not experienced side effects themselves, because the vast majority reported a history of side effects. It is unclear, however, whether such a comparison would be informative; there is little consensus on what proportion of the population has experienced side effects, as studies on the topic are typically condition- or medication-specific. For example, one survey of over 2,000 adults across the United States found that 37% of participants reported suffering from a prescription drug side effect in the last 5 years.(32) However, that sample was younger (mean 46 years), included a wider age range (8–94 years), and only 52% of participants were female. Additionally, they limited their reporting to the last 5 years (versus lifetime). It may be useful to determine side effect history rates in the population overall and within demographic subgroups and to explore how this experience may shape future side-effect perceptions.

Participants who had ever experienced a side effect were asked to report the severity of the side effect; however, participants may have experienced more than one side effect, with a range of severities, so we are unable to determine for which side effect participants chose to report. While it may be that participants with multiple side effect experiences reported their highest-intensity side effect, we do not know with certainty. Future research should explore whether a participant reports ever having a severe side effect and, if so, to examine how that experience is associated with their spontaneous associations.

Other important questions to address in future research include: (1) how does direct-to-consumer prescription drug advertising influence the development of spontaneous associations with side effects; (2) do spontaneous associations about medication side effects predict actual treatment decisions; (3) how are spontaneous associations related to intentions to ask a doctor about being prescribed a medication; and (4) how are spontaneous associations related to medication adherence? It may also be useful to examine whether the extent to which patients have difficulty comprehending prescription drug label information (43) may predict spontaneous associations and subsequent treatment decisions. A final limitation of the current study is that it did not assess health literacy and did not exclude individuals who may have more specialized knowledge of side effects (e.g., healthcare and pharmaceutical industry workers). For example, people who misunderstand information located in drug labels may have more affectively-laden spontaneous associations than people who comprehend the information more easily. Understanding these issues would help determine whether interventions to modify such associations might improve medical decision making.

### 4.3. Conclusion

The term “side effect” spontaneously elicited comments related to identifying health problems, engaging in decision-relevant evaluations, and expressing negative emotions. These spontaneous associations occurred among women of all demographic backgrounds. This suggests that the associations may be driven more by cognitive and affective processes that are common to the experience of making medication decisions, and less by experiences unique to any particular demographic group.



#### 4.4. Practice Implications

It is likely that patients who engage in treatment discussions with their providers experience spontaneous associations at the mention of a side effect. Addressing these commonly-held associations and acknowledging the negative affect that side effects provoke are simple first steps that healthcare providers can take towards improving informed and shared decision making among patients.

#### Acknowledgments

This work was supported by the Barnes Jewish Hospital Foundation.

