

Risk Communication After Health Care Exposures: An Experimental Vignette Survey With Patients

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Abstract

Purpose. We investigated how health care systems should communicate with patients about possible exposures to blood-borne pathogens that may have occurred during their care. Our goal was to determine how best to communicate uncertain risk information in a way that would minimize harm to patients, maintain their trust, and encourage patients to seek follow-up treatment. **Methods.** Participants ($N = 1103$) were randomized to receive one of six vignette surveys; 997 (98.4%) responded. All vignettes described the same event, but differed by risk level and recommendations (lower risk v. higher risk) and by communication mode (telephone, letter, social media). We measured participants' perceived risk of blood-borne infection, trust in the health care system, and shared decision making about next clinical steps. Open-ended questions were analyzed using grounded thematic analysis. **Results.** When the vignette requested patients to undergo testing and practice certain health behaviors (higher risk), participants' likelihood of seeking follow-up testing for blood-borne pathogens and their understanding of health issues increased. Perceived trust was unaffected by risk level or communication processes. Qualitative data indicated a desire for telephone communication from providers known to the patient. **Limitations.** It is not clear whether higher risk language or objective risk levels in vignettes motivated patients' behavioral intentions. **Conclusion.** Using higher risk language when disclosing large-scale adverse events increased participants' willingness to seek follow-up care. **Implications.** Health care organizations' disclosures should focus on the next steps to take after health care exposures. This communication should involve helping patients to understand their personal health issues better, make them feel that they know which steps to take following the receipt of this information, and encouraging them to seek follow-up infectious disease testing in order to better take care of themselves.

Keywords

experimental study, healthcare exposures, risk communication, veterans, vignettes

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Introduction

When unanticipated events occur during the delivery of health care, such as the discovery of unsafe clinical practices that can lead to blood-borne pathogen exposure (i.e., improper equipment sterilization procedures), health care leaders investigate the health risk the event poses to patients and debate the value of communicating

this risk information to patients. Risk communication is fraught with challenges,¹ and some wonder whether, in

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certain cases, it may do more harm than good by making patients very anxious about what occurred even though they are at extremely low risk of becoming infected from the event.² In many cases, decisions are made not to share such risk information with patients;³ in other cases, this risk information is communicated, but at a cost to both the health care system and patients, with unintended consequences of patients leaving the health care system due to lack of trust and damaging media coverage.^{4,5} Often, when risk information is communicated to patients in health care settings, risks are minimized because they are uncertain,⁶ but also because of the fear of upsetting patients unnecessarily and concerns about reputational harm to the organization, which can potentially result in a breach of trust with patients.⁷ Yet, it is unknown whether risk information is helpful to patients in determining how best to manage their health, nor is it known which process of communication—telephone call,

letter, or through social media—health care systems should use to engage patients.

One example of an unsafe clinical practice involves breaches of reprocessing procedures for endoscopes.⁸ Because of their complex design, endoscopes, such as those used in colonoscopy procedures, will not withstand steam sterilization to eliminate potential blood-borne pathogens.⁹ Instead, reprocessing requires manual outer surface cleaning, brushing to access inner channels and ports, and leak testing to ensure endoscope integrity followed by high-level disinfection, often performed in automated endoscope reprocessors.¹⁰ Although the incidence of endoscope-associated infection is reported to be very low (approximately 1 in 1.8 million procedures),¹¹ hepatitis B virus (HBV) and hepatitis C virus (HCV) infection transmission has been attributed to gastrointestinal endoscopy,⁹ though confirmation of infection through genetic assay has led to unclear results.⁸ Nevertheless, lawsuits have been filed, indicating the distress that many patients felt following disclosure of events related to contaminated endoscopes in several US Veterans Affairs (VA) medical centers, and the potential, albeit remote, of contracting blood-borne pathogens such as HIV, HBV, or HCV following this exposure.¹² Communication and resolution programs (CRPs) now operate across many states and health systems, and are designed to encourage disclosing unanticipated care outcomes to affected patients and proactively providing resolutions, including offering an apology, an explanation, and, where the outcome was caused by error or system failure, reimbursement or compensation.¹³ Empirical data on how risk information should be framed for patients will also provide further evidence for the operation of these CRPs.

Perceived Lower or Higher Risk of Contracting HIV or Hepatitis

Qualitative interviews with patients who previously received written notifications about an exposure indicated that they wanted to receive timely, direct, and detailed information about their health risks.⁷ Yet the best way to communicate this information, to encourage patients to return to the health care system to undergo HIV or hepatitis testing, remains unclear. Experimental study designs are helpful for determining what type of communication messages maximize the chance that patients may return for blood-borne pathogen testing at a hospital where a health care exposure occurred.¹⁴ Therefore, we conducted a randomized, experimental, vignette-based survey with Veterans. We chose to test an approach for communicating risk information that

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Table 1 Risk Manipulation Differences Between the Lower Risk Vignettes versus the Higher Risk Vignettes

Lower Risk Vignettes	Higher Risk Vignettes
<ul style="list-style-type: none"> • Cleaning process is a multiple step process and one of those steps was not completed • Apologizes for error and any anxiety it has caused you • Risk of exposure to viral diseases is “very low” • Optional testing is available at no cost to you, to alleviate any concerns you may have • Risk is low enough that VA is not requiring testing • Encourages you to call if you have additional questions 	<ul style="list-style-type: none"> • Cleaning process is a multiple step process and two of those steps were not completed • Apologizes for error and any anxiety it has caused you • Panel of experts has reviewed issues • Recommends that you come in for testing, which will be done at no cost • Some precautions you should take until testing results are available in 10 days • Practice safe sex; do not donate blood, share razors, or tooth brushes • No alcohol and do not take Tylenol • Encourages you to call if you have additional questions

involves sharing minimal information on the health care incident and providing an option for blood-borne pathogen testing but not requiring it (perceived lower risk of contracting HIV/hepatitis), compared with an approach where specific next steps and behaviors are emphasized in the communication process (perceived higher risk of contracting HIV/hepatitis). It is possible that patients receiving information about unanticipated health care events that differs in perceived risk will react differently to the event. For example, those who receive lower risk information may report greater trust in the health care system and may continue seeking health care there, whereas those who receive higher risk information may decide to seek health care at a different facility, or not at all.

