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Patient preference and recall of results of EUS-guided FNA

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Abstract

Background—There are no clear guidelines regarding the best way, in terms of timing and setting, to deliver results to patients who undergo EUS-guided FNA (EUS-FNA) of suspected pancreatic masses.

Objective—We aimed to study (1) whether patients undergoing EUS-FNA prefer to receive preliminary results immediately after the procedure or at a later date, after final results are known; and (2) to assess the accuracy of patients' recollection of information given to them regarding their FNA diagnosis.

Design—We enrolled patients presenting to our endoscopy center for EUS-FNA of suspected pancreatic masses and obtained data through 4 pilot surveys.

Settings—University-based endoscopy center.

Patients—Sixty patients who were referred for EUS-FNA of suspected pancreatic masses.

Results—A total of 57 of 59 patients (96.6%) wanted preliminary results the same day as the procedure. Twenty-eight of 60 (42.7%) knew they were having a biopsy, and 42 of 60 (70%) knew cancer was suspected. Of those who received preliminary results, 31 of 41 (75%) remembered the diagnosis correctly the next day, and 32 of 38 (84%) remembered the diagnosis correctly 1 week later.

Limitations—Single-center pilot study.

Conclusions—The majority of our patients wished to receive preliminary results the same day as the procedure. Although most patients remembered results correctly, 25% of patients did not remember the correct diagnosis the next day. Further work is needed to improve patient's understanding of the reasons for the EUS-FNA and recall of preliminary EUS-FNA results.

There are no clear guidelines regarding the best way, in terms of timing and setting, to deliver bad medical news to patients, although some recommendations are available. Those recommendations are primarily based on surveys of medical providers who deliver bad news, but some data also exist on the opinions of patients and family members who have received such bad news.^{1–6} It is agreed that the accuracy of the information delivered is of utmost importance. There is also general agreement on the importance of the physical and social setting, with both givers and receivers of bad news suggesting that the news be

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DISCLOSURE

The authors have nothing to disclose.

delivered in a quiet, private setting, in an unhurried fashion, with family members or other support persons present.

The exchange of medical information, including bad news, is often complicated by other issues for which there are no clear guidelines and no existing data. One obvious difficulty arises when important medical information is delivered to a patient while the patient is under the influence of drugs related to the diagnostic procedure that impair cognitive processing and memory. For example, short-term amnesia associated with drugs used for endoscopic conscious sedation may interfere with a patient's ability to comprehend information provided at that setting.⁷⁻¹⁰ Pancreatic carcinoma is one of the most serious diagnoses that is delivered after an EUS-guided FNA (EUS-FNA). Conscious sedation may impair a patient's ability to comprehend and remember a diagnosis of pancreatic cancer, the significance of that diagnosis, and the discussions regarding treatment options that accompany a pancreatic cancer diagnosis. While EUS is increasingly used to diagnose pancreatic carcinoma, little is known about when and how to deliver this diagnosis in terms of (1) patient preferences for the timing of diagnosis delivery and (2) the accuracy of patient recollection of the information, particularly when recovering from conscious sedation. Accordingly, we evaluated whether patients undergoing EUS-FNA for suspected pancreatic cancer at our institution preferred to receive preliminary results immediately after the procedure or at a later date, after final results are known. We also assessed the accuracy of patient recollections of information given regarding preliminary FNA diagnosis.

PATIENTS AND METHODS

This study was conducted at the Endoscopy Center of Washington University School of Medicine/Barnes-Jewish Hospital, after approval by the human studies committee of our institution.

In this pilot study, we enrolled patients who were referred for EUS and possible FNA of suspected pancreatic neoplasms. Patients were recruited over a 9-month period, between September 2004 and May 2005. The patients were primarily recruited from a single investigator (D.S.E.); 35 of 42 patients were included in the study for this investigator. Inpatients were excluded from the study. The remaining 15 patients were recruited from the other investigators' (S.A.E., R.A.) patients, in a nonconsecutive fashion during the same time period. All outpatients presenting for EUS with an indication of pancreatic mass seen or suspected based on outside imaging were eligible for participation. Thirty-four patients were referred by gastroenterologists, 18 patients were referred by surgeons, 5 patients were referred by primary care physicians, and 3 patients were referred by oncologists. The referral forms indicated that a pancreatic mass was seen or suspected based on previous imaging (CT, magnetic resonance imaging, and/or ERCP) in all cases; the ultimate decision to perform FNA rested with the endosonographer. Patients were not provided specific preprocedure information aside from standard upper endoscopy preparation. Before taking a history or discussing the procedure with the patient, the endosonographer introduced the patient to the study and obtained written consent. The first of 3 data collections occurred after written consent was obtained. At this time, 2 surveys were completed by the patient (Appendices A and B, available online at www.giejournal.org); 1 gathered demographic information and the second survey assessed patient knowledge regarding the planned procedure, the possible diagnoses, their level of anxiety, and their preferred method of receiving FNA results. The investigators developed a simple anxiety check scale for this pilot study as follows: "Please choose the response below that best describes your anxiety level regarding what will be found on today's test (circle the phrase that best describes your anxiety level right now)." Response choices were 1, not at all; 2, a little; 3, moderately; 4, a lot; 5, extremely. Patients were asked to complete the survey on their own and were afforded

