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Patients' Experiences with Disclosure of a Large-Scale Adverse Event

Carolyn D. Prouty, Mary Beth Foglia, and Thomas H. Gallagher

ABSTRACT

Background

Hospitals face a disclosure dilemma when large-scale adverse events affect multiple patients and the chance of harm is extremely low. Understanding the perspectives of patients who have received disclosures following such events could help institutions develop communication plans that are commensurate with the perceived or real harm and scale of the event.

Methods

A mailed survey was conducted in 2008 of 266 University of Washington Medical Center (UWMC) patients who received written disclosure in 2004 about a large-scale, low-harm/low-risk adverse event involving an incomplete endoscope cleaning process. The survey measured patients' satisfaction with this disclosure, their concerns about healthcare outcomes, and their recommendations for future communication, given similar circumstances.

Results

Surveys were received from 127 of 266 (48 percent) of eligible respondents; 98 percent thought that UWMC was right to inform them about this event, and mean satisfaction with the disclosure was 7.7 on a 0 to 10 scale. Of the 127 respondents, 64 percent were somewhat or very concerned that the endoscope cleaning problem might cause them health problems; 60 percent reported their impressions of UWMC's honesty and integrity had increased; 31 percent said their perceptions of the quality of care had increased; 94 percent agreed that institutions should tell patients about any error in their care, even when the risk of harm was low, although 28 percent agreed that such notifications would make them anxious. Respondents who reported concern that the event could cause them health problems were less likely to be satisfied with the institution's disclosure. Patients cited their right to know information material to their own health and healthcare as an important reason for disclosure.

Conclusion

Recipients of disclosure of a large-scale, low-harm/low-risk event overwhelmingly supported being told of the event and endorsed notification of patients for similar events in the future. Although informing patients may cause concern for some, institutions should ensure their disclosure policies and procedures reflect their patients' preferences.

Carolyn D. Prouty, DVM, was a Research Scientist in the Department of Medicine in the University of Washington School of Medicine in Seattle, and is currently Visiting Faculty at the Evergreen State College in Olympia, Washington.

Mary Beth Foglia, RN, PhD, MA, is Affiliate Faculty in the Department of Bioethics and Humanities in University of Washington School of Medicine, and Health Care Ethicist at the National Center for Ethics in Health Care, Veterans Health Administration.

Thomas H. Gallagher, MD, is Professor in the Departments of Medicine and Bioethics and Humanities in the University of Washington School of Medicine, Director of the UW Program in Hospital Medicine, and Director of the UW Medicine Center for Scholarship in Patient Care Quality and Safety, *thomasg@uw.edu.*

There is widespread agreement that patients have a compelling interest in being told about harmful medical errors in their care. The ethical justifications for disclosure of harmful medical errors involving an individual patient have been well described,[1] and include respect for patients' autonomy, informed decision making, and careproviders' professional obligation to be truthful. These essential elements of medical ethics are integral to patient-centered care, and ensure that patients have full knowledge of events in their healthcare. Additionally, disclosure strengthens patients' perceptions of the quality of healthcare provided, and helps identify opportunities to prevent future errors.

To date, most research on institutional disclosures envisions situations in which an individual patient is affected by an adverse event.[2] However, situations do occur in which a breakdown in the care process affects multiple patients; these have been termed "large-scale adverse events" (LSAEs).[3] These events are not uncommon; publicly described events have affected well over 100,000 patients, with varying levels of harm.[4]

The decision whether, and how, to disclose an LSAE to potentially affected patients is complex, particularly in situations in which the probability that patients have been harmed is extremely low. Studies examining patients' preferences suggest they favor disclosure any time an error has caused harm.[5] Yet patients have more mixed opinions regarding learning about "near-miss" errors in their care (errors that did not cause harm): some wanted to know, while others think it would make them nervous.[6] Low-harm/low-risk LSAEs are likely to resemble near misses, since most patients will not experience physical harm from the exposure itself. Thus, there is genuine uncertainty about patients' disclosure preferences in the case of low-harm/low-risk LSAEs.