Our study aimed to test the hypothesis that participants who perceived a higher risk of contracting an infectious disease, who believed that the health care system put a lot of effort into communicating health risks to them, and who received information requesting that they undertake specific health behaviors, would be more likely to seek follow-up testing for HIV, HBV, and HCV. In this way, the higher risk communication about contracting HIV/hepatitis approach emphasizes the positive consequences of health behaviors, such as follow-up testing.¹⁵ Additionally, in our prior work, Veterans involved in a health care exposure who had received a letter from their VA medical center stated that they would have preferred a phone call from a health care provider they knew, so that they could talk about the risks of the event and about their likelihood of contracting HIV, HCV, or HBV⁷ (see Appendix 1 for a de-identified example of a previous notification letter). Thus, based on this prior qualitative work, we hypothesized that participants receiving a telephone call as a first

step in the communication process about the unanticipated event would be more likely to report greater trust in the health care system than those who received other modes of communication.

Methods

Overview

We contracted with GfK,¹⁶ a market research company, to conduct an experimental vignette survey with Veterans included in their online research panel of approximately 50,000 US residents, known as KnowledgePanel (KnowledgePanel is now owned by Ipsos, headquartered in New York, New York).¹⁷ The VA provides care to approximately 6.1 million men and women who are eligible for inpatient care, outpatient care, purchased (fee basis) care, long-term services and support, or pharmacy care¹⁸ through a network of 170 VA medical centers and over 1200 community-based outpatient clinics. Panel members were asked to indicate whether they had received VA health care in the last 3 years. Those who reported having used VA health care in the past 3 years were then randomly assigned one of six vignettes. Each vignette depicted a Veteran named Mr. Jones who had recently undergone a colonoscopy at a fictional VA medical facility, and was notified that the colonoscopy equipment was not properly sterilized before his procedure (see below and Appendix 2). Each vignette varied according to one of two risk scenarios for undergoing testing for blood-borne pathogens (perceived higher or lower risk for contracting HIV/hepatitis; Table 1), and the communication process by which the Veteran learned of this risk (telephone call, mailed letter, or through a social media announcement; Table 2). All survey questions

Table 2 Vignette Communication Modes and Risk Communication Approach

Vignette	Communication Mode	Risk Communication Approach
1	Social media → Provider call → VA letter	Higher risk
2	VA letter → Provider call	Higher risk
3	Provider call → VA letter	Higher risk
4	Social media → Provider call → VA letter	Lower risk
5	VA letter → Provider call	Lower risk
6	Provider call → VA letter	Lower risk

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were the same across each of the six vignettes. GfK presented de-identified survey data to the study team for analyses. This study was deemed exempt from human subjects review by the Stanford University Institutional Review Board (Protocol ID: 23411, PI: [Todd Wagner, PhD], Veteran and Staff Perceptions of VHA Large Scale Adverse Event Communications).

Survey Design

The survey uses a complex survey design.¹⁹ GfK weights the survey data using a three-step weighting strategy that uses populations distributions derived from the most recent Current Population Survey estimates of gender, age, race/ethnicity, education, Census region, metropolitan statistical area, and internet access,²⁰ any noncoverage and nonresponse due to panel recruitment methods and attrition, and the surveys' nonresponse using an iterative proportional weighting ("raking") strategy.²¹ These weighted analyses, along with corrections to the standard errors based on variance linearization,¹⁹ yield estimates that are representative of the US veteran population. Further information about the KnowledgePanel design, recruitment methodology, sampling, response rates, and statistical weighting are available elsewhere.^{17,22}

Vignette Descriptions

Participants were randomly assigned to one of six vignette conditions within which they were asked to imagine they had been exposed to a potentially unsafe clinical practice. Each vignette began as follows:

Your name is Mr. Jones. You are 52 years old and routinely use your local VA medical center, the Eastville VA, for medical care. Your regular doctor, Dr. R, has recommended that you have a colonoscopy, a test recommended for all patients your age. It is a cancer screening procedure that requires your doctor to check your colon for suspicious

growths by looking through a camera attached to a medical device that is inserted in your colon while you are under general anesthesia. You agree to have the colonoscopy procedure. The procedure is performed a week later at the Eastville VA Medical Center by VA staff. Afterwards, Dr. R contacts you to let you know that "everything is fine and there is no follow-up care needed."

Vignettes were then manipulated to convey either lower risk or higher risk for contracting HIV/hepatitis. Table 1 provides an overview of how vignettes differed. The following is an example of a lower risk communication approach that followed the aforementioned vignette delivered by letter written by the fictional VA medical center director:

A month and a half after your colonoscopy, you receive a letter from the Eastville VA Medical Center Director, explaining that there was an issue with your colonoscopy. The letter explains that the colonoscopy equipment wasn't cleaned properly by the staff. The cleaning process is a multiple step system and one of those steps was not completed.

The Medical Center Director apologizes on behalf of the Eastville VA Medical Center for the error and any anxiety it may cause you. The letter tells you that the risk of exposure to viral diseases like HIV, hepatitis B, and hepatitis C is "very low." However, optional testing is available at no cost to you to alleviate any concerns you may have. Testing results should be ready within 10 days. The letter explains that the use of this equipment could lead to infections if one patient comes into contact with the same equipment used on a patient with an infectious disease. The Medical Center Director's letter tells you that the risk is low enough that the VA isn't requiring testing, but the VA will provide you with testing and any follow-up care that is needed. The letter provides you with a special phone number at the Eastville VA Medical Center set up specifically for Veterans to call with questions about this event. The letter encourages you to call if you have any additional questions about what happened or are ready to set up a testing appointment.

