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The Use of Anecdotal Information in a Hypothetical Lung Cancer Decision

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### Abstract

This mixed-methods study examined variables associated with use of experience-based strategies among 85 undergraduates presented with two hypothetical lung cancer scenarios. Participants were asked to think-aloud while they made their treatment choice. Eleven decisional strategies were identified and grouped into either data or experience-based strategies. Approximately 25% of participants used experience-based strategies. Use of experience-based strategies was more likely if the participant reported involvement in the life of someone going through cancer treatment, and if they rated print-based media sources as less important. Use of experience-based strategies was associated with choosing surgery instead of radiation for lung cancer treatment.

Keywords: lung cancer, medical decision making, mixed methods, think aloud

### The Use of Anecdotal Information in a Hypothetical Lung Cancer Treatment Decision

Years of decision making research suggests that, when people make decisions, they often ignore pertinent statistical information while focusing attention on less important variables in a given scenario (Tversky & Kahneman, 1974). In the context of high-stakes decisions, such as medical decisions, the emotional nature of the decision may make it more likely that individuals rely on anecdotal, or second-hand, information when making their decision (Fagerlin, Wang, & Ubel, 2005; Verhoef, Mulkins, Carlson, Hilsden, & Kania, 2007).

Although there is more recent research devoted to the topic of internet use for obtaining medical information (Mueller et al., 2017), there is little research on the extent to which anecdotal information is used in the process of making a major medical decision. The goal of the current study was to determine variables associated with use of experience-based (i.e., anecdotal) strategies among an undergraduate sample presented with hypothetical lung cancer scenarios. Although we anticipated that the sample would have very limited personal experience with cancer, we were interested in the other sources of information they brought to the decisions. We were also particularly interested in whether vicarious, or second-hand, experience with cancer, such as through family or friends, was associated with increased use of experience-based strategies.

Individuals who are facing medical decisions may obtain information from multiple sources, including health care professionals, family, friends, the internet, and other media sources (Massey, 2016). Recent research has documented the volume of information available to patients through the internet, particularly through the use of information provided by other individuals on social media (Kallinikos & Tempini, 2014; Ng, Tarazi, Byrne, Baker, & McCabe, 2017). Obtaining second-hand information through social media may lead to situations where

statistical outcome information is viewed as less important than personal research and experiences (Couper et al., 2010). For example, laboratory studies suggest that when anecdotal information is clearly positive or negative, it is weighted more heavily than base-rate or other statistical information (Freymuth & Ronan, 2004). The affect heuristic (Slovic, Peters, Finucane, & MacGregor, 2005) suggests that our decision making process is highly influenced by an overall affective impression of the decision, which may be particularly strong for major medical decisions such as cancer treatments.

Fagerlin, Wang, and Ubel (2005) suggest that anecdotal information is powerful because it provides a straightforward outcome; either a patient was cured or not cured. It is also possible that statistical information is not used as frequently as personal experience due to the patient's lack of comprehension of statistical information, or uncertainty about recommended guidelines (Record et al., 2017). Indeed, research suggests that numeracy may play an important role in understanding the statistical information presented in major medical decisions (Låg, Bauger, Lingberg, & Friberg, 2014). Additionally, when treatment or screening guidelines are changed, individuals may rely more on other people's experiences, as demonstrated by Record et al. (2017) in a study of Appalachian women's understanding of breast cancer screening guidelines.

Anecdotal information is sometimes incorporated into narratives that are used in decision aids (Winterbottom, Bekker, Conner, & Mooney, 2008). The use of first- and third-person narratives in patient decision aids is increasing, and may be particularly effective for individuals who rely on an oral storytelling tradition for transmitting information (Wise, Han, Shaw, McTavish, & Gustafson, 2008). However, some research suggests that narratives may encourage the use of a heuristic rather than systematic processing approach (Winterbottom et al., 2008), and that narratives may inadvertently provoke resistance to health information (Quintero Johnson,

Yilmaz, & Najarian, 2017). Outside of the context of decision aids, it remains unclear what the effects are of personal narratives from friends and family within an individual's social network.