Institutions may have important reasons to be reluctant to disclose LSAEs for which the risk is very small. Institutional leaders may wonder if the anxiety produced by learning of such events would outweigh patients' desire for disclosure. Additional factors complicating these LSAE disclosure decisions include difficulty in identifying and contacting patients, potential litigation, negative publicity, and loss of reputation and public trust.[7]

Understanding the preferences and experiences of patients who have been the recipients of an actual LSAE disclosure could provide helpful information to institutional leaders contemplating how to respond to future LSAEs. While research is beginning to explore patients' and family members' experiences with actual disclosures to individual patients,[8] to our knowledge no prior studies have examined the perspectives of patients who have actually experienced a disclosure of an LSAE and their recommendations for how communication about future LSAEs should be handled.

In February 2004, staff at the University of Washington Medical Center (UWMC) noticed a shortened cleaning cycle in one of their newly installed endoscope cleaners. Subsequent investigation revealed that, over the previous three months, nearly 600 patients had gastrointestinal endoscopy procedures using incompletely cleaned equipment. Although the risk of infection associated with the use of such equipment was estimated to be no more than baseline for such procedures, approximately one in 1.8 million,[9] the UWMC, following deliberation amongst medical staff, administrative leaders, and ethicists, opted to immediately disclose the endoscope cleaning problem, in writing, to all affected patients. The letter contained an explanation of the event, the estimated risk of infection, and instructions for how to obtain further information. The letter did not mention specific diseases that patients may have been exposed to or provide options for obtaining testing. UWMC created a special hotline where affected patients could call with questions, a detailed protocol for responding to these queries, and issued a news release about the event.[10]

In July 2008, we surveyed these patients to assess the impact of this LSAE disclosure, its effects on their impressions of the institution's honesty, integrity, and quality of care, and to learn their recommendations for disclosure, should a similar event occur in the future.

METHODS

Study Purpose

The purpose of this study was to characterize patients' satisfaction with disclosure practices among individuals who had received a disclosure of an actual low-harm/low-risk LSAE. Two additional goals were to compare the responses of patients who were concerned about a potential health impact from the LSAE to those who were not, and to qualitatively describe patients' reasons in support of or against disclosure of similar events in the future.

Data Collection Methods

A 14-question survey consisting of open and closed ended questions was developed by two of the authors (TG and CP), in consultation with UWMC leaders and risk managers. A cover letter

briefly explained that UWMC was interested in learning about the recipients' reaction to how the LSAE was disclosed to them and their recommendations regarding communication about events such as these in the future. Respondents were initially asked: (1) if they recalled receiving the original letter; if so, (2) if the letter provided them with sufficient information; (3) if, after reading, they were concerned that the cleaning problem might cause them health problems; and (4) if they thought, at the time, that UW was right to inform them. A sealed envelope with the original disclosure letter was included with the survey. All respondents were asked to read the disclosure letter in the sealed envelope and answer the remaining survey questions concerning satisfaction with UWMC's communication; the effects of the disclosure on beliefs about UWMC's honesty, integrity, and quality of care; and recommendations for disclosure in any similar future episode.

The anonymous survey of exposed patients was conducted between August 2008 and July 2009. Informed consent was implied by returning the survey. The survey was mailed from the medical director's office to the known current addresses of patients, including a card to decline participation. The original disclosure letter had been translated into Spanish, Vietnamese, Russian, and at least three other languages for non-English-speaking patients; these patients did not receive the survey. Participation (completing the survey) was encouraged through repeated mailings and telephone calls. There was no incentive provided for participation. The University of Washington Institutional Review Board approved this project.

Data Analysis

Data from the surveys were entered and analyzed using the Statistical Package for the Social Sciences 18.0 for Windows with the statistical significance set at .05 for all comparisons. Our first aim was to characterize patients' perceptions regarding how this endoscopy LSAE was disclosed to them. Descriptive statistics were calculated for each item in the survey to establish overall response distributions. A second aim was to compare the responses of patients who were concerned about a potential health impact with those who were not concerned about a health impact from the LSAE. One-way analysis of variance (ANOVA) and *post hoc* tests were used to establish which groups differed significantly from one another on a particular response. We applied the Scheffe *post hoc* test to significant findings. A final aim was to examine the relationship between patients' characteristics and their responses to survey items. One-way analysis of variance and *post hoc* tests were used to explore differences in responses based on age and educational level.

Responses to the open-ended questions were coded by one investigator (CP), using conventional content analysis to identify major themes.[11] These themes were validated by another investigator (TG); inter-rater differences were resolved by consensus.