An example of a higher risk communication approach that followed the vignette delivered by telephone by Dr. R is as follows:

A month and a half after your colonoscopy, Dr. R calls you at home to talk about an issue with colonoscopies. He explains that the colonoscopy equipment wasn't cleaned properly by the staff. He provides more detail about the cleaning process. It is a multiple step system and two of those steps were not completed.

He apologizes on behalf of the Eastville VA Medical Center for the error and any anxiety it has caused you. Dr. R tells you that a panel of experts has reviewed the issues. They recommend that you come in for testing for viral diseases like HIV, hepatitis B, and hepatitis C. He says the testing will be done at no cost to you. Testing results should be ready within 10 days. Dr. R tells you that there are some precautions you should take before you receive your test result: "You should not donate blood, share razors, or tooth brushes. You should practice safe sex, which includes the use of a condom. You should not drink alcohol or take Tylenol products because they could be harmful to you if you have one of these diseases."

Dr. R asks if you have any questions that he can answer and you spend some time discussing the level of risk to you. He explains that the use of this equipment could lead to infections if one patient comes into contact with the same equipment used on a patient with an infectious disease. Dr. R explains that the VA will provide you with testing and any follow-up care that is needed. He gives you a special phone number at the Eastville VA Medical Center set up specifically for Veterans to call with questions about this event. He encourages you to call if you have any additional questions about what happened or are ready to set up a testing appointment. Finally, he lets you know that "You should receive a follow-up letter from the Eastville VA soon with the information we discussed today."

Measures

We tracked eight outcomes. The key variables of interest in analyses were 1) risk perception of the vignette (perceived lower risk v. perceived higher risk), as well as 2) mode of communication (1] social media to call to letter, 2] call to letter, and 3] letter to call). We measured *risk perception* using two questions. The first item read: "Given what you have just read, how likely do you think it is that you might get HIV from this event?" The response options for this item ranged from 1 (very unlikely) to 10 (very likely). The second item had the same structure but asked about hepatitis instead of HIV. Next, we asked respondents about the effort made in the

disclosure to help them understand their health: "How much effort was made to help you understand your health issues?" The response options for this item ranged from 1 (no effort) to 10 (every effort). This item was previously validated.²³ This was followed by: "How much effort was made to include what matters most to you in choosing what to do next?" The response options for this item ranged from 1 (no effort) to 10 (every effort). This item was previously validated.²³ We then asked two questions about their *intended behavior*: "Would you get HIV, hepatitis B, and hepatitis C testing?" The response options were "Yes," "No," and "Not sure." Few respondents said they would not seek testing at all ($n = 27$ respondents indicated "No"). Therefore, "Not sure" and "No" were collapsed to reflect individuals who were ambivalent about testing. We then asked, "Would you get that testing from the VA?" The responses were binary: "Yes" and "No." We also assessed participants' baseline level of trust in the health care system, using four questions to ask participants to rate their level of agreement on a scale of 1 (strongly disagree) to 10 (strongly agree) with the following statements, based on their experience with the VA: 1) I trust the VA to put my medical needs above all other things; 2) the medical skills of the VA doctors and nurses are not as good as they should be; 3) I trust the VA will give me all the information I need about my treatment; 4) the VA system will not give me the best care possible.²⁴ Reliability was strong for the VA trust item (Cronbach's $\alpha = .85$). Finally, two open-ended questions at the end of the survey were presented: "What did you like about this notification?" and "What did you dislike about this notification?" Responses from these open-ended questions were used as qualitative manipulation checks, and to identify additional themes that may be important for communicating risk information.

We asked respondent gender, racial and ethnic identification, marital status, age, educational attainment, household income estimate, residence in a metropolitan statistical catchment area (a proxy for urban/rural residence), household size (continuous), branch of military service, how long the Veteran respondent had served in the military, and an estimate of the last time the respondent had sought care in the VA, and an item asking whether the respondent had been notified by the VA of potential exposure.

In addition to these respondent characteristics, respondents completed the General Self-Efficacy Scale (GSE),²⁵ which we included to assess how much self-efficacy may play a role in the decision-making process

of a patient when notified about a potential infectious disease exposure. GSE internal reliability was strong in this study (Cronbach's $\alpha = .91$). We also assessed the state anxiety immediately prior to the notification through the state short-form anxiety scale from the State-Trait Anxiety Inventory (STAI) using the validated STAI-6 short form state inventory.²⁶ Internal reliability was also strong in this study (Cronbach's $\alpha = .86$).

Because VA health care is often reported negatively by the media,⁵ we also included an item assessing the respondent's familiarity with a recent wait-times scandal affecting the VA that the respondent may reference for a similar situation of widespread negative publicity for the VA in the media.

Analyses

Our quantitative analyses involved two stages. First, for each of the outcomes described we fit a grouped-regularization machine learning model to select respondent characteristics that were most strongly associated with each of the outcomes. We selected characteristics based on the grouped-Minimax Concave Penalty (grouped-MCP) using 10-fold cross-validation.^{27,28} The MCP relaxes the thresholding penalty and often produces less biased estimates than the Least-Absolute-Shrinkage-and-Selection-Operator (LASSO) it is adapted from. We fit the "grouped form" such that all categories of a particular demographic feature are either included or excluded from the final feature selection. For example, age categories would all be selected or all be excluded. All grouped-MCP models used either the linear or logistic generalized linear model framework. From the grouped-MCP models fit, we selected all characteristics identified in any of the models for inclusion in the second stage of analysis. However, because regularization penalty machine learning models produced biased estimates relative to unpenalized parametric alternatives (e.g., maximum likelihood), we refit models with these selected characteristics in a second stage of analysis.

The second stage of analysis was fit with linear and logistic regression models accounting for survey design weights and clustering for respondents in US states as different areas of the country have very different Veteran residence. This approach uses Taylor variance linearization to produce robust-standard errors of parameter estimates.²⁹ We included all respondent characteristics identified in the grouped-MCP regularization selection models in the first stage. These characteristics included gender, age category, racial/ethnic identification in the survey, educational attainment category, the last time

the respondent sought care in the VA, pre-vignette state anxiety, household size, self-efficacy scores, VA trust in health system scores, whether the respondent had been previously notified about possible exposure, and the degree of familiarity with media about the wait-times concerns that have most prominently featured the VA in a negative light in recent years.