privacy to do so. The second and third data collections were in the form of a telephone interview 1 day after the procedure and 5 to 7 days after the procedure.

After the preprocedure surveys were complete (first data collection), the endosonographer obtained a focused history in the usual fashion, obtained informed consent for the procedure, and answered questions regarding the procedure. For conscious sedation, all patients received midazolam, with a mean and standard deviation (SD) dose of 7 ± 3.6 mg. Patients also received meperidine ($n = 8$, mean dose 95.3 ± 16.3 mg), fentanyl ($n = 51$, mean dose 165.5 ± 82.5 mcg), or propofol ($n = 17$, mean dose 500.19 ± 355.65 mg).

When EUS-FNA is performed at our institution, a cytopathologist is not present during the procedure; however, a cytology technologist is present during the procedure to prepare the slides. The technologist then delivers the slides to the cytopathologist who provides a preliminary diagnosis by telephone to the attending endosonographer approximately 30 to 45 minutes after completion of the procedure. Our current practice pattern is to conduct a discussion with the patient and family members in the recovery area just before discharge from the endoscopy center. The main points of the discussion include the following: (1) articulation of the preliminary diagnosis; (2) a general discussion regarding treatment options; and (3) a recommendation regarding follow-up, such as return to referring physician when appropriate (if referring physician will be treating the cancer) or an offer to initiate referral to a physician who can treat the cancer, or suggested follow-up if cancer is not found. Written discharge instructions are given to each patient, with the above information included. The patient and the family are told that they will be telephoned with final results in 5 to 7 days by either an endoscopy nurse or a physician who was involved in the care. The endosonographer or the endoscopy nurse subsequently contacts the patient by telephone 5 to 7 days after the procedure to give the final diagnosis. During this conversation, information provided during the earlier discussion (day of procedure) is reiterated when necessary or amended if the final diagnosis differs from the preliminary diagnosis. A new cancer diagnosis is routinely delivered by the physician; nurses only deliver a cancer diagnosis if it confirms a preliminary cancer diagnosis that was provided the day of the procedure. Patients enrolled in the study received preliminary results in the fashion outlined above.

The second data collection was in the form of a telephone interview 1 day after the procedure (Appendix C, available online at www.giejournal.org). This survey was administered by one of the coinvestigators or by a registered nurse in the endoscopy department with knowledge of the patient's procedure and findings. The survey asked, "What was found or diagnosed on yesterday's exam," "What is the next step in your medical care regarding this particular issue," and again elicited patient preference for receiving results. During this interview, the survey was administered first, then information that had been given to the patient the day of the procedure was reinforced and questions were answered. If we could not contact subjects the day after the procedure, no further contact was attempted until the follow-up call 5 to 7 days later with the final cytology results.

The third data collection was in the form of a telephone interview 5 to 7 days after the procedure and was essentially identical to the 1-day postprocedure survey (Appendix D, available online at www.giejournal.org). During this interview, the survey was administered first. Then, the final diagnosis was given and information regarding recommendations for follow-up care was provided, as per usual practice. As per Health Insurance Portability and Accountability Act (HIPAA) requirements and standard practice, telephone results were given to the patient, so that responses to the survey questions reflected the patient's level of understanding at the time the survey is administered. It is acknowledged that family members may contribute to the patient's level of understanding. It was not felt necessary to distinguish what details were remembered by the patient without family assistance from the

details that were remembered with family assistance, because an aim of the study was to determine patient recall of results in the usual clinical setting.