#### References

1. U.K. General Medical Council. Consent: patients and doctors making decisions together London, UK2008. [Available from: [http://www.gmc-uk.org/guidance/ethical\\_guidance/consent\\_guidance\\_index.asp](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp)]
2. Lewis CL, Pignone MP. Promoting informed decision-making in a primary care practice by implementing decision aids. *N C Med J.* 2009; 70(2):136–9. [PubMed: 19489371]
3. Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. Washington, DC: National Academies Press; 2001.
4. Sheridan SL, Harris RP, Woolf SH, Shared Decision-Making Workgroup of the USPSTF. Shared decision making about screening and chemoprevention. a suggested approach from the U.S. Preventive Services Task Force. *Am J Prev Med.* 2004; 26(1):56–66. [PubMed: 14700714]
5. Waters EA, Weinstein ND, Colditz GA, Emmons K. Aversion to side effects in preventive medical treatment decisions. *Br J Health Psychol.* 2007; 12:383–401. [PubMed: 17640453]
6. Port ER, Montgomery LL, Heerdt AS, Borgen PI. Patient reluctance toward tamoxifen use for breast cancer primary prevention. *Ann Surg Oncol.* 2001; 8(7):580–5. [PubMed: 11508619]
7. Kraut A, Graff L, McLean D. Behavioral change with influenza vaccination: factors influencing increased uptake of the pandemic H1N1 versus seasonal influenza vaccine in health care personnel. *Vaccine.* 2011; 29(46):8357–63. [PubMed: 21888939]
8. Bauermeister JA, Meanley S, Pingel E, Soler JH, Harper GW. PrEP awareness and perceived barriers among single young men who have sex with men. *Current HIV research.* 2013; 11(7):520–7. [PubMed: 24476355]
9. Breen S, Ritchie D, Schofield P, Hsueh YS, Gough K, Santamaria N, et al. The Patient Remote Intervention and Symptom Management System (PRISMS) – a Telehealth- mediated intervention enabling real-time monitoring of chemotherapy side-effects in patients with haematological malignancies: study protocol for a randomised controlled trial. *Trials.* 2015; 16:472. [PubMed: 26481873]
10. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Cure me even if it kills me: Preferences for invasive cancer treatment. *Med Decis Making.* 2005; 25:614–9. [PubMed: 16282212]
11. Holmberg C, Waters EA, Whitehouse K, Daly M, McCaskill-Stevens W. My Lived Experiences Are More Important Than Your Probabilities: The Role of Individualized Risk Estimates for Decision Making About Participation in the Study of Tamoxifen and Raloxifene (STAR). *Med Decis Making.* 2015; 35(8):1010–22. [PubMed: 26183166]
12. Wolfe F, Michaud K. Resistance of rheumatoid arthritis patients to changing therapy: discordance between disease activity and patients' treatment choices. *Arthritis Rheum.* 2007; 56(7):2135–42. [PubMed: 17599730]
13. Dibonaventura M, Gabriel S, Dupclay L, Gupta S, Kim E. A patient perspective of the impact of medication side effects on adherence: results of a cross-sectional nationwide survey of patients with schizophrenia. *BMC Psychiatry.* 2012; 12:20. [PubMed: 22433036]