For each of the outcomes, we tested two models with the Risk and Approach-to-Notification (ATN) vignette conditions. The first was an additive model (Risk + ATN) and the second was an interaction model (Risk-by-ATN, which is analogous to a six-category model in the case of the two-by-three factor variables). The additive model provided better fit (further details upon request from the author). As a result, we present results from only the additive models that are adjusted for characteristics identified in the first stage of analysis described above. With all descriptive and inferential regression model parameter estimates, we present 95% confidence intervals (CIs) reflecting the survey weights. In addition to model parameter estimates, we estimated weighted average marginal predictions from models to provide estimates of positive goal framing versus the standard approach vignette conditions and the three communication modes. The marginal predictions were based on covariates at their observed values.

Qualitative responses were organized using NVivo 10 software.³⁰ A grounded thematic analysis approach was used.³¹ Two coders independently coded a sample of 10 sets of comments for each of the six vignettes ($n = 120$; 60 for each qualitative question). Coding was compared and any variances were discussed until coding agreement was reached. Coders then completed additional coding for a total of 240 sets of comments (120 of each of the two questions) until saturation was reached. The final coding framework is presented in Table 3.

Role of Study Funder

The study funders had no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the manuscript; or in the decision to submit the manuscript for publication. Data are available from the first author upon request.

Results

Survey Response and Sample Characteristics

GfK sent the survey to people who had previously indicated that they were aged 18 years and older residing in the United States and previously served as active duty military ($N = 4672$). Of these, 3453 (73.9%) responded

Table 3 Qualitative Themes and Codes and Example Quotes

Themes and Codes	Example Quote
General reaction to the vignette event	“Just the fact that I was notified would amaze me.”
Receiving notification in general	“That they were open and honest about what happened and told me openly about the possible consequences of what may happen.”
Directness of communication language	“It gave all necessary information and provided contact points.”
Level of detail of information	“Also, of course, I am angry that these mistakes took place making it necessary for me to receive a notification.”
General dislike of event itself	
Taking responsibility for the event	
Apology from health care organization	“It explains the potential problems and solutions. The VA takes full responsibility.”
Accountability of health care organization	“Nobody was going to be fired so that they could not cause a similar event. It did not give confidence in future VA services.”
Reassurance	“It spelled it out, apologized, attempted to start the ball rolling on what to do, and then reassured the patient that all will be done that needs to be done.”
Ways of communicating with patients	
Order of communication	“That it came ‘out of the blue.’ I would have appreciated a phone call first.”
Who notified patient	“Not only did the director send a letter but the physician also sent one.”
Personalized communication	“It felt like a canned response.”
Formality of communication process	“VA notices tend to be dry and formal to a fault.”
Timing of communication	“Got it in a timely manner.”
Processing the risk	
Risk level	“They downplayed the event. They tried to make me feel the risk was very low and testing was not important.”
	“It lacked details I would appreciate to hear, including if there even were patients that had those diseases that used the machine and exactly what method of cleaning should have been performed that was not.”
VA trust	“The VA always tries to down play mistakes so I would not trust the notification.”
Fear of event	“I know it’s a very real chance of contracting one of these diseases through improper procedures like the cleaning procedures in this story and I know the personal costs, fears and shock you go through in a situation like this.”
Action item for patient	“The VA was honest with me and offered additional testing for HIV and hepatitis, which in this case, I would definitely get tested for both. Just to be on the safe side.”

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to this screening survey, and 1013 (29.3%) stated they had used VA health care services in past 3 years, qualifying them for the experimental vignette study. Of these 1013 participants, 997 (98.4%) of these panel participants completed the main experimental vignette survey items. The weighted demographics of the vignette participants are presented in Table 4; the weighting samples may not sum to exactly 997.

Adjusted Results

Because it can be difficult to interpret beta coefficients and odds ratios, we computed the average marginal

predictions for lower risk versus higher risk vignettes in Figure 1. Figure 2 presents the average marginal predictions for all communication modes. Higher risk vignettes recommending specific behaviors to engage in (e.g., testing) and behaviors to avoid (e.g., unprotected sex) significantly increased participants’ perceived likelihood of HIV infection, though perceived likelihood of HIV infection did not significantly vary as a function of communication mode. The same pattern was present for perceived likelihood of HBV or HCV infection with those receiving higher risk vignettes reporting increased perceived likelihood of infection, but no significant variation among communication modes in the vignette condition. Higher