Although not a primary focus of the current study, the frame of the information can also influence medical decision making. Rothman, Bartels, Wlaschin, and Salovey (2006) found that gain-framed messages were most persuasive when advocating prevention of health-related issues. Conversely, advocating behavior that would detect any health-related issues was most persuasive when loss-framed. The framing of treatment options appears to impact the trade-offs that patients are willing to make between short-term risks and long-term benefits (e.g., Kim, Goldstein, Hasher, & Zacks, 2005; McNeil, Pauker, Sox, & Tversky, 1982; O'Connor et al., 1985). For instance, studies suggest that presenting treatment outcome data in terms of survival rates, as opposed to mortality rates, is related to an increased willingness to trade short-term risks for long-term benefits (e.g., McNeil et al., 1982; O'Connor et al., 1985).

### **Current Study**

The above research suggests that anecdotal information and the frame of the information may significantly influence major medical decisions. Although the framing effect has been studied extensively (Kim et al., 2005; McNeil et al., 1982; O'Connor et al., 1985; Woodhead, Lynch, & Edelstein, 2011), it is unclear the extent to which anecdotal information is incorporated into the decision making process and what factors are associated with the type of information that people use. The current study utilized a mixed-methods approach to determine what types of information undergraduate students used to make hypothetical lung cancer treatments used; we also assessed how the use of specific types of information were associated with treatment choice.

### **Method**

## Participants

This study included 85 undergraduate students enrolled at [BLINDED FOR REVIEW]. On average, participants were 20 years old ( $M = 19.84$ ,  $SD = 2.98$ , range = 18-40) and reported 14.27 years of formal education ( $SD = 1.73$ ). The sample was predominately female (69.9%). The majority of participants were single (98.8%) and rated their current health as good or excellent (71.8%). Participants reported their ethnicity as Asian American (42.2%), Caucasian (24.1%), Hispanic (22.9%), African American (4.8%) or mixed race (6.0%). Students completed the study in order to receive research participation credit for their introductory psychology courses. The study was approved by the Institutional Review Board at [BLINDED FOR REVIEW].

## Measures

**Equipment.** Think-aloud protocols were recorded using a digital audio recorder. Recording started after the participant completed the practice think-aloud problems. All interviews were transcribed following the session.

**Demographic.** All participants completed a demographic questionnaire. The questionnaire asked the participants to provide basic information such as age, gender, years of education, marital status, ethnicity, and current health status.

**Cancer-related experience questionnaire.** Participants completed a survey about their cancer-related experiences. The survey included questions about whether participants obtained cancer-related information from various media outlets (television, radio/podcasts, articles) and if so, how important this information was in influencing their thinking about cancer (1=not at all important to 5=very important; television  $M = 3.21$ ,  $SD = 1.24$ ; radio/podcasts  $M = 2.78$ ,  $SD = 1.57$ ; articles  $M = 3.74$ ,  $SD = 1.07$ ). This questionnaire also included questions about whether the

participant had ever discussed the treatment of cancer with someone who was receiving cancer treatment (yes = 42.1%) and if so, how involved they were in that person's life while he/she was receiving treatment (1 = not at all involved to 5 = very involved;  $M = 2.34$ ,  $SD = 1.72$ ). None of the participants reported a personal history of cancer.

**Practice think-aloud problems and instructions.** Prior to asking the participant to practice thinking aloud, the think-aloud technique was modeled using a simple arithmetic problem. Participants were then asked to practice two think-aloud problems. These problems, taken from Ericsson and Simon (1984), aimed to have participants verbalize their thought process while engaging in the task.

**Participant instructions.** The participant instructions were adapted from McNeil et al. (1982) and provided participants with background information on the two cancer treatment options, surgery and radiation.

**Stimulus materials.** The hypothetical lung cancer scenarios used in the current study were taken from McNeil et al. (1982). The scenarios presented outcome data in a cumulative probability format with outcomes framed either in terms of survival rates or in terms of mortality rates. All participants received both frames (survival and mortality) in a within-subject design, with order of frame counter-balanced across participants.