Descriptive statistics were used to report the preprocedure and postprocedure preference, knowledge, and recall. The Fisher exact test was used to analyze the type of referring physician with respect to preprocedure knowledge. The MEANS procedure was used to analyze dose of midazolam with respect to accuracy of recall of diagnosis and recall of the next step in medical management.

RESULTS

Sixty patients participated in the study. The average age was 64 years, with a range of 42 to 86 years. There were 36 women and 24 men. The average number and SD of years of school completed was 11.9 ± 2.6 years. The average income was \$35,700/y (range, \$500-\$150,000/y). Responses to the preprocedure survey are outlined in Table 1. Fewer than half of the patients knew they were having a biopsy, and only 70% knew cancer was suspected. All patients had achieved a postprocedure level of consciousness comparable with the preprocedure level, as documented by Aldrete scores. Preprocedure knowledge was analyzed with respect to the type of referring physician. There was not a statistical association between preprocedure knowledge and type of the referring physician.

Eleven of the 60 patients did not have a mass seen on EUS and, therefore, did not undergo FNA. Two procedures were aborted because of an inability to sedate; 3 patients had a common bile duct stricture on CT or MRCP, but no mass was seen on EUS; and 6 patients had a mass suspected by CT that was not seen on EUS. Four patients did not receive preliminary results; 2 of the 4 did not want preliminary results, 2 of the 4 were not able to receive preliminary results because the procedure was performed late in the day and cytology interpretation was not available. Of the 45 patients who received a preliminary diagnosis, there were 24 preliminary diagnoses of cancer, 19 diagnoses negative for cancer, and 2 diagnoses suspicious for cancer. There was 1 instance in which a preliminary diagnosis of suspicious for cancer was changed to positive for cancer on the final diagnosis. Five patients could not be reached by telephone the next day, including 1 patient who did not receive preliminary results. Therefore, 41 patients were available to answer all the 1-day postprocedure survey questions, and 39 patients answered the preference question on the 1-day postprocedure survey. An additional 3 patients could not be reached for the 1-week postprocedure survey. The results of the 1-day and 1-week postprocedure surveys are summarized in Table 2. As can be seen, 75% of subjects remembered the preliminary diagnosis correctly 1 day after the procedure, and 84% remembered it correctly 1 week after the procedure. Surprisingly, slightly more patients remembered the recommendation for the next step in their medical care than remembered the correct diagnosis (92.7% vs 75.6% at 1 day and 86.8% vs 84.2% at 1 week). The percentage of patients who preferred to receive preliminary results the day of the procedure remained higher than 90% when asked at the 1-day and 1-week follow-up survey.

Recall of the correct diagnosis and the next step in medical care were analyzed according to the dose of midazolam, which has retrograde amnesia properties. Recall was not analyzed with respect to the other sedative/analgesic agents, because they do not produce retrograde amnesia. Recall of correct diagnosis or the correct next step at the 1-day postprocedure survey and recall of correct next step at the 1-week postprocedure survey did not correlate with the midazolam dose. A lower dose of midazolam was actually associated with a higher likelihood of not remembering the correct diagnosis at the 1-week postprocedure survey ($P = .02$).

DISCUSSION

There are no clear guidelines for delivering bad medical news, although accuracy of patient understanding and recollection of information provided is crucial.¹⁻⁶ With the emergence of EUS-FNA of suspected pancreatic lesions, endosonographers are in a position to diagnose pancreatic cancer on a regular basis; a diagnosis that is generally considered extremely grave. There is neither uniform practice nor are there guidelines regarding the best manner in which to deliver a diagnosis after EUS-FNA of a pancreatic mass. Many institutions have an onsite cytopathologist, so that a positive diagnosis of cancer can be made during or immediately after the procedure. Other institutions, similar to ours, do not have an onsite cytopathologist but have the capability to obtain a preliminary diagnosis soon after the procedure. Even in centers where a preliminary diagnosis can be rendered during or after the procedure, endosonographers may not provide that preliminary diagnosis to the patient, preferring to wait for the final diagnosis. The issues of onsite vs offsite cytopathology have been studied, but with end points, eg, number of passes needed to make a diagnosis, and quality of cytologic material submitted.¹¹⁻¹⁵ No studies to our knowledge have specifically addressed the issue of onsite or preliminary cytology interpretation from the patient's standpoint, ie, is delivering a preliminary diagnosis in the patient's best interests?