Table 4 Veteran Respondent Characteristics

Vignette Conditions	<i>n</i> ^a	SE (<i>n</i>)	<i>p</i> ^a	SE(<i>p</i>)	95% CI	
					LL (<i>p</i>)	UL (<i>p</i>)
Vignette risk level						
Randomized to lower risk vignette	526		.53			
Randomized to higher risk vignette	471		.47			
Vignette communication mode						
Randomized to “Letter to Call” approach	346		.35			
Randomized to “Call to Letter” approach	317		.32			
Randomized to “Social Media to Call to Letter” approach	334		.33			
Survey respondent characteristics and background						
Age						
a. 75 or older	156	30	.16	.02	.13	.19
b. 65 to 74	324	48	.32	.01	.3	.35
c. 55 to 64	225	35	.23	.02	.19	.26
d. 18 to 54	293	46	.29	.02	.25	.33
Racial-ethnic identification						
a. Non-Hispanic White	683	96	.69	.03	.62	.75
b. African American	179	44	.18	.03	.12	.24
c. Hispanic	99	28	.1	.02	.06	.14
d. Other	37	9	.04	.01	.02	.05
Gender						
Male	893	131	.9	.01	.87	.92
Female	104	19	.1	.01	.08	.13
Urban-rural MSA status						
Metro	822	137	.83	.02	.78	.87
Non-Metro	175	21	.17	.02	.13	.22
Notified by VA about possible exposure						
No	943	133	.95	.01	.93	.97
Yes	54	16	.05	.01	.03	.07
Military service branch						
a. Army	526	74	.53	.02	.48	.57
b. Air Force	154	23	.15	.01	.13	.18
c. Navy	197	37	.2	.02	.16	.23
d. Marine Corps	83	20	.08	.01	.06	.11
e. Other	39	12	.04	.01	.02	.06
Education						
a. BA/BS/higher	252	38	.25	.01	.22	.28
b. Some college	434	67	.44	.02	.4	.47
c. HS or less	312	49	.31	.02	.27	.35
Household income						
a. <\$25,000	209	35	.21	.02	.18	.24
b. \$25,000–49,000	258	41	.26	.02	.22	.29
c. \$50,000–74,000	227	36	.23	.01	.2	.26
d. \$75,000–99,000	165	36	.17	.02	.12	.21
e. >\$99,000	140	24	.14	.02	.1	.18
Last time in care at VA						
a. <6 months	691	106	.69	.02	.66	.73
b. 6 to 12 months	125	23	.12	.01	.1	.15
c. 12 to 24 months	83	17	.08	.01	.05	.11
d. >24 months or unsure	99	20	.1	.02	.07	.13
Length of military service (years)						
a. <2	185	33	.19	.02	.15	.22
b. 2–3	179	33	.18	.02	.14	.21
c. 3–4	260	38	.26	.02	.23	.29
d. 5–9	149	27	.15	.01	.12	.18
e. 10–19	86	21	.09	.02	.05	.12
f. 20+	141	29	.14	.02	.1	.18

(continued)

Table 4 (continued)

Vignette Conditions	<i>n</i> ^a	SE (<i>n</i>)	<i>p</i> ^a	SE(<i>p</i>)	95% CI	
					LL (<i>p</i>)	UL (<i>p</i>)
Marital status						
a. Married	610	84	.61	.03	.56	.67
b. Divorced or separated	209	38	.21	.02	.18	.24
c. Single	132	29	.13	.02	.1	.17
d. Widowed	47	10	.05	.01	.03	.06
Familiarity with VA wait times scandal						
I have heard a lot of news media coverage about VA's wait times.	726	102	.73	.02	.69	.76
I have heard some news media coverage about VA's wait times.	215	41	.22	.02	.18	.25
I have not heard any news media coverage about VA's wait times.	57	14	.06	.01	.03	.08

CI, confidence interval; LL, lower limit; MSA, metropolitan statistical area; SE, standard error of the estimate; UL, upper limit; VA, Veterans Affairs.

^a*n* = survey weighted subsample size.

^b*p* = survey weighted proportion.

risk vignettes also appear to have increased perceptions that the notification process helped participants understand the health issues faced as a result of exposure, though communication modes did not result in meaningful differentiation in this outcome. Notably for the item assessing perceptions of how much effort was made to include what matters to the participant in choosing what to do next, neither lower risk or higher risk vignettes nor communication mode of the vignette appeared to significantly vary the outcome. Appendix 3 presents all parameter estimates of the four linear models.

Of the behavioral intention outcomes, respondents presented with higher risk vignettes had a lower odds of indicating they would be ambivalent toward seeking testing. Communication mode presented in the vignette did not appear to alter ambivalence toward testing. Similarly, individuals presented with a higher risk vignette were less likely to report that they would not seek testing at the VA, though communication mode also did not appear to affect how likely the respondent would be to seek testing at a VA. Participants who responded positively to the item "I have heard some news media coverage about VA's wait times in the last month" were more likely to state that they are unsure or would not seek testing for HIV or hepatitis at all, not specifically at a VA medical center. Appendix 4 presents all parameter estimates for the binary logistic regression models.

Qualitative Results

Nearly all (*n* = 982; 98.5%) respondents completed both of the open-ended questions. Responses to these

questions indicated that study participants had placed themselves in the position of Mr. Jones when completing the survey questions, suggesting that the experimental manipulation had been successful; verbatim responses using "I" and "my" words illustrate this. For example, one participant stated, "I'm glad they told me" about the large-scale adverse event. Another said, "I feel that the VA was sincerely concerned." One Veteran stated, "I felt that it [the notification] sincerely conveyed concern about my welfare, that it took full responsibility for what had happened, and that it assured me of any and all follow-up care should any be needed."

Through a consensus and discussion process, we collapsed the 16 emergent codes presented in Table 3 into four main themes, described below.

General Reactions to the Vignette Event

Following the vignette, participants were first asked, "What did you like about this notification?" Respondents who received any of the six vignettes discussed their satisfaction receiving a notification in general. "The fact I was notified in itself is a great step" was a common type of response and highlighted that patients were satisfied that the medical center came forward to tell them about the event. Many respondents throughout all six vignettes liked the honesty and straightforwardness of the communication, reflected in this statement: "That they were open and honest about what happened and told me openly about the possible consequences of what may happen. Also, that they offered alternatives for me to think about and act on."