**Treatment choice questionnaire.** Directly following presentation of each scenario (survival and mortality frames), participants were asked to state their preferred treatment choice. In the cumulative probability format, 54.9% of participants chose surgery.

## **Procedure**

First, participants reviewed the informed consent document and provided written consent for participating in the study. Next, they completed the demographic questionnaire and the

cancer-related experience questionnaire. Participants then completed the practice think-aloud instructions and read the participant instructions for the lung cancer scenarios. They were then asked to provide written and verbal consent for audio recording their responses to the four hypothetical scenarios. Participants read each scenario to themselves, and then were asked to engage in the think-aloud procedure when making their treatment decision. They were required to make a decision for each of the scenarios. Once the scenarios were completed, the researcher stopped the recording and the study was complete.

### **Analysis Plan**

For coding the decisional strategies, the authors read through all of the transcripts for the cumulative probability. Each participant contributed two transcripts for each scenario (survival and mortality frame) resulting in a total of 170 transcripts. Preliminary codes were created by each person and then compared and refined to develop a final list of 11 codes (see Table 1). Following this, 20 transcripts were given to two independent raters to establish adequate interrater reliability via the intraclass correlation coefficient. Interrater reliability was above 0.70 for all codes. All of the transcripts were then coded using the 11 codes created by the research team. Each transcript could receive multiple codes. For our final analyses, these codes were collapsed into two major themes of data- and experience-based strategies (Table 1). Six codes were summed to create the experience theme and five codes were summed to create the data theme.

Our analyses first examined the frequency of decisional strategies for all participants and the average number of coded decisional strategies per transcript. We used 2x2 chi-square analyses to determine whether specific decisional strategies were associated with choosing

surgery or radiation. We limited this analysis to decisional strategies used in more than 10 transcripts (see Table 1).

To examine predictors of decisional strategy, two hierarchical linear regression analyses were used (one for each decisional strategy). Predictors entered were frame (survival or mortality), current health, number of other people known with cancer, involvement ratings for those participants who had discussed cancer treatment with someone going through it, and importance ratings assigned to television/internet programs, radio/podcast programs, and articles about cancer.

To examine predictors of treatment choice, one hierarchical logistic regression analysis was used. Predictors included frame (survival or mortality), and the summed number of themes in participant transcripts representing experience and/or data-based strategies. The demographic variables of age, sex, ethnicity, marital status, and years of education were initially included in all of the regression models but were not associated with outcomes and were therefore removed from the final models. All analyses were conducted using SPSS version 22. An alpha level of .05 was used for all analyses.

## **Results**

### **Use of Decisional Strategies**

The majority of transcripts received one to two codes ( $M = 1.35$ ,  $SD = 0.75$ , Range 0-4). The average number of experience-based strategies used in the transcripts was 1.37 ( $SD = 0.69$ ). The average number of data-based strategies used in the transcripts was 1.14 ( $SD = 0.34$ ). The specific experience-based and data-based strategy codes that were used are presented in Table 1 along with examples from transcripts.

Experienced-based strategies were used in 25.3% of the transcripts ( $n = 43$ ). The most commonly used experience-based strategies focused on pre-existing attitudes toward treatment, vicarious experience with cancer or surgery, side effects of treatment, and factors related to the process of getting treatment. The pre-existing attitudes toward treatment were typically focused on negative attitudes toward radiation, for example, “I would trust a surgeon more than chemicals (from radiation).” The code of side effects of treatment also tended to reflect perceptions of the negative side effects of radiation, for example, “I just think surgery is better because it’s a lot less painful for the person and their family doesn’t have to see them struggling like losing their hair.” Out of the 13 transcripts that were coded as pre-existing attitudes, 92.3% ( $n=12$ ) chose surgery, compared to 51.7% choosing surgery from transcripts not coded as pre-existing attitudes ( $\chi^2(1) = 7.99, p = 0.005$ ). Out of the 15 transcripts that were coded as side effects of treatment, 86.7% ( $n=13$ ) chose surgery, compared to 51.7% choosing surgery from transcripts not coded as pre-existing attitudes ( $\chi^2(1) = 6.74, p = 0.009$ ). The vicarious experience code and treatment process code was not significantly associated with choosing surgery or radiation ( $\chi^2(1) = 2.71, p = 0.10$ ;  $\chi^2(1) = 2.90, p = 0.09$ , respectively).