RESULTS

Response Rates and Sample Characteristics

We sent 544 surveys to patients at the addresses listed at the time of their endoscopy. Of these, 278 were found to be ineligible, because they were deceased, they indicated to researchers that they were unable to sufficiently comprehend written English, their survey was undeliverable and they were not able to be reached by phone to confirm a different address, or other reasons. These left 266 eligible respondents, from whom we received 127 surveys, yielding a response rate of 47.7 percent (figure 1).

Sample characteristics for this study are summarized in table 1. Nearly 85 percent of the respondents were White, followed by Asian (9 percent), and African-American (3 percent). All respondents had some type of health insurance coverage; 12 percent had a four-year college degree, and nearly 45 percent of the respondents had more than a four-year college degree.

Survey Responses

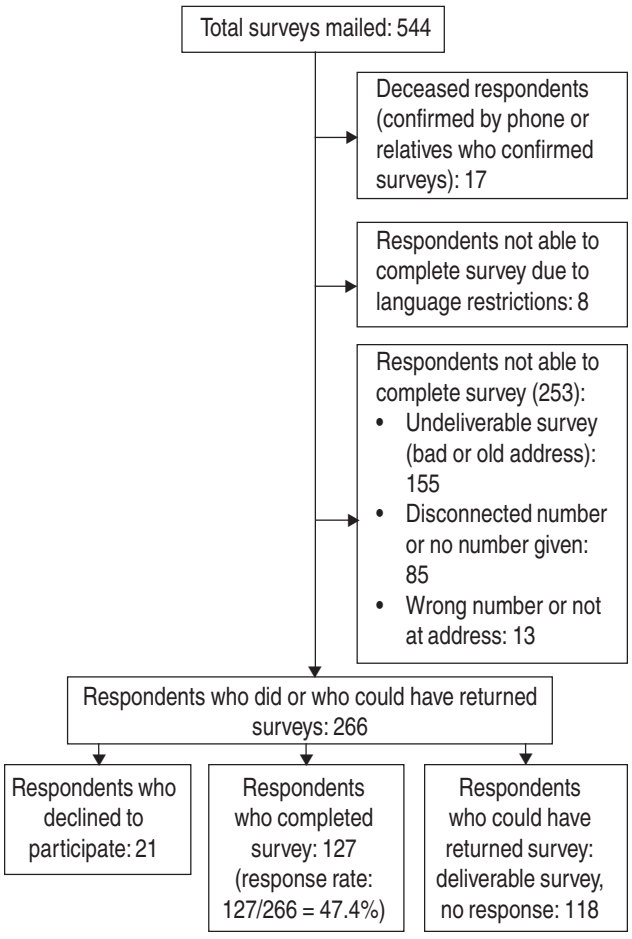
The overall response distribution of the sample is summarized in table 2. More than 80 percent of the respondents recalled having received a letter from UWMC that disclosed the problem with endoscope cleaning equipment. Of the respondents who recalled receiving a letter, 90 percent thought the letter provided them with the information they needed to understand the event. More than 98 percent of the respondents who recalled receiving a letter, thought that UWMC was right to inform them about the problem at the time. A majority of respondents who recalled receiving the letter was either "very concerned" (15 percent) or "somewhat concerned" (49 percent) that the problem with the endoscope cleaning might cause them health problems.

Of the 127 respondents, 60 percent reported that this disclosure experience increased their impression of UWMC's honesty and integrity. While 22 percent said their impression regarding the quality of care provided by UWMC had decreased due to this experience, more than 30 percent of the respondents reported their impression of the quality of care

had increased. Of the respondents, 11 percent reported they had contacted the medical center for more information about what had happened, and 8 percent reported they requested to be tested for potential infections after this event. Mean satisfaction with the way in which UWMC communicated with respondents about the event was 7.7 (SD = 2.431) on a scale in which 0 equals "extremely dissatisfied" and 10 equals "extremely satisfied."

When asked how such events should be handled in the future, more than 90 percent of the total respondents "strongly agreed" or "somewhat agreed" that medical centers should tell patients about an error in their care, even if the chance of harm is extremely low. Furthermore, more than 97 percent of respondents thought that if a similar episode happened in the future, healthcare organizations should inform patients about what happened. However, 28 percent "agreed strongly" or "agreed somewhat" that it would make them nervous to be told about an error in their healthcare, even if the chance of harm is extremely low.