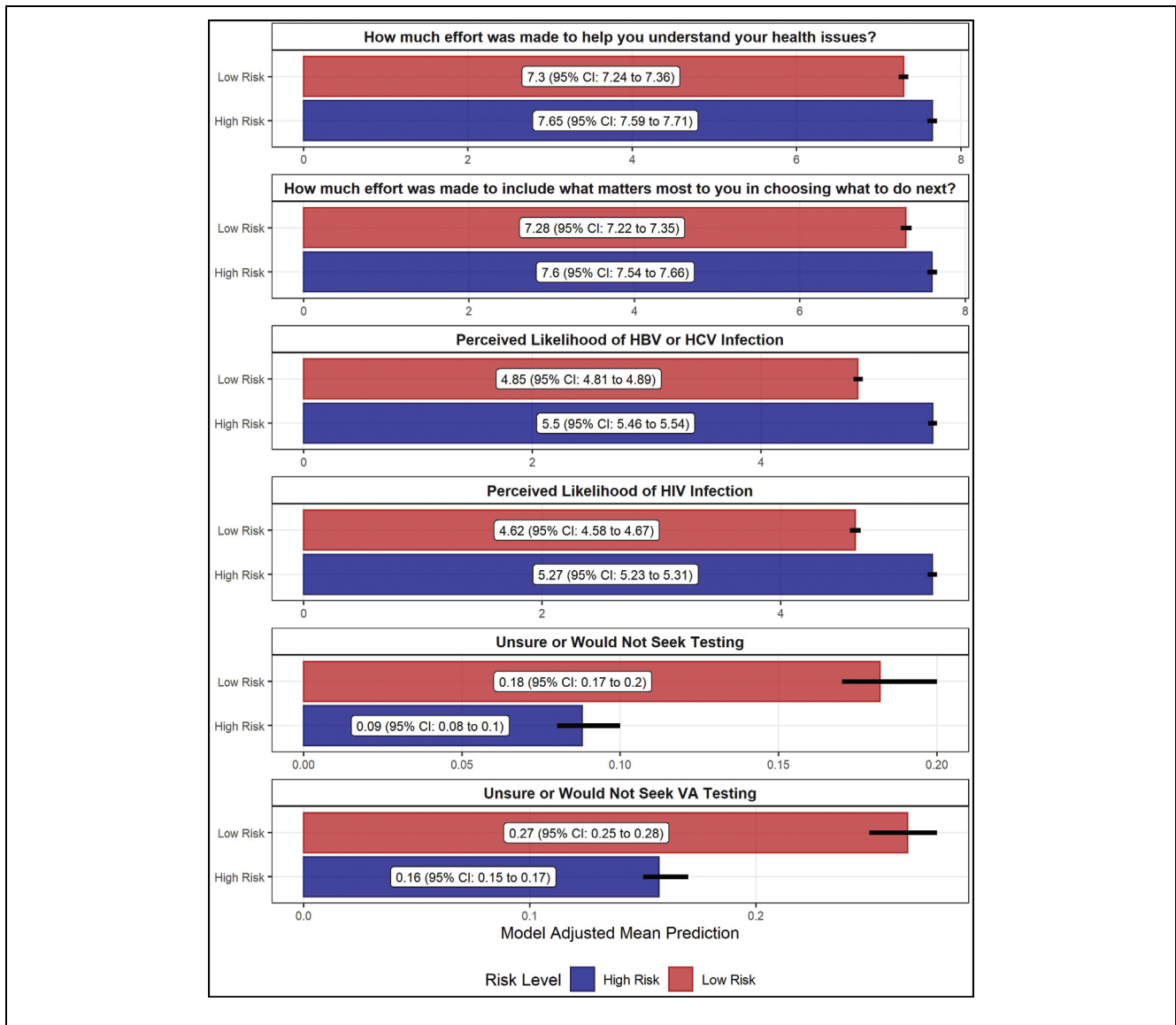


Figure 1 Vignette risk framing model with adjusted prediction estimates.

For the second question, “What did you dislike about this notification?” participants responding to any of the vignettes often responded that they did not like the exposure/event itself. “Just what the notification represents. The fact the person may have a disease they shouldn’t have.” Thinking through the possibility of being notified about an avoidable error in their medical care was a negative for study participants, including the potential impact it could have on their personal health. In general, participants seemed to take the vignette seriously and carefully thought through their responses to the

qualitative questions asked. At times, they related the vignette to their past experiences receiving care from the VA, either positively or negatively.

Taking Responsibility

The use of apology and taking responsibility for the unsafe clinical practice was noted as a positive feature to some respondents, when responding to what they liked about the notification: “The VA takes full responsibility” and “That they acknowledged their mistake and my