The majority of transcripts used at least one data-based strategy (87.1% [ $n = 148$ ]). The qualitative analyses found that most data-based strategies were focused on either the long or short-term outcome data. For example, one participant stated, “it’s kind of all about the long term so I would go with the surgery over, instead of radiation.” Participants who focused on short-term data typically made statements such as, “radiation, because no patients died during treatment and that is like the main part, like, am I going to die or something.” Transcripts from participants who focused on the long-term outcome data were significantly more likely to choose surgery over radiation (95.4% vs. 38.0%;  $\chi^2(1) = 73.44, p < 0.001$ ) whereas transcripts from

those who focused on the short-term outcome data were significantly more likely to choose radiation over surgery (93.7% vs. 14.9%;  $\chi^2(1) = 97.29, p < 0.001$ ).

### **Linear Regressions Predicting Decisional Strategy**

Use of experience-based strategies was more likely in the transcripts of participants who reported more involvement in the lives of people going through cancer treatment and those who rated articles about cancer as less influential. Use of data-based strategies was more likely in the transcripts of participants reporting knowing more people with cancer and among those who rated television programs about cancer as less influential (Table 2).

### **Logistic Regressions Predicting Treatment Choice**

For the cumulative probability format, choosing surgery was more common among participants when they received the survival frame ( $Exp(B) = 2.544$ , 95% CI 1.310 – 4.941,  $p = 0.006$ ) and when their transcripts showed use of experience-based strategies ( $Exp(B) = 2.868$ , 95% CI 1.448 – 5.678,  $p = 0.003$ ). Use of data-based strategies was not associated with treatment choice ( $Exp(B) = 0.744$ , 95% CI 0.369 – 1.499,  $p = 0.408$ ).

## **Discussion**

The current study examined variables associated with use of experience-based strategies among an undergraduate sample presented with hypothetical lung cancer scenarios. Our results suggest that most participants used data-based strategies where decisions were made primarily based on the presented survival and mortality data. However, approximately 25% of participants used experience-based strategies. We anticipate that the percentage of individuals using experience-based strategies may be higher among those who are faced with real medical decisions, as opposed to hypothetical scenarios. When participants did have vicarious experience with cancer, in the form of knowing other individuals with cancer, they were more likely to use

data-based strategies. The use of experience-based strategies was more likely when the participant was significantly involved in the life of someone going through cancer treatment.

The types of experience-based strategies that were coded in the participants' transcripts reveal that patients bring multiple types of beliefs into the medical decision-making process (Bickell, Weidmann, Fei, Lin, & Leventhal, 2009). For example, some of our participants were worried about the impact of treatment on their family, the overall length of treatment and the amount of time that would be spent on treatments on a daily basis, as well as information they had previously heard about the treatments. This suggests that, even when patients have limited personal experience with a medical decision, a potentially significant portion of their decision-making process involves factors not necessarily related to the information provided by their health care team.

The regression analyses suggest that involvement in the life of someone receiving cancer treatment was associated with increased use of experience-based strategies. In contrast, knowing more people with cancer was associated with increased likelihood of using data-based strategies. It's possible that knowing people with cancer made the task more personally relevant, leading some participants to pay more attention to the scenarios than those who did not know anyone with cancer. One interpretation of our regression results is that individuals need a deeper connection with an individual going through treatment in order to incorporate experience-based strategies. Personal narratives are strong influences on medical decisions, the effects of which are not yet clearly understood (Winterbottom et al., 2008). Much of the medical information presented by the media contains personal narratives, yet we often know little about what types of experiences the patient's friends and family have had with similar treatments, or how those experiences influence the patient's decision making process.