14. Aikens JE, Nease DE Jr, Nau DP, Klinkman MS, Schwenk TL. Adherence to maintenance-phase antidepressant medication as a function of patient beliefs about medication. *Ann Fam Med.* 2005; 3(1):23–30. [PubMed: 15671187]
15. Harder H, Ballinger R, Langridge C, Ring A, Fallowfield LJ. Adjuvant chemotherapy in elderly women with breast cancer: patients' perspectives on information giving and decision making. *Psychooncology.* 2013; 22(12):2729–35. [PubMed: 23813806]
16. Pachur T, Galesic M. Strategy Selection in Risky Choice: The Impact of Numeracy, Affect, and Cross-Cultural Differences. *J Behav Decis Mak.* 2013; 26(3):260–71.
17. Waters EA, Pachur T, Colditz GA. Side Effect Perceptions and Their Impact on Treatment Decisions in Women. *Med Decis Making.* 2016
18. Fagerlin A, Zikmund-Fisher BJ, Nair V, Derry HA, McClure JB, Greene S, et al. Women's decisions regarding tamoxifen for breast cancer prevention: responses to a tailored decision aid. *Breast Cancer Res Treat.* 2010; 119(3):613–20. [PubMed: 19908143]
19. Waters EA, Weinstein ND, Colditz GA, Emmons K. Reducing aversion to side effects in preventive medical treatment decisions. *J Exp Psychol Appl.* 2007; 13(1):11–21. [PubMed: 17385998]
20. Waters EA, Weinstein ND, Colditz GA, Emmons K. Explanations for side effect aversion in preventive medical treatment decisions. *Health Psychol.* 2009; 28(2):201–9. [PubMed: 19290712]
21. Pachur T, Hertwig R, Wolkewitz R. The affect gap in risky choice: Affect-rich outcomes attenuate attention to probability information. *Decision.* 2014; 1(1):64.
22. Reyna VF. How people make decisions that involve risk: A dual-process approach. *Curr Dir Psychol Sci.* 2004; 13(2):60–6.
23. Chen, S., Chaiken, S. The heuristic-systematic model in its broader context. In: Chaiken, S., Trope, Y., editors. *Dual-Process Theories in Social Psychology.* New York, NY: The Guilford Press; 1999. p. 73-96.
24. Petty, RE., Cacioppo, JT. The elaboration likelihood model of persuasion. In: Berkowitz, L., editor. *Adv Exp Soc Psychol.* Vol. 19. New York, NY: Academic Press; 1996. p. 123-205.
25. Finucane ML, Alhakami A, Slovic P, Johnson SM. The affect heuristic in judgments of risks and benefits. *J Behav Decis Mak.* 2000; 13(1):1–17.
26. Moser RP, Arndt J, Han P, Waters EA, Amsellem M, Hesse BW. Perceptions of Cancer as a Death Sentence: Prevalence and Consequences. *J Health Psychol.* 2014; 19(12):1518–24. [PubMed: 23864071]
27. Hollands GJ, Prestwich A, Marteau TM. Using aversive images to enhance healthy food choices and implicit attitudes: An experimental test of evaluative conditioning. *Health Psychol.* 2011; 30(2):195. [PubMed: 21401253]
28. Scherer LD, de Vries M, Zikmund-Fisher BJ, Witteman HO, Fagerlin A. Trust in deliberation: The consequences of deliberative decision strategies for medical decisions. *Health Psychol.* 2015; 34(11):1090–9. [PubMed: 25844905]
29. Condit CM. Public attitudes and beliefs about genetics. *Annu Rev Genomics Hum Genet.* 2010; 11:339–59. [PubMed: 20690816]
30. Bates BR, Templeton A, Achter PJ, Harris TM, Condit CM. What does “A gene for heart disease” mean? A focus group study of public understandings of genetic risk factors. *Am J Med Genet.* 2003; 119A:156–61. [PubMed: 12749055]
31. Szalay, LB., Deese, J. *Subjective meaning and culture: An assessment through word associations.* Hillsdale, NJ: Erlbaum; 1978.
32. Slovic P, Peters E, Grana J, Berger S, Dieck GS. Risk perception of prescription drugs: Results of a national survey. *Drug Information Journal.* 2007; 41:81–100.
33. Neuendorf, KA. *The content analysis guidebook.* Thousand Oaks, CA: Sage Publications; 2002.
34. Hamilton JG, Lillie SE, Alden DL, Scherer L, Oser M, Rini C, et al. What is a good medical decision? A research agenda guided by perspectives from multiple stakeholders. 2016
35. Samson P, Waters EA, Meyers B, Politi MC. Shared Decision Making and Effective Risk Communication in the High-Risk Patient With Operable Stage I Non-Small Cell Lung Cancer. *Ann Thorac Surg.* 2016; 101(6):2049–52. [PubMed: 27211932]

36. West SL, Squiers LB, McCormack L, Southwell BG, Brouwer ES, Ashok M, et al. Communicating quantitative risks and benefits in promotional prescription drug labeling or print advertising. *Pharmacoepidemiol Drug Saf.* 2013; 22(5):447–58. [PubMed: 23440924]
37. Slovic P, Peters E, Finucane ML, Macgregor DG. Affect, risk, and decision making. *Health Psychol.* 2005; 24(4 Suppl):S35–40. [PubMed: 16045417]
38. Finucane ML, Alhakami A, Slovic P, Johnson SM. The affect heuristic in judgments of risks and benefits. *Journal of behavioral decision making.* 2000; 13(1):1.
39. Pachur T, Hertwig R, Steinmann F. How do people judge risks: availability heuristic, affect heuristic, or both? *J Exp Psychol Appl.* 2012; 18(3):314–30. [PubMed: 22564084]
40. Farrell MH, Murphy MA, Schneider CE. How underlying patient beliefs can affect physician-patient communication about prostate-specific antigen testing. *Eff Clin Pract.* 2002; 5(3):120–9. [PubMed: 12088291]
41. The SHARE Approach—Essential Steps of Shared Decision Making. Rockville, MD: Agency for Healthcare Research and Quality; 2014. [Available from: <http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/tools/tool-1/index.html>]
42. Peters E, Diefenbach MA, Hess TM, Västfjäll D. Age Differences in Dual Information-Processing Modes: Implications for Cancer Decision Making. *Cancer.* 2008; 113(12 Suppl):3556–67. [PubMed: 19058148]
43. Gardner PH, McMillan B, Raynor DK, Woolf E, Knapp P. The effect of numeracy on the comprehension of information about medicines in users of a patient information website. *Patient Educ Couns.* 2011; 83(3):398–403. [PubMed: 21621949]