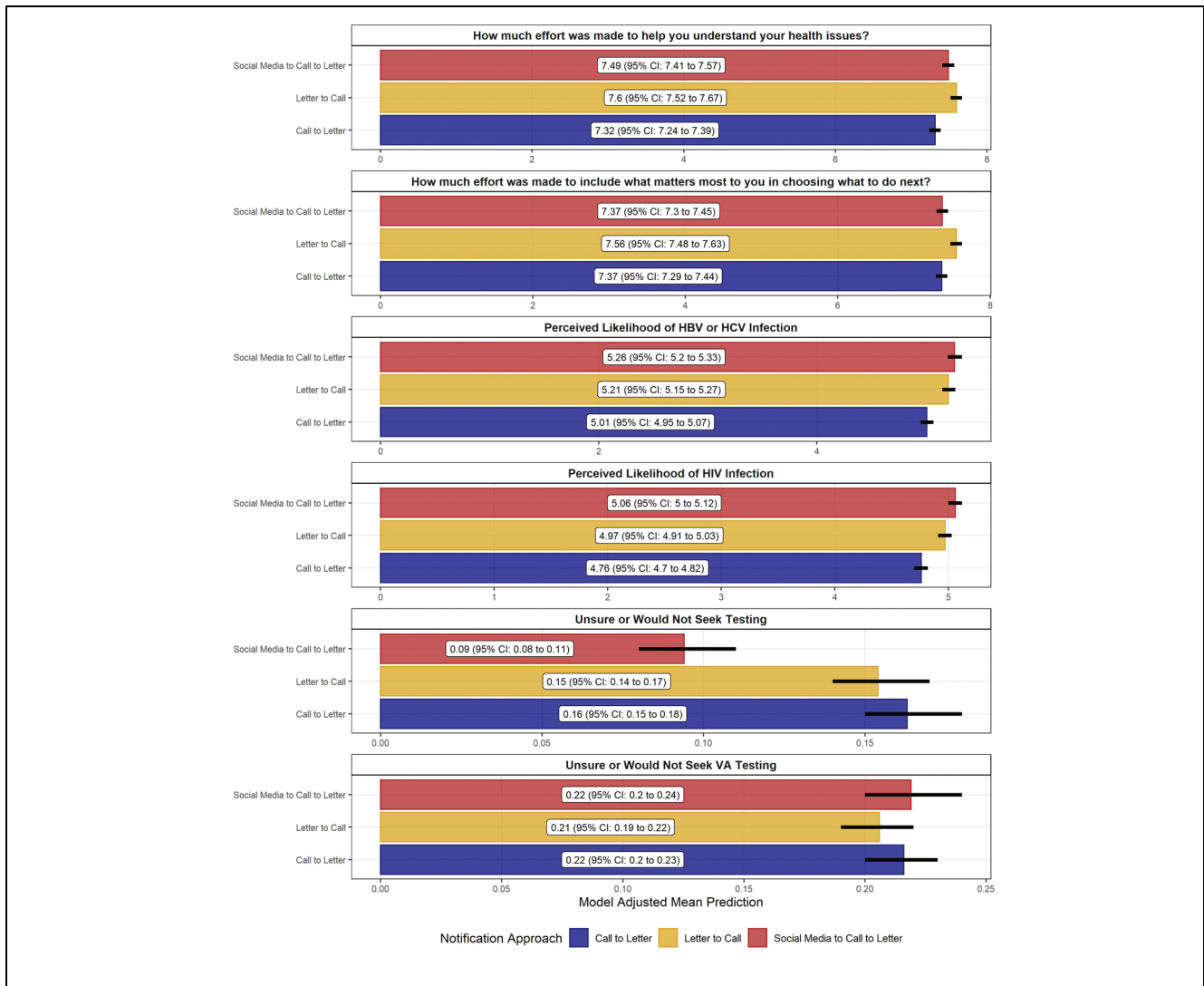


Figure 2 Vignette notification approach model with adjusted mean predictions.

possible exposure, and offered additional testing if desired for my own peace of mind.” The importance of apology has been well studied in relation to adverse events in health care.³² In the vignettes, apologies were made by the doctor during the phone call and by the medical center director in the letter. Responses reflect that both apologies were noteworthy to participants.

Ways of Communicating With Patients

We looked at qualitative responses according to the different communication modes and order of communication patterns to determine what participants thought

about these methods. The quantitative analysis of the order of communications (letter → call, call → letter, or social media → call → letter) showed no significant impact on trust, perceived risk, or willingness for testing (Figure 2). Qualitative responses, however, revealed that order of communications was important to patients. Some patients who received a first notice of the event from either social media or a letter made comments about these methods, noting their desire for a phone call to be the first form of contact: “Notification should have been by phone followed up by a letter” and “(I disliked) that it came ‘out of the blue.’ I would have appreciated a phone call first.”

There were comments about the multiple forms of communication and efforts made to reach patients. Patients appreciated multiple, personalized forms of contact: “It was thorough, personal, and presented in both written and oral” and “It was repeated using different methods.” Some discussed how the letter follow-up to a phone call helped them take in the information provided: “The written form allows one to reread parts for a more thorough understanding if necessary.”

In addition, who made the contact seemed to make a positive impression on the participants. The vignettes featured a provider (Dr. R) making a phone call to the participant (Mr. Jones), and the letter was signed by the hospital director: “Not only did the director send a letter but the physician also sent one” and “The doctor called first, not an aide.” Respondents recognized who contacted them and appreciated the effort made by either someone they had a relationship with or who was a leader in the organization.

Processing the Risk

The level of risk varied among those receiving higher risk vignettes where testing was “recommended” compared to those receiving lower risk vignettes where testing was “optional.” With the higher risk vignettes, many patients had questions about the other patients who were in the affected cohort. They commented with questions about whether anyone actually had HIV or hepatitis already or had since tested positive. These questions and comments about others were strategies to help them assess the risk level to them personally. “It didn’t tell me how many known diagnosed patients with either hepatitis or HIV had colonoscopies during the subject time period.”

For the lower risk vignettes, there were some comments about wanting more detail about whether others had these diseases. Unique to the lower risk vignettes were many comments that the communication was downplaying the level of risk. “They downplayed the event. They tried to make me feel the risk was very low and testing was not important.” These comments about downplaying the risk were not present for those who received the higher risk vignettes. With the lower risk vignettes, many comments were around the “option” for testing, signaling that patients understood that testing was being offered but not required or recommended. “It gave me the option to get checked out for free and let me know the risk is very low.”

Discussion

Using a higher risk communication approach when disclosing a large-scale adverse event increased participants’ likelihood of seeking follow-up testing for HIV or hepatitis, and their interest in understanding their health issues and making subsequent health care decisions, compared with the lower risk approach to communicating risk information. The higher risk approach to communication in this study consisted of highlighting the benefits or gains that a participant would receive, in this case, of undergoing HIV and hepatitis testing, to increase their health and well-being. When the benefit of undergoing testing was perceived to be positive, participants indicated strong intentions for getting tested, and stated that they wanted to understand more about their health issues.

On the contrary, the lower risk approach to communication was associated with a lower likelihood of seeking testing. This suggests that health care institutions have the ability to communicate information about health care exposure risks in a way that supports or minimizes the need for patients’ follow-up testing and that patients’ subsequent behaviors will be in line with this. Our higher risk communication approach highlights that people respond positively to clear messages describing benefits to them, such as returning to the health system for testing, and practicing safe and healthy behaviors. While health care systems may wish to downplay health care events and next steps, as was the approach taken in the lower risk vignettes (i.e., not recommending testing explicitly but offering it if patients are interested; not providing specific behaviors to follow), this communication about the health care event appeared to result in patient confusion and is difficult for patients to process. Disclosure processes used in CRPs throughout US health systems may also benefit from taking a higher risk approach to communication, highlighting the benefits in taking steps to promote patients’ health and well-being in the face of any health system error or unanticipated outcome. Higher risk communication approaches may also promote patient satisfaction and feelings of being treated with respect during disclosures.³³ Moreover, some of the participants’ qualitative responses indicated that they needed more information to assess their personal risk of contracting HIV or hepatitis, such as whether or not anyone with these diseases had undergone colonoscopies at the same time as them. This is information that health systems, and CRPs, could include in their approaches to

disclosure, to help people make informed decisions about their next steps and future behavior.