FIGURE 1. Flow chart of survey collection data.



Comparisons between Respondents Based on Concerns about Health Outcomes

Further data analysis was conducted to explore whether survey responses differed based on how concerned respondents were that the problem with the endoscope cleaning equipment might cause health problems. The respondents who recalled receiving the disclosure letter were classified into three groups according to whether they were "not at all concerned," "somewhat concerned," or "very concerned" that the problem with the endoscope clean-

TABLE 1. Respondents' sociodemographics (*N* = 127)

	n	Valid %
Age (*n* = 122)		
25-34	2	1.6
35-44	2	1.6
45-54	20	16.4
55-64	54	44.3
65-74	28	23.0
75 or older	16	13.1
Highest grade level achieved (*n* = 120)		
8th grade or less	1	0.8
Some high school	3	2.5
High school graduate or GED	13	10.8
Some college or 2-year degree	36	30.0
4-year college graduate	14	11.7
More than 4-year college graduate	53	44.2
Are you Hispanic or Latino? (*n* = 117)		
Yes	1	0.9
No	116	99.1
Race/ethnicity (*n* = 118)		
White	98	83.1
Black or African-American	4	3.4
Asian	11	9.3
American Indian	2	1.7
Other	3	2.5
Insurance (*n* = 119)		
Medicare or Medicaid	27	22.7
Employment-related	45	37.8
Washington State Basic Health Plan	7	5.9
Private	24	20.2
Medicare or Medicaid and employment-related	7	5.9
Medicare or Medicaid and private	7	5.9
Medicare or Medicaid and Washington State Basic Health Plan	2	1.7

TABLE 2. Overall response distribution (*N* = 127)

Survey item	Response categories	*n*	Valid %
Do you recall having received a letter in 2004 about the problem with the endoscope cleaning equipment? (*n* = 127)	Yes	103	81.1
	No	24	18.9
If yes, did the letter provide you the information you needed to understand this event? (*n* = 103)	Yes	93	90.3
	No	10	9.7
After reading this letter, were you concerned that the problem with the endoscope cleaning equipment might cause health problems for you? (*n* = 104)	Not at all concerned	37	35.6
	Somewhat concerned	51	49.0
	Very concerned	16	15.4
At the time, did you think UWMC was right to inform you of this problem? (*n* = 103)	Yes	101	98.1
	No	2	1.9
(After reading letter): Does the letter provide you the information needed to understand this event? (*n* = 121)	Yes	110	90.9
	No	11	9.1
How did this experience affect your impression of UWMC regarding their honesty and integrity? (*n* = 124)	Decreased a lot	1	0.8
	Decreased a little	7	5.6
	No change	42	33.9
	Increased a little	38	30.6
	Increased a lot	36	29.0
How did this experience affect your impression regarding the quality of care provided by UWMC? (*n* = 124)	Decreased a lot	9	7.3
	Decreased a little	18	14.5
	No change	59	47.6
	Increased a little	16	12.9
	Increased a lot	22	17.7
On a scale from 0 to 10, where "0" is "Extremely Dissatisfied" and "10" is "Extremely Satisfied," how satisfied were you with the way that UWMC communicated with you about this event? (*n* = 121)	0 = Extremely dissatisfied (0 to 1)	2	1.7
	2	4	3.3
	3	3	2.5
	4	1	0.8
	5	17	14.0
	6	6	5.0
	7	8	6.6
	8	25	20.7
	9	16	13.2
	10 = Extremely satisfied	39	32.2
Imagine that a similar event happens in the future, where an error occurs that affects many patients but that has very little chance of causing harm to these patients. Do you agree or disagree with the following statements?			
a. Medical centers should tell patients about any error in their care, even if the chance of harm is extremely low. (*n* = 123)	Disagree strongly	1	0.8
	Disagree somewhat	6	4.9
	Agree somewhat	14	11.4
	Agree strongly	102	82.9
b. It would make me nervous to be told about an error in my healthcare, even if the chance of harm is extremely low. (*n* = 120)	Disagree strongly	74	61.7
	Disagree somewhat	12	10.0
	Agree somewhat	26	21.7
	Agree strongly	8	6.7