**Table 1**

## Participant Characteristics (N=144)

	% (n)
<b>Age</b> (mean, SD)	56.5 (7.5)
Age >50 years	82.6 (119)
<b>Educational Attainment</b>	
Less than high school	1.4 (2)
High school degree	10.4 (15)
Vocational/technical school	2.1 (3)
Some college, no degree	21.5 (31)
Associate degree	11.1 (16)
Bachelor's degree	26.4 (38)
Graduate degree	27.1 (39)
<b>Race/Ethnicity</b>	
Hispanic	2.1 (3)
Black/African American	21.5 (31)
White/Caucasian	77.1 (111)
<b>Personal History of Side Effects</b> <sup>*</sup>	81.3 (117)
Side effect severity <sup>†</sup> (mean, SD)	2.0 (1.0)

<sup>\*</sup> Do you think you've ever had a side effect from taking a prescription drug?

<sup>†</sup> Side effect severity: (1) Not at all serious (2) A little bit serious (3) Somewhat serious (4) Very serious

**Table 2**

## Code Definitions, Grouped by Theme

<b>Code</b>	<b>Definition</b>
<b>Health Problems</b>	<b>Medical conditions that may develop as a consequence of taking a medication</b>
General	Other non-specific/general description of side effects, including defining the words “side effect”
Worsening Health	A belief that new health problems will arise or existing problems worsen as a result of taking a medication
Permanent Effects	Evaluating whether the medication will cause irreversible, long lasting health problems or if the problems are temporary
Specific symptoms	Specific health problems resulting from taking a medication, including references to an allergic reaction
<b>Negative Affect</b>	<b>Negative affective words or responses to potential side effects of medications</b>
Mild	A mild or moderately negative term or subjective experience resulting from the drug
Strong	A clearly negative emotional response or evaluation, or the use of terms that elicit a strong negative emotional response
<b>Decision-Relevant Evaluations</b>	<b>Responses suggesting engagement in thinking about key issues related to making medication decisions</b>
Alternative Options	Seeking information about other treatment options
Efficacy	An evaluation of whether or not the medication will work to solve target health problem, or the strength of the medication
To Be Expected	When taking a medication, side effects are to be expected
Questioning	Using questions to seek more information about the side effects
Rare	Belief that side effects occur infrequently among individuals taking a medication or that not everyone experiences the side effect
Risk	Evaluation of drawbacks and/or benefit of taking a medication; includes considering the probability/possibility of something occurring
Severity	Evaluating/wondering about the seriousness of the drug side effects
<b>Practical Considerations</b>	<b>Actions or thoughts related to avoiding side effects or their consequences</b>
Responsive Actions	Steps taken or not taken to avoid potential side effects of a medication, not including stopping a medication.
Unable to Take	Individuals discontinue/decide not to take a medication due to side effect potential; includes considering if one is “able” to take the drug
<b>Miscellaneous</b>	<b>Responses that do not fit the other themes.</b>