In our study, information from various media sources was associated with differential use of decisional strategies. Specifically, participants who used experience-based strategies seemed to be less influenced by information presented in articles. It is possible that these individuals are more influenced by visual and verbal rather than print-based information. Visual and verbal medical information is often influential in major medical decisions, potentially by increasing hope for certain treatments or adding to confusion about available treatment options (Chen & Siu, 2001; Passalacqua et al., 2004).

When examining predictors of treatment choice, we replicated previous studies suggesting that the frame of information is associated with treatment choice. Specifically, framing outcomes in terms of survival rates often leads people to a choice of surgery, which has more short-term risk but better long-term outcomes (Woodhead, Lynch, & Edelstein, 2011). One possible mechanism for this is that the frame of information changes treatment choice by shifting participants' focus on short-term versus long-term outcomes of treatment options<sup>1</sup>.

Finally, our results suggest that use of experience-based strategies may also lead people to choose a riskier treatment (surgery). In the case of cancer treatment, individuals may choose surgery because of preconceived notions about radiation and its side effects. For example, the associated nausea, hair loss, and the conception that it is a "poisonous" treatment (Dauer et al., 2011). Therefore, anecdotal and second-hand information may bias individuals away from a certain treatment.

### **Limitations**

The major limitation of the current study is the use of an undergraduate sample presented with hypothetical vignettes. Our main interest in designing the study was in how participants

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<sup>1</sup> Our results also support this finding. In our sample, 47.5% of transcripts from the mortality framed data received a code of short-term focus versus 29.3% from the survival framed data. 48.8% of transcripts from the survival framed data received a code of long-term focus versus 29.3% from the mortality framed data.

pulled on information that they had obtained from other sources, particularly through talking to family or friends. Because of this, we did not expect or require participants to have personal experience with cancer. Despite this limitation, our results add to the limited literature on the use of anecdotal information in medical decision making, and suggest areas for future research. Future research could examine the use of anecdotal information among participants who have had cancer, and this may yield different results.

The vignettes that we used were from a prior study and may not reflect current outcome data with regard to surgery and radiation treatment for lung cancer. The vignettes from the McNeil et al. (1982) study on framing effects were chosen in order to compare our findings across several studies that have used these vignettes, and to select vignettes that have been used consistently across multiple samples. These reasons were also why we chose to not update the outcome data presented in the vignettes. Although the outcome data was accurate at the time of the McNeil et al. study, and is likely now out of date, our interest in the current study was more about how the information was processed at a broader level, as opposed to how participants reacted specifically to the outcome data.

### **Conclusions and Future Directions**

The results of the current study suggest that the affect heuristic operates even in the context of hypothetical lung cancer decisions (i.e., Slovic et al., 2005). Although our sample had very limited personal experience with cancer, approximately a quarter of our participants incorporated experience-based strategies, mostly second-hand experience obtained from friends and family. Merely knowing individuals with cancer did not increase the likelihood of using experience-based strategies. Use of these strategies was more common if the individual was significantly involved in the life of the person receiving cancer treatment. Therefore, certain

experiences may be more influential than others when it comes to factors that are incorporated into a medical decision. We found that information from the media about cancer and cancer treatment influenced the type of strategy used by participants. It is unclear what effect the use of experience-based strategies may have on the decision making process (Winterbottom et al., 2008). It may be helpful for providers to specifically ask patients about their experience with a specific medical treatment in order to better understand how patients may incorporate personal and vicarious experience into the decision making process. Although the experience that an individual has may be at odds with evidence-based guidelines, a discussion about his or her specific experiences may increase acceptability of treatment and improve physician-patient communication.

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Table 1

*Qualitative Themes and Examples*

Overarching Category	Specific Theme	Theme Definition	Transcript Example
Experience-Based Strategies	Personal Experience with Treatments (n=1)	Participant discusses personal experience with cancer treatments, surgery, or radiation (for any type of condition).	I've had surgery getting my wisdom teeth removed but I don't think surgery is as bad as people make it out to be because the doctors do have to train for 10 years before they become a surgeon so I would trust a surgeon more than chemicals.
	Vicarious Experience with Treatments (n=10)	Participant discusses experiences of others who went through cancer treatments, surgery, or radiation (for any type of condition).	My mom's best friend went through radiation for breast cancer and she wasn't a fan. I think I would just rather take the chance of having a onetime surgery and then recuperating.
	Pre-Existing Beliefs about Treatment (n = 10)	Participant discusses information about the treatments that was not	Radiation therapy does affect your whole body too. I don't think I like the whole idea

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	presented during the study.	of a lot of chemicals going through my body so I choose surgery.
Side Effects of Treatment (n = 14)	Participant discusses medical or practical side effects of treatment that may or may not have been presented during the study.	I know with different kinds of radiation there are different side effects like you may lose a lot of weight, you lose your hair, stuff like that.
Relationship Variables (n = 3)	Participant indicates that they would need to consider how the treatments would impact relationships with family and/or friends.	I think I would be emotionally be able to handle surgery more than radiation, especially with all my family and friends. I would feel just like a burden and embarrassed even when there's nothing to be embarrassed about.
Treatment Process Variables (n = 13)	Participant discusses factors related to the logistics of getting each treatment (i.e., length of treatment).	For surgery...the patient will have to come back to the hospital two or three times...sorry, the patient would have to stay at the hospital for two to three weeks

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			and then they spend a month or so recuperating at home.
Data-Based Strategies	Long-Term Focus (n = 68)	Participant is primarily focused on the 1 or 5 year survival/mortality data.	Because fewer of the patients die by five years which means there's more successful cases than the second one. Even though the 10 died during treatment still I feel like it would be more successful than radiation.
	Short-Term Focus (n = 66)	Participant is primarily focused on the survival/mortality data immediately after treatment.	Yeah, the patients with surgery 10% of them die during the treatment, so I wouldn't take that risk. I would just go with not dying and taking the 4.7 years.
	Discounting the Data (n = 8)	Participant shows evidence of equating the survival/mortality data or rounding the numbers up or down.	In the long-run, it's kinda like almost the same, 'cause there's 32 by one year for the surgery and then there's 23 by one year for radiation and for the...in five years, it's 66 for surgery and 78 for radiation. So, I feel

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		like it kinda...evens out.
Disregarding the Data (n = 6)	Participant shows no evidence of referencing the survival/mortality data.	If there's a 3rd option I would prefer not to have surgery or radiation because I believe that people should go with natural selection. There's too much overpopulation and there's a reason why the weak die off. That's my choice.
Statistical Misinterpretation of the Data (n = 20)	Participant makes an incorrect statement about the survival/mortality data.	Radiation therapy is more effective than surgery because no patients die at all with the radiation therapy. Compared to surgery.

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*Note.* Numbers add up to more than 170 because each transcript could receive multiple codes.

Table 2

*Regressions Predicting Decisional Strategy*

Variable	Cumulative Probability Format					
	Experience Strategy			Data Strategy		
	$\beta$ (SE)	Beta	$t$	$\beta$ (SE)	Beta	$t$
Frame	-0.031 (0.126)	-0.029	-0.249	-0.047 (0.114)	-0.047	-0.412
Current health	-0.088 (0.075)	-0.149	-1.167	0.031 (0.068)	0.057	0.460
Number of other people known with cancer	0.022 (0.034)	0.084	0.639	0.090 (0.030)	0.378	2.964**
Involvement level with person receiving cancer treatment	0.075 (0.036)	0.251	2.060*	0.034 (0.033)	0.124	1.047
Importance rating TV	0.020 (0.083)	0.047	0.236	-0.201 (0.075)	-0.519	-2.673**
Importance rating radio/podcast	0.007 (0.059)	0.020	0.115	0.074 (0.053)	0.231	1.389
Importance rating articles	-0.189 (0.082)	-0.418	-2.309*	0.051 (0.074)	0.122	0.692

*Note.* Experience strategy: Adjusted  $R^2 = .114$ ; data strategy: Adjusted  $R^2 = .159$ .

\*  $p < 0.05$ ; \*\*  $p < .01$