TABLE 2 *(continued)*

Survey item	Response categories	*n*	Valid %
All things considered, if a similar episode happened in the future, would you recommend that organizations like UWMC: (*n* = 118)	Inform patients about what happened	115	97.5
	Not inform patients about what happened	3	2.5
	*Marked both "Inform" and "Not inform"**	*5*	
At the time of the event, did you contact the medical center for more information about what had happened? (*n* = 120)	Yes	13	10.8
	No	97	80.8
	Not sure	10	8.3
Did you request to be tested for potential infections after this event? (*n* = 117)	Yes	9	7.7
	No	103	88.0
	Not sure	5	4.3

Note: The total number of responses per item varies with the number of respondents who left the question blank.
* Five respondents checked both boxes, and provided written reasons for both why to and why not to inform patients.

TABLE 3. ANOVA comparisons: level of concern about health outcomes

				Group differences		Group means	
Survey item	d.f.	F-ratio	*p*-value	Groups*	*p*-value	Group	Mean score
Letter provided information needed to understand event (for those who remembered receiving the letter)	101	11.83	.000			N	1.00
						S	1.08
						V	1.40
Affected impression of quality of care provided	101	6.719	.005	N-S	.005	N	3.65
						S	2.86
						V	3.07
Satisfaction with the way UWMC communicated	98	26.696	.003	N-V	.005	N	8.85
						S	7.80
						V	6.67
Nervous to be told about an error in my healthcare, even if chance of harm is extremely low	96	3.126	.05	N-S	.03	N	1.38
						S	1.88
						V	2.00
Requested to be tested for potential infections	95	4.071	.020			N	2.00
						S	1.96
						V	1.69

Note: d.f. = degrees of freedom. N = Not at all concerned. S = Somewhat concerned. V = Very concerned.
* Even though the F-ratio was significant, not all of the pair-wise group comparisons were significant due to the stringency of the *post-hoc* tests in avoiding Type 1 error. The F-ratio is used to determine whether the variances in two independent samples are equal.

ing equipment might cause health problems. The ANOVA results and *post* hoc tests for multiple group comparisons are summarized in table 3.

There were significant group differences based on whether participants believed the notification letter provided the information they needed to understand the event, their impressions of the quality of care provided by UWMC, their satisfaction with the way UWMC communicated about the event, whether the respondents requested testing, and whether respondents would be nervous to be told about an error in healthcare, even if the risk was low. Even though the F-ratio was significant, not all of the pair-wise group comparisons were significant due to the stringency of the *post-hoc* tests in avoiding Type 1 error. A means plot for each comparison suggested that responses were in the expected direction. Respondents who were "somewhat" or "very concerned" that the adverse event might cause problems with health outcomes reported less-favorable responses to whether the notification letter provided needed information, lower impressions of the quality of care provided by UWMC, greater nervousness over being told about an error, and lower levels of satisfaction with the way UWMC communicated about the event.

Comparisons between Respondents Based on Select Demographics

Analyses were also conducted to explore whether survey responses differed based on select demographics. Respondents with less education (a high school diploma, GED, or less) were more likely than respondents with more education (some college or two-year degree, four-year college degree, or more than a four-year college degree) to agree that it would make them nervous to be told about an error in their healthcare, even if the chance of harm is very low. Respondents who were 65 years of age or older were more likely than respondents between the ages of 45 and 64 years of age to report that their impression of the quality of care at UWMC had increased as a result of the disclosure.

Reasons for and against Disclosure

Respondents were asked if they would recommend that organizations like UWMC inform or not inform patients, should a similar episode happen in the future, and to provide the most important reason that they would or would not recommend this. Respondents gave numerous reasons (133 total responses) for recommending that patients be informed, including wanting/having the right to personal healthcare information, concerns about risk, and desires for honesty, integrity, trust, and confidence in the institution. Sample responses are listed in table 4. The most commonly given reason for recommending not informing patients, of eight total responses, was the low risk of infection.

COMMENT

Large-scale adverse events, and their associated media coverage, create public concern about healthcare quality and pose challenges for healthcare institutions around disclosure. One key question healthcare leaders face when contemplating disclosure of such events is whether patients would believe that the anxiety created by the notification would outweigh the benefits of being told what happened. Our study, the first to assess the experiences and recommendations of patients who have been the actual recipients of an LSAE disclosure, highlights patients' unequivocal support for such disclosure.

The overwhelming majority (98 percent) of these patients thought that the institution was right to disclose the problem, were satisfied with the disclosure (7.7 on a scale of 10), and strongly supported future disclosure of similar events (98 percent). The most common rationale patients cited for recommending disclosure was their right to know—almost half of the comments received from patients emphasized that they needed and wanted information relevant to their own health. A smaller number cited honesty, integrity, and confidence in healthcare institutions as the most important reasons for disclosure, findings consistent with existing literature on the benefits of disclosure.[12] Previous studies have affirmed patients' preferences to be told of medical errors in their care as individual patients,[13] and our findings suggest that those preferences extend to large-scale, low-harm adverse events as well.

Despite institutional unease about negative publicity and loss of public trust, the majority of patients in this study had an improved perception of the institution's honesty and integrity. Other research found no long-term impact on use of the hospital after public investigation of such incidents,[14] and multiple studies indicate that patients and families believe that disclosure may improve relationships with careproviders.[15] These collective findings provide compelling evidence for institutions to disclose even low-harm/low-risk LSAEs to patients, as the benefits of these disclosures appear to outweigh institutions' concerns.

Although support for disclosure was extremely high, an important subset of patients expressed some

anxiety about potential health problems. Nearly 30 percent said it would make them nervous to be told, and a small proportion contacted the hospital after disclosure, including a few who asked for testing. Those who were more concerned about health impacts were the least satisfied with how the disclosure was conducted, with the adequacy of the information the letter provided, and had decreased impressions of the quality of care. Research in risk perception may help to explain these patients' experiences. Perception of risk is determined by a number of factors including dread of the outcome, whether the risk is voluntary or imposed, and familiarity with the risk.[16] Risks that are dreaded and out of one's control tend to be overestimated,[17] and a lack of knowledge of probability and scale can also hamper risk perception, even in a highly educated cohort, such as the subjects of this study.[18] It is also important to note that patients and experts apply different paradigms when assessing risk.[19] For example, uncertainty is accepted by experts, but in lay people this can increase perception of risk.

Concerns about disclosure causing increased anxiety in patients have been used by institutions as a reason not to disclose.[20] However, even these concerned respondents agreed patients should be told about any error in care and recommended disclosure for any future error similar to this one.

These findings highlight the importance of organizations' use of thoughtful, multi-modal approach to communicating with patients affected by large-scale adverse events, taking into account pa-

TABLE 4. Sample of responses: reasons to inform or not inform patients about large-scale adverse events (LSAE)

Text from the survey*:* All things considered, if a similar episode happened in the future, would you recommend that organizations like University of Washington Medical Center:

- Inform patients about what happened?
- Not inform patients about what happened?
- What is the most important reason you would recommend this?

Reasons given for why to inform patients of LSAE (total number of comments: 133):

Patients' right/desire/need to know information for their own health (54 comments):

- The right of patients to know about anything that might impact the quality of their care.
- So that any untoward health developments could be recognized and tested.
- It may make me anxious but is also my right as a patient to know.
- Knowledge gives a person the ability to make sound decisions regarding their medical care.
- It is my body—I have a right to know what was done.

Honesty, integrity (15 comments):

- It demonstrates integrity and good faith.
- I want to know that errors in care are communicated. I would be more concerned to think that errors are being made and covered up.
- It goes to the overall integrity or trustworthiness of the institution.

Confidence in institution (12 comments):

- Helps patients understand how much effort and level of care goes into a specific procedure.
- It's an indicator that UW is diligent about maintaining high standards.
- It would increase my confidence in the UW medical center. Errors happen, being open and honest about them indicates that patient welfare is the UW primary interest.

Trust (6 comments):

- Trust in the personnel giving me the best healthcare possible.
- It builds trust, that UW won't try to hide important information from me.
- Maintaining my trust in the UWA Medical Center. No one is perfect and the most important thing is open and honest communication. I like information!