Our results demonstrate that in our single-institution pilot study, almost all patients preferred preliminary results. However, only 75% remembered the preliminary diagnosis correctly the day after the procedure, and 84% of patients remembered it correctly 1 week later. These percentages may seem acceptable to some; however, in the context of a diagnosis of pancreatic cancer, these investigators find these numbers disturbingly low. In centers where onsite cytopathology is available, the results are likely available sooner, whereas we frequently wait 30 to 45 minutes for a preliminary cytology interpretation. Thus, it is possible that our patients are even more awake when we deliver results, compared with those at centers with onsite cytopathology. Even though a higher midazolam dose did not correlate with lower recall, we still believe that an inability to correctly recall preliminary results is associated with the retrograde amnesia properties of midazolam. This could only be confirmed by a randomized study in which some patients did not receive midazolam for the EUS-FNA procedure.

It is not clear why more subjects remembered the diagnosis correctly 1 week later compared with 1 day later. This may reflect input from family members or other physicians involved in their care who may have contributed to the patients' recall and understanding between the 2 surveys. Recall of postprocedure information has not been evaluated with respect to other open-access procedures at our center.

Limitations to our study include that it is a single-center study and that the surveys and anxiety scales had not been previously validated. In addition, we were unable to reach several patients for the postprocedure surveys, which limited our final analysis to fewer than 60 patients in several categories.

Although not a primary aim of this study, we also found that only 70% of subjects knew beforehand that cancer was a possible diagnosis. We were fairly lenient in allowing terms other than "cancer" to qualify as a "correct" answer (for example, "mass," "tumor," "growth"), so that 30% of our subjects truly may not have known that cancer was a possible diagnosis. Nearly all of our EUS-FNAs for possible pancreatic cancer occur on an "open-access endoscopy" basis, so extensive patient education and counseling is required before the procedure to ensure that patients are well informed of the test indications and possible outcomes.

Open-access endoscopy adds another dimension to the issue of delivering bad news. That is, should preliminary results/bad news be delivered by the endosonographer, whom the patient just met (in open-access cases), or by a physician with whom the patient has an existing relationship, such as the referring gastroenterologist or the primary care physician? This issue could be an area of future investigation.

The results of our single-institution pilot study suggest that, even though nearly all patients preferred a same-day preliminary diagnosis, delivering a preliminary diagnosis immediately after EUS-FNA may not be advisable. Rather, awaiting a final diagnosis and delivering this diagnosis when the patient is not under the influence of amnestic medications may be more ideal. Further studies are needed to clarify this issue. In particular, issues of patient satisfaction, anxiety, and level of understanding should be compared between a setting in which a preliminary diagnosis is delivered with a setting in which only a final diagnosis is delivered.

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Appendix A Preprocedure Survey

Your Name _____

1. What is the name of the test that you will be having today?

2. Why are you having this test performed?

3. What have you been told are the things that might be diagnosed or found on today's exam?

4. Our usual practice is to give you (and your family if you wish) a preliminary diagnosis before you leave us today. We then call you with the final diagnosis in about 7 days. Sometimes (although not usually) the final diagnosis is different from the preliminary diagnosis.
Often, the sedative that we give to make you comfortable for the procedure prevents you from remembering things that take place soon after the procedure, and might prevent you from remembering correctly what we tell you about the preliminary diagnosis.

Based on the above information, which of the following is your preference as regards to how you will receive your diagnosis (circle the one you prefer):
 1. I want to know the preliminary results today and be called in 7 days with the final diagnosis.
 2. I want to wait for the final diagnosis and be called on the phone with the final diagnosis.
 3. I want to wait for the final diagnosis, and come back and meet with the doctor in person to hear and discuss the final diagnosis.

Please choose the response below that best describes your anxiety level regarding what will be found on today's test (circle the phrase that best describes your anxiety level right now).

1. Not at all
2. A little
3. Moderately
4. A lot
5. Extremely

YOU ARE FINISHED COMPLETING THE SURVEY

Pre-procedure Aldrete score: _____

Post-procedure Aldrete score: _____

Appendix B Demographic Survey

THIS INFORMATION WILL BE KEPT IN STRICT CONFIDENCE.
THE INFORMATION WILL BE LINKED TO YOUR STUDY NUMBER BUT NOT DIRECTLY TO YOUR IDENTIFYING INFORMATION.