Importantly, patients' trust in the VA health system appears unaffected by communicating risk information at all; therefore, health care systems and leaders should feel assured that being transparent about potential risks is the correct patient-centered policy to adopt. Additionally, there were no differences in how patients' perceived risk information resulting from different communication processes. In our previous qualitative research, participants reported wanting to learn about risk information directly from their own provider,⁷ though this finding did not hold in our quantitative analyses. As one of the main reasons for communicating risk information is to help engage receivers of the communication in a particular behavior,³⁴ it appears that higher risk communication provided more motivation to patients to seek blood-borne pathogen testing, as opposed to those who received a lower risk communication approach, where testing was optional and no specific next steps were provided. Using higher risk communication language appears to be important for information about any level of risk exposure that health systems needs to communicate to patients and their families.

In our qualitative analyses, we found that the participants who received higher risk vignettes indicated that they understood the need for follow-up testing and were willing to have that testing to reduce uncertainty. Although participants appeared to understand their risk, they asked for even more information related to risk, including whether others had tested positive. The risk in these events is likely unfamiliar to these patients as most indicated that they had not previously been involved in a large-scale adverse event of this type. When risk is unfamiliar, patients seek out details to help better understand that risk.³⁵ These participants felt that the organization was being honest and open with them overall, but looked for more information to assess how they felt about the risk and what actions they wanted to take.

In contrast, those who received the lower risk vignettes were more uncertain about risk levels and whether the health care organization was being transparent with them. These responses tell us that more communication is needed to help clarify the risk level, what personal action is needed, and how the organization is responding to issues. Overall, respondents appreciated being told about events of this type, whether the information received was in a higher or lower risk communication approach. This fits with our previous understandings that disclosure is important to patients.^{5,7} Transparency

in communication was noted as important and a straightforward, personalized approach to communication was ideal. This finding has implications for how health care systems and providers are communicating information about COVID-19 exposures as well: Lessons learned from this study suggest that systems and providers should not minimize any risks to patients, be transparent about numbers of patients affected by the coronavirus, and be as personalized as possible about the way this information is communicated.

There were several findings about the mode of communication that can be immediately utilized by health care organizations implementing these types of disclosure communications. First, instead of utilizing a call center approach, having a provider who the patient knows make the initial outreach can be important in making sure patient questions are answered right away and by someone known to the patient. Indeed, participants indicated in qualitative responses how glad they were to receive information from their doctor directly. Participants indicated that by the doctor calling the patient, they showed that they cared for the patient, and this helped reduce the anxiety that resulted from learning about the exposure. Second, patients appreciated the letter signed by the medical center director, signaling the importance and priority of the patient to the health system. Third, participants confirmed that receiving information by phone, where they could discuss and ask questions of a trusted provider, and in written follow-up form, where they could review the information provided, was ideal. Receiving messages in multiple forms helps patients process information,³⁶ and initial telephone contact allows patients to ask questions and then think through information before they engage in follow-up care.³⁷ Providers may need support or training to conduct these disclosure communications and accurately describe the potential risk to patients.

Limitations

Our study is not without limitations. Although our study indicated that using specific, higher risk messaging during disclosures was likely to lead to patients' follow-up testing, it is difficult to know if this finding would hold if the objective amount of risk presented in the vignettes was the same across both lower and higher risk scenarios. The lower risk vignettes indicated that one step in the equipment cleaning process was missed, and the higher risk vignettes indicated that two steps were missed. Thus, it is not clear whether the higher risk language of recommending testing and encouraging health behaviors was

the motivation for patients' reported intentions for getting tested for HIV/hepatitis, or if the objective risk levels presented about the equipment reprocessing steps missed also motivated patients' intentions. Further studies are needed where objective risk information is held constant and where vignettes utilize a framing effect of risk communication, to better understand how to communicate uncertain risk information. For example, large-scale disclosures guided by goal framing would frame the decision of HIV or hepatitis testing on the potential benefits or gains (taking care of one's health) or potential losses to avoid (engaging in unprotected sex prior to knowing one's HIV or hepatitis status).¹⁵

Additionally, we relied on qualitative methods to assess whether the experimental manipulation between the higher risk vignette and the lower risk vignette was successful. Responses to two qualitative questions at the end of the survey indicated that study participants had placed themselves in the position of Mr. Jones when completing the survey questions, suggesting that the experimental manipulation had been successful. However, this was not a quantitative analysis of the experimental manipulation. Additionally, while we saw no direct impact of the three different communication modes (letter, phone call, social media notification) on participants' intentions to undergo testing for HIV or hepatitis, we did see in our qualitative results that participants preferred a phone call from a known provider. Participants also stated that they liked receiving a letter from the medical center director. Thus, our conclusion for health systems to utilize a provider phone call as the first step in the disclosure process is based on qualitative findings, in this study and our prior work. A final limitation is that while behavioral intentions are considered important antecedents for predicting future behavior,³⁸ we cannot make the assumption that in an actual large-scale disclosure situation that participants who indicated they were likely to seek testing for HIV or hepatitis would actually follow through with these intentions. Despite these limitations, we feel that there are many strengths of this study, such as its large sample size, comparison of different approaches to communicating risk of contracting blood-borne pathogens in the disclosure notifications, and the mixed methods design.





Conclusion and Implications

A higher risk communication approach after health care exposures helps patients understand their personal health issues better, makes them feel that they know which steps to take following the receipt of this information and

encourages them to seek follow-up infectious disease testing in order to better take care of themselves.

Given our prior⁷ and current qualitative evidence, and that all communication processes appeared equally acceptable to participants in these quantitative findings, we recommend the provider phone call as the first step in the communication process in health care systems' policies for increasing transparency and reducing unintended consequences resulting from communicating risks to patients.

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Supplemental Material

Supplemental material for this article is available on the *Medical Decision Making Policy & Practice* website at <https://journals.sagepub.com/home/mpp>.

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