Reasons given for why *not* to inform patients of LSAE (total number of comments: 8):

- If there is no appreciable risk.
- The chance of risk if very low. To inform this would make some people nervous and no advantage.
- Since there was no increased risk, I don't see any reason to inform patients.
- Scares old people.

tients' characteristics such as health literacy, language spoken, and level of anxiety, and including explicit plans to provide free follow-up diagnostic testing and treatment. For events for which the probability of harm is higher or when the affected patient is anxious and concerned about health outcomes, institutions should undertake additional measures such as notifying or following up with patients individually via treating physicians and providing emotional and clinical support through qualified healthcare professionals.[21]

Institutions may also benefit from consulting with risk communication experts when planning communication and follow up. Risk communication is the science of communicating health risk under conditions of high public concern and uncertainty, and when there are differences in interpersonal power between the parties involved in the event. This literature recognizes the psychological, social, and cultural contexts that shape patients' risk perceptions, as well as their emotional and informational needs.[22] The content of disclosure communications should address what the patients want to know, what careproviders deem to be critical, as well as what is likely to be misinterpreted if not explained. Perception of uncertainty increases with changing or incomplete information, and when unfavorable information appears at the end of a letter.[23] Integrating knowledge of risk communication, infectious diseases, ethics, and disclosure into a disclosure of a large-scale adverse event is complex and resource intensive, but may pay off in the long run by preserving the patients' and the public's trust in the integrity of the healthcare institution and its staff.

The recent experience of the Everett Clinic, in Everett, Washington, with an LSAE disclosure highlights the benefits of a thoughtful, proactive approach.[24] The clinic discovered that, during an eight-month period in 2012, more than 2,000 patients were potentially exposed to a fungus *Acremonium,* due to contamination of equipment used during evaluation for chronic sinusitis. While *Acremomium* exposure does not usually cause infection in patients with normal immune systems, patients with weakened immune systems could be at additional risk of sinus infection. As soon as the problem was identified, the clinic worked closely with experts in infectious disease, ethics, communication, and patient safety, as well as with state public health agencies, to formulate a comprehensive approach to identifying and fixing the problem and to notifying affected patients. The clinic developed customized notification letters based on whether a patient had previously had a prior sinus culture, and, if so, whether that culture was positive or negative for *Acremonium*, and then mailed 2,200 letters at approximately the same time that a press release was provided to the media. A hotline was established at the clinic that patients could call for more information, along with a dedicated *Acremonium* clinic. Both the letter to patients and the press release expressed the clinic's regret about what had happened. The resulting media coverage lasted for one day, was balanced, and the story in the *Everett Herald* newspaper included a comment from a local public health officer noting, "I feel they've taken all appropriate steps."[25]

There are several limitations to this study. Although we attempted to maximize the number of respondents, the time between the event and its disclosure in 2003/2004 and the survey in 2008 made it impossible to contact many who received the original disclosure. Also, given the time between the disclosure and the survey, respondents' memories and attitudes may have changed due to recall bias. *Recall bias* can be found in any study that asks participants to reflect on a past event or experience, and subsequent experience may color the participants' current beliefs and attitudes. However, what is compelling in this study is the near universal agreement in the necessity of disclosure of a low-harm/low-risk LSAE. Additionally, those who responded to the survey were largely White, well-educated, and could read English, and may not be typical of a more representative sample of the patient population, but research on patients' preferences for disclosure of (hypothetical) individual errors, using a larger and more diverse sample, found no relationship between disclosure preferences and patient race/ethnicity, gender, age, or education level.[26] Given our respondents' unequivocal endorsement for disclosure, we expect that our results would be replicated in more diverse populations. However, more study is required to improve our understanding of how to shape disclosure to meet the needs of specific patient groups.

While much ground has been gained in the movement toward transparency in healthcare, there is still a great deal of progress to be made. Patients' preferences, coupled with the ethical analysis of disclosure of large-scale adverse events,[27] create an unambiguous argument in favor of disclosure. Institutions should develop policies that are guided by these findings to ensure full transparency with patients when LSAEs with low levels of risk occur. Careful planning is warranted in the delivery of the disclosure, as some patients will have health concerns that may cause them to lose trust in the organization. Future study should explore which com-

munication strategies best support patients who are anxious about an LSAE's impact on their health, and how LSAE communication strategies should account for variation in the nature and degree of harm of these events. While the process required for an effective large-scale adverse event disclosure may be lengthy and even uncomfortable, the benefits of transparent communication on patients' and the public's perceptions of trust and quality of the institution highlight the importance of pursuing this path of openness.

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DISCLAIMER

The views expressed herein do not necessarily represent the views of the Department of Veterans Affairs or the U.S. government.

NOTES

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