1. What is your age? _____
2. What is your gender? ____ Male ____ Female
3. What is the highest grade level you completed (examples, 8th grade, graduated high school, two years college, college degree, etc.) _____
4. What is the average yearly income of your household? _____
5. How many people live in your household?
 - a. Number of adults _____
 - b. Number of children under 18 _____

Appendix C Post Procedure Survey next day

Phone script

Hello, this is Dr. X or Nurse Y calling from the Endoscopy center at Washington University in St. Louis/Barnes Jewish Hospital. Yesterday, you agreed to participate in a survey regarding results from your test. If it's OK with you, I would like to ask you the questions on the follow up survey that we have.

Your Name _____

Do not ask questions 3,4,6 and 7 for subjects who did not receive preliminary results on the day of the test.

1. What is the name of the test that you had yesterday?

2. Why did you have this test performed?

3. What was diagnosed or found on yesterday's exam?

4. What is the next step in your medical care regarding this particular issue?

5. Yesterday, we asked you your preference about how and when you wanted to receive the results from biopsies taken during this test. If you had to do it again, and based on your experience so far, we would like to know your preference as to how to receive results from this test. *(circle number that patient chooses)*.
 1. I would want to know the preliminary results the same day and be called in 7 days with the final diagnosis.
 2. I would want to wait for the final diagnosis and be called on the phone with the final diagnosis.
 3. I would want to wait for the final diagnosis, and come back and meet with the doctor in person to hear and discuss the final diagnosis.
6. Did you have any help recalling this info? __Y __N
7. If yes, from whom? _____

FOR INTERVIEWER:

Patient's preliminary diagnosis: _____

Recommendations that were made: _____

Appendix D Post Procedure Survey 1 week

Phone script

Hello, this is Dr. X or Nurse Y calling from the Endoscopy center at Washington University in St. Louis/Barnes Jewish Hospital. Last week, you agreed to participate in a survey regarding results from your test. If it's OK with you, I would like to ask you the questions on the follow up survey that we have. After that, we will give you the final diagnosis from your test.

Your Name _____

Only ask question 3 for subjects who did not receive preliminary results on the day of the test.

1. What was diagnosed or found on last week's exam?

2. What is the next step in your medical care regarding this particular issue?

3. Before your test a week ago, we asked you your preference about how and when you wanted to receive the results from biopsies taken during this test. If you had to do it again, and based on your experience so far, we would like to know your preference as to how to receive results from this test. *(circle number that patient chooses)*.
 1. I would want to know the preliminary results the same day and be called in 5-7 days with the final diagnosis.
 2. I would want to wait for the final diagnosis and be called on the phone with the final diagnosis.
 3. I would want to wait for the final diagnosis, and come back and meet with the doctor in person to hear and discuss the final diagnosis.
4. Did you have any help recalling this info? __Y __N
5. If yes, from whom? _____

FOR INTERVIEWER:

Patient's preliminary diagnosis: _____

Recommendations that were made: _____

Capsule Summary

What is already known on this topic

- The accurate exchange of medical information, including bad news, is often compromised by the influence of drugs used during the diagnostic procedure that impair the patient's cognitive processing and memory.

What this study adds to our knowledge

- In a single-center survey of patients who were referred for EUS and possible FNA of suspected pancreatic neoplasms, 57 of 59 (96.6%) wanted preliminary results the same day as the procedure; 31 of 41 (75%) of these individuals remembered the diagnosis correctly the next day and 32 of 38 (84%) remembered correctly 1 week later.

TABLE 1

Results from preprocedure survey (n = 60)

	Yes, no. (%)	No, no. (%)	Mean	SD
Knew they were having a biopsy	28 (46.7)	32 (53.3)		
Knew cancer was a possible diagnosis	42 (70)	18 (30)		
Wanted to receive preliminary results same day [*]	57 (96.5)	2 (3.4)		
Anxiety score [†]			2.75	1.27

^{*} One patient did not answer.

[†] 1, not at all; 2, a little; 3, moderately; 4, a lot; 5, extremely.

TABLE 2

Results from 1-day and 1-week postprocedure survey

	1-D postprocedure survey		1-Wk postprocedure survey	
	Yes, no. (%)	No, no. (%)	Yes, no. (%)	No, no. (%)
Knew correct diagnosis	31 (75.6)	10 (24.4)	32 (84.2)	6 (15.8)
Knew correct “next step” in medical care	38 (92.7)	3 (7.3)	33 (86.8)	5 (13.2)
Wanted to receive preliminary results the same day*	36 (92.3)	3 (7.7)	37 (90.2)	4 (9.8)

* Five patients did not answer this question on the 1-day postprocedure survey, 2 of whom did answer it on the 1-week postprocedure survey.