**Table 3**

Participant Responses Overall and by Demographics\*

Codes	Total		Age		Education		Non-Hispanic White		p	
	n=144 % (n)	50 n=25 % (n)	>50 n=119 % (n)	No college n=20 % (n)	Some college n=124 % (n)	Yes n=111 % (n)	No n=33 % (n)			
<b>Health Problems</b>	70.8 (102)	66.7 (18)	71.8 (84)	0.6	70.0 (14)	71.0 (88)	0.93	69.4 (77)	75.8 (25)	0.48
Specific Symptoms	35.4 (51)	22.2 (6)	38.5 (45)	0.11	40.0 (8)	34.7 (43)	0.64	32.4 (36)	45.5 (15)	0.17
General	32.6 (47)	44.4 (12)	29.9 (35)	0.15	15.0 (3)	35.5 (44)	0.07	35.1 (39)	24.2 (8)	0.24
Worsening Health	11.8 (17)	14.8 (4)	11.1 (13)	0.53	15.0 (3)	11.3 (14)	0.71	9.9 (11)	18.2 (6)	0.22
Permanent Effects	9.7 (14)	0	12.0 (14)	0.07	5.0 (1)	10.5 (13)	0.69	8.1 (9)	15.2 (5)	0.31
<b>Decision-Relevant Evaluations</b>	52.8 (76)	70.4 (19)	48.7 (57)	<b>0.04</b> <sup>†</sup>	60.0 (12)	51.6 (64)	0.49	52.3 (58)	54.5 (18)	0.82
Risk	36.1 (52)	40.7 (11)	35.0 (41)	0.58	40.0 (8)	35.5 (44)	0.7	36.9 (41)	33.3 (11)	0.71
Severity	18.1 (26)	33.3 (9)	14.5 (17)	0.05	20.0 (4)	17.7 (22)	0.76	18.0 (20)	18.2 (6)	0.98
Rare	9.0 (13)	14.8 (4)	7.6 (9)	0.27	0.0	10.5 (13)	0.22	9.9 (11)	6.1 (2)	0.73
Questioning	6.9 (10)	3.4 (1)	7.6 (9)	0.69	15.0 (3)	5.6 (7)	0.15	6.3 (7)	9.1 (3)	0.7
Efficacy	4.9 (7)	3.7 (1)	5.1 (6)	1.0	5.0 (1)	4.8 (6)	1.0	5.4 (6)	3.0 (1)	1.0
To Be Expected	4.2 (6)	7.4 (2)	3.4 (4)	0.31	0.0	4.8 (6)	0.6	3.6 (4)	6.1 (2)	0.62
Alternative Options	2.1 (3)	0	2.6 (3)	1.0	0.0	2.4 (3)	1.0	2.7 (3)	0	1.0
<b>Negative Affect</b>	30.6 (44)	25.9 (7)	31.6 (37)	0.56	25.0 (5)	31.5 (39)	0.56	31.5 (35)	27.3 (9)	0.64
Strong	19.4 (28)	11.1 (3)	21.0 (25)	0.23	20.0 (4)	19.4 (24)	11.0	17.1 (19)	27.3 (9)	0.2
Mild	16.0 (23)	14.8 (4)	16.0 (19)	1.0	5.0 (1)	17.7 (22)	0.2	20.7 (23)	0	<b>0.004</b> <sup>†</sup>
<b>Practical Considerations</b>	18.1 (26)	25.9 (7)	16.2 (19)	0.27	20.0 (4)	8.1 (10)	0.11	20.7 (23)	9.1 (3)	0.13
Unable to Take	11.1 (16)	14.8 (4)	10.3 (12)	0.5	0.0	12.9 (16)	0.13	13.5 (15)	3.0 (1)	0.12
Responsive Actions	7.6 (11)	11.1 (3)	6.8 (8)	0.43	10.0 (2)	7.3 (9)	0.65	8.1 (9)	6.1 (2)	1.0
<b>Miscellaneous</b>	9.7 (14)	7.4 (2)	10.3 (12)	1.0	20.0 (4)	8.1 (10)	0.11	10.8 (12)	6.1 (2)	0.52

\* Fisher's exact test used for expected cell counts <5.

<sup>†</sup> Significant at  $p < 0.05$

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript