Patient Comprehension of Emergency Department Care and Instructions: Are Patients Aware of When They Do Not Understand?

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Study objective: To be able to adhere to discharge instructions after a visit to the emergency department (ED), patients should understand both the care that they received and their discharge instructions. The objective of this study is to assess, at discharge, patients' comprehension of their ED care and instructions and their awareness of deficiencies in their comprehension.

Methods: We conducted structured interviews of 140 adult English-speaking patients or their primary caregivers after ED discharge in 2 health systems. Participants rated their subjective understanding of 4 domains: (1) diagnosis and cause; (2) ED care; (3) post-ED care, and (4) return instructions. We assessed patient comprehension as the degree of agreement (concordance) between patients' recall of each of these domains and information obtained from chart review. Two authors scored each case independently and discussed discrepancies before providing a final concordance rating (no concordance, minimal concordance, partial concordance, near concordance, complete concordance).

Results: Seventy-eight percent of patients demonstrated deficient comprehension (less than complete concordance) in at least 1 domain; 51% of patients, in 2 or more domains. Greater than a third of these deficiencies (34%) involved patients' understanding of post-ED care, whereas only 15% were for diagnosis and cause. The majority of patients with comprehension deficits failed to perceive them. Patients perceived difficulty with comprehension only 20% of the time when they demonstrated deficient comprehension.

Conclusion: Many patients do not understand their ED care or their discharge instructions. Moreover, most patients appear to be unaware of their lack of understanding and report inappropriate confidence in their comprehension and recall. [Ann Emerg Med. 2009;53:454-461.]

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INTRODUCTION

In the emergency department (ED), the effective exchange of information between patients and health care providers is critically important to patient care. Yet, the chaotic nature of the environment and transient interactions pose significant challenges to communication.[1-3]

Previous research suggests that patients often have difficulty understanding discharge instructions provided in the ED. Frequently, written materials exceed patients' literacy levels, which may contribute to problems with comprehension.[4,5] Direct assessments of patient and caretaker comprehension after ED discharge have demonstrated difficulties with recalling diagnoses and discharge instructions.[6-9] These deficits have been shown to exist immediately after an ED visit and thus are not merely a function of people forgetting information over time.

Deficiencies in patient comprehension represent communication failures. Identifying and addressing these problems are essential steps to improving patient care. During the past 20 years, most of the research on patient-provider communication has been conducted in primary care settings and has focused on patient-physician interactions.[10] Numerous studies have shown that patients desire information about their medical care and identify communication as a critical element of their interactions with health care providers.[10-14] In the ED, communication is recognized as a key factor in patient

Editor's Capsule Summary

What is already known on this topic

Patients often have difficulty recalling and comprehending their treatment in the emergency department (ED) and understanding what they were told about post-ED care.

What question this study addressed

Whether patients discharged from the ED understand their ED diagnosis, care, post-ED care instructions, and return instructions and whether they can correctly identify which information they failed to understand.

What this study adds to our knowledge

In 140 patients from 2 sites that use handwritten discharge instructions, miscomprehension was common, especially for post-ED care instructions. Only 20% of patients whose comprehension was deficient correctly perceived what information they failed to comprehend.

How this might change clinical practice

Practitioners should develop mechanisms for improving patient understanding of their ED care and their after-care instructions and cannot rely on patients to accurately identify the areas in which their understanding is poor.

satisfaction, and problems with communication have been found to be a leading cause of patient complaints.[15-21]

So why do communication failures occur? The answers are complex and multifaceted. They reflect countless factors on the part of the patient, physician, health care team, and the environment. Unfortunately, there are many aspects of the ED setting and our interactions with patients that are difficult to control, and ED providers cannot hope to ensure perfect communication with every patient. We can, however, strive to minimize communication failures by characterizing them and determining why they occur and how we may intervene to reduce or prevent them. Patient comprehension serves as a meaningful measure of what the patient takes away from their visit and thereby provides a valuable tool for communication research.[22-24]

Previous research in the ED setting has focused predominantly on patient understanding of their diagnosis and discharge instructions. Assessments of patient understanding of their ED care (tests and treatments) have not been included. Because insight into patient comprehension difficulties in this area may provide additional valuable information about the communication process, it is important to include this domain in measures of patient comprehension.

The objective of this study, therefore, was to assess patients' comprehension across several distinct domains of the ED visit and also to determine patients' awareness of deficiencies in their comprehension. The authors are not aware of any previous research that has specifically explored patients' insight into their comprehension deficits. This research is an important step in directing future efforts to identify and intervene with patients who demonstrate comprehension deficits.

MATERIALS AND METHODS

Study Design

We conducted a cross-sectional, interview-based study of 140 adult English-speaking patients or their primary caretakers after ED discharge. Approval for this study was obtained from the appropriate institutional review boards. Written consent was obtained from all participants before enrollment.

Setting

This study was conducted at 2 EDs in southeastern Michigan: The University of Michigan Hospital, an academic teaching hospital in Ann Arbor, whose ED cares for approximately 51,000 adult patients per year; and St. Joseph Mercy Hospital, a community teaching hospital in Ypsilanti, whose ED provides care for approximately 63,000 adult patients per year. The 2 hospitals cosponsor a 4-year residency program in emergency medicine. Similar handwritten discharge instruction sheets were provided to patients at both institutions, with specific spaces provided for diagnosis, medications/prescriptions, and instructions.

Selection of Participants

In this study, we enrolled patients who were discharged from the ED. The study was conducted between October 2003 and April 2004. Five graduate-level research assistants were trained in conducting patient interviews with mock patients. Audiotapes from these sessions were reviewed with the research assistants to emphasize important skills. Two research assistants were present in the ED during established shifts. Data collection times were 4 to 6 hours in duration and chosen randomly according to research assistant availability, with an even distribution including weekdays and weekends and daytime and evening hours at both facilities. No data collection was conducted during overnight shifts. Fifty-seven data collection shifts were conducted, with the endpoint determined by a goal of 150 enrolled patients and the completion of the graduate school year.

Research assistants approached patients immediately after discharge or while they were awaiting their discharge paperwork. Although every effort was made to approach consecutive patients, some patients were missed because of logistical issues (ie, simultaneous discharge of 2 patients, patient left before approached, research assistant occupied with another subject). Physicians and physician assistants were made aware of the study before its start, but research assistants did not consult

directly with physicians, nurses, or technicians to avoid influencing patient-provider interactions. Instead, research assistants used ED computer records and other mechanisms to identify appropriate patients.

Exclusion criteria were inability to speak English, younger than 18 years, inability to speak or hear, discharge from the ED to another facility or unit, a primary diagnosis of alcohol intoxication or abuse, resident of a prison facility, or a compromised mental status (failure of Mini-Cog test) without an accompanying primary caretaker.

After 18 patients had been approached, we added an additional question to assess overall satisfaction for patients who refused to participate. At the completion of every data collection shift, the research assistants reviewed the ED log to determine how many patients were missed.

On enrollment, participants underwent an assessment of cognitive function, Mini-Cog, which is a brief screening test for the presence of dementia that includes 3-word recall and drawing of a clock face. If a patient completed the Mini-Cog successfully, then he or she was asked to participate in a 15- to 20-minute face-to-face audiotaped interview conducted by a research assistant who was blinded to the patient's discharge instructions. If a patient failed the Mini-Cog, the patient's primary caretaker was approached and, on enrollment, cognitive testing was conducted.

Methods of Measurement

Enrolled subjects participated in an audiotaped interview that assessed their subjective understanding of the information provided by their medical team, their recall of their ED care and discharge instructions, their satisfaction with their care, and their behavioral intentions on discharge. Participants were allowed to refer to their discharge instructions during the interview. Subjects were compensated with a gift certificate ($5).

If it was not possible to conduct a face-to-face interview with the participant, the research assistant attempted to schedule a telephone interview. All telephone interviews were completed within 24 hours of discharge to minimize recall bias.

The interview guide was developed by all of the authors, who met as a group biweekly throughout study development and data collection. In addition, input was obtained from survey and qualitative research experts at our institutions. The interview guide was extensively tested with colleagues and friends, and their feedback was used to make changes to the wording of questions. Additional changes were incorporated after an initial phase of data collection, according to a review of preliminary results, as well as feedback from the research assistants.

During the interview, participants rated their perceived comprehension on a 5-point scale (poor to excellent) for each of 4 domains: (1) diagnosis and cause, (2) ED care (tests and treatments), (3) post-ED care (prescriptions, ancillary measures, and follow-up), and (4) return instructions. After 19 patients had been enrolled, an additional question assessing perceived difficulty of understanding was added in an attempt to provide a more sensitive indicator. Figure 1 provides the wording of both question types.

1. Using the poor to excellent scale, how would you rate your understanding of…*underlined*?
   Poor **Fair** **Good** **Very Good** **Excellent**

2. Using the second scale, how difficult was it for you to understand…*underlined*?
   Not at all **A little** **Moderately** **Quite a bit** **Extremely**

- **Diagnosis & cause**
  - your diagnosis; in other words, what the medical team thought was wrong with you today (or yesterday).
- **ED care**
  - what was done for your medical problem in the emergency department.
- **Post ED care**
  - what you have to do to take care of your medical problem at home.
- **Return instructions**
  - which symptoms or changes should cause you to return to the emergency department.

Figure 1. Patient interview questions to assess perceived comprehension.

All interviews were transcribed in full. The accuracy of transcription was assessed by review of each transcript by an author (K.G.E.) immediately after transcription. If there were missing words or any areas of concern, then the complete audiotape was reviewed and appropriate changes were made to the document. Patient (or caretaker) comprehension was determined for each domain of the ED visit according to the concordance between direct patient recall and ED chart review. A 5-category concordance coding scale (no concordance, minimal concordance, partial concordance, near concordance, complete concordance) and specific guidelines were established by the consensus of all the authors after reviewing a subset of cases. The patient interview guide, as well as the concordance coding scale and guidelines, are provided as Appendix E1 and E2 (available online at http://www.annemergmed.com). Two authors (coders) rated each case independently. For the majority of cases, 1 physician coder and 1 nonphysician coder were assigned to each case. In a minority of cases, 2 physicians were assigned. We required that a physician code each case to help interpret whether or not the patient's description was consistent with the medical record. Discrepancies between the 2 scores for each case and domain were discussed by the 2 authors during a debriefing session, before each provided a final score. Coders did not have to agree on their final scores.

Primary Data Analysis

Descriptive statistics were used for the analysis. For our analysis of subjective understanding, we dichotomized the scales (Figure 1) for perceived comprehension and difficulty of understanding to identify those patients (or caretakers) who perceived comprehension difficulties. Our interpretation of the scales was intended to be as sensitive as possible in identifying patients who perceived some comprehension difficulty. For the first question (perceived comprehension), a score of less than "very good" (ie, good, fair, poor) was interpreted as a perceived

Table 1. Demographic data for sample and refusal populations.

Demographic data	Sample (n=140)	Refusals (n=195)
Age (y, SD)	39 (15); range 19–83	43 (19); range 18–93
Sex (% female)	82 (59)	107 (55)
Race (%)		
Black	27 (19)	49 (25)
White	95 (68)	131 (67)
Other	12 (9)	10 (5)
Missing	6 (4)	5 (3)
Education (%)		
Less than high school	14 (10)	
High school graduate	35 (25)	
College	64 (46)	
Graduate school	26 (19)	
Overall satisfaction (1–5 scale)	4.1	4.2

comprehension difficulty. For the second scale (perceived difficulty of understanding), a score of more than "a little" (ie, moderately, quite a bit, extremely), was interpreted as a perceived comprehension difficulty. Any patient (or caretaker) fulfilling either of these 2 criteria was considered to have perceived a comprehension difficulty. In addition, patients who reported less than "best" for both questions (ie, "very good" comprehension and "a little" difficulty) were also believed to have a perceived comprehension difficulty. Subsequent analysis to determine patient awareness of comprehension deficits was conducted by examining how results for subjective understanding corresponded to comprehension scores.

All data were double entered with Microsoft Access and inconsistent data were identified and reconciled. Statistical analysis was conducted with Stata 9.0 (StataCorp, College Station, TX).

RESULTS

During the study period, 366 patients were approached and 175 agreed to participate (48%). Of the 175 patients who agreed to participate, 29 did not complete their telephone interview (25 were not able to be reached and 4 refused at the telephone contact). Thus, 146 participants were enrolled in the study. The 195 patients (52%) who refused to participate were asked several demographic questions, their chief complaint, and the reason for their refusal. A total of 358 patients were missed during our study period.

Of the 146 patients who were enrolled, 141 completed the interview (97%). For one patient, our audiotape recorder malfunctioned and the interview was lost. The remaining 4 interviews were incomplete because of interruptions (ie, patient's cab arrived, telephone conversation disconnected, patient no longer desired to continue). One patient who failed the Mini-Cog actually completed the interview, but this case was subsequently dropped. Thus, our total sample population is 140. Caretaker interviews were conducted for 2 cases. Telephone interviews were conducted for 36 cases (26%).

Demographic data for our sample and refusal populations are provided in Table 1. Education data were obtained only for the sample population. No differences were noted in the demographic data or overall satisfaction scores for the sample and refusal populations.

Initial comprehension ratings given by the 2 independent reviewers were in agreement 63% (353/560) of the time, with a range of 56% to 70% agreement across the 4 domains of the ED visit. Approximately 16% (34/207) of the disagreements reflected a lack of medical knowledge on the part of the nonphysician reviewer. Only 18% (38/207) of the disagreements reflected differences of greater than 1 category between the 2 reviewers. Four percent (8/207) of the disagreements were due to one reviewer giving the domain a score of NA (not able to score). The remainder of the disagreements was due to coder error, indicating that one coder had missed information or failed to follow a scoring guideline. None of the disagreements was due to differences in interpretation of the coding guidelines, and, after debriefing, there was 99% agreement in the final ratings given by the 2 reviewers.

Table 2 provides illustrative examples of what each comprehension rating represents, with data provided from patient interviews and corresponding ED chart review. We provide examples for each of the 4 domains of the ED visit, with ratings ranging from no concordance to near concordance.

Table 3 shows the distribution of comprehension ratings for all patients, across all 4 domains of the ED visit. Each patient contributed up to 4 comprehension ratings, 1 for each of the 4 domains of interest: diagnosis and cause, ED care, post-ED care, and return instructions. Our results indicate that the majority of domains were rated as complete concordance (62%, or 341 domains). However, for 25% (136 domains) of the scored domains, patients' comprehension was rated as near concordance, and for 14% (76 domains) their comprehension was partial concordance or worse (ie, minimal or no concordance).

Although many patients demonstrated excellent comprehension (complete concordance) in 1 or more domains, only a minority of patients demonstrated such comprehension in all 4 domains. As shown in Figure 2, only 22% of patients had complete

Table 2. Examples of comprehension scores.

Examples	Patient Interview	ED Chart Review	Omitted or Discordant Information	Rating Given
Diagnosis and cause	No diagnosis, "They don't know."	Pelvic inflammatory disease	Not aware of diagnosis documented by MD	No concordance
ED care	Tests: blood tests with unknown results (patient states results not available for 3 days); culture test; Treatments: "shot to ease my stomach to stop the vomiting . . .that's all"	Tests: CBC, Chem7, LFTs, Amy/Lip, Ca/Mg/Phos—all NL; UA (5 WBC, 5 RBC, 3+ protein) with culture and sensitivity sent; Treatments: IVF 500 mL, Reglan IV, prednisone PO, ciprofloxacin PO	Tests: not aware of NL results for blood tests or abnormal UA results; Treatments: omits IVF, prednisone, ciprofloxacin	Minimal concordance
Post-ED care	Meds: Vicodin Ancillary measures: none Follow-up: 4-5 days at clinic	Meds: Motrin, Vicodin if pain still uncontrolled Ancillary measures: drink plenty of fluids Follow-up: 5-7 days at clinic	Meds: omits Motrin Ancillary measures: omits fluids	Partial concordance
Return instructions	". . .vomiting or shortness of breath or diarrhea or something like that"	Return for fever, vomiting, chest pain, shortness of breath, worsening abdominal pain or other concerns	Omits fever, chest pain	Near concordance

CBC, complete blood cell count; *Chem7*, chemistry panel; *LFT*, liver-function tests; *Amy/Lip*, amylase/lipase; *WBC*, white blood cells; *RBC*, red blood cells; *NL*, Normal; *IVF*, intravenous fluid; *UA*, urinalysis.

Table 3. Distribution of comprehension scores.

Distribution	Total Number of Scored Domains* (%)	95% CI
Complete concordance	341 (62)	57–65
Near concordance	136 (25)	21–28
Partial concordance (or worse)	76 (14)	11–17

*Seven domains were scored as not able to code and so are not included.

Table 4. Comprehension deficiencies by domain of ED visit.

Comprehension	Total Number of Deficient Domains* (%)	95% CI
Diagnosis and cause	32 (15)	11–21
ED care	61 (29)	23–35
Post-ED care	73 (34)	28–41
Return instructions	46 (22)	16–28

*A deficient domain is one in which concordance was rated as less than complete concordance (ie, near concordance, minimal concordance, partial or no concordance).

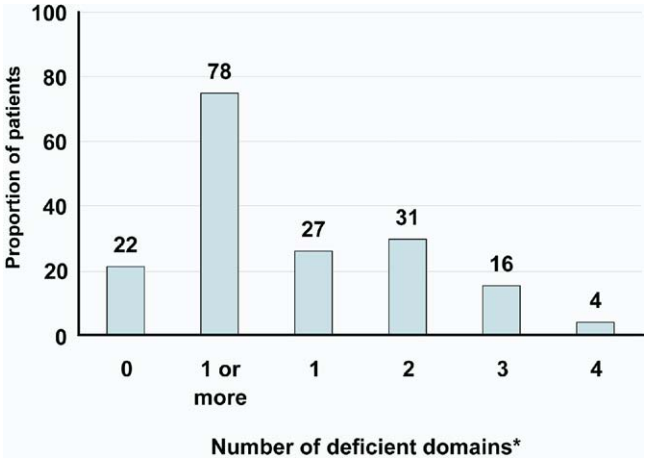

Figure 2. Comprehension deficiencies. A deficient domain is one in which concordance was rated as less than complete concordance (ie, near, minimal, partial, or no concordance).

concordance in all 4 domains, meaning that 78% of patients demonstrated deficient comprehension in at least 1 domain. For 51% (71/140) of patients, we documented deficiencies in 2 or more domains. Five patients (4%) demonstrated deficient comprehension in all 4 domains. For those participants with a comprehension deficit in only 1 domain, nearly a third (32%) of the time, concordance was rated as partial or worse for the deficient domain. For those cases with 2 or more domains deficient, the majority (61%, or 43/71) demonstrated at least 1 domain of partial concordance or worse.

Table 4 shows the distribution of comprehension deficiencies across the 4 domains of the ED visit. Patients had the greatest difficulty with post-ED care, and 34% of comprehension deficiencies occurred in this domain. Patients seemed to have the least difficulty recalling their diagnosis, with only 15% of deficiencies occurring in this domain.

A sensitivity analysis comparing interviews conducted immediately after discharge to those performed by telephone

Table 5. Awareness of comprehension deficiencies.

Awareness	Total Number	Number With Perceived Deficit/Difficulty (%)
Total scored domains	553* (140 Patients×4 domains)	118 (21; 95% CI 18–25)
Domains with complete concordance	341	76 (22; 95% CI 18–27)
Domains with less than complete concordance	212	42 (20; 95% CI 15–26)

*Seven domains were scored as not able to code and so are not included.

revealed no significant differences in the distribution of comprehension (concordance) scores or the proportion of participants with comprehension deficiencies. For telephone interviews, comprehension deficiencies occurred with the greatest frequency in the domain of ED care (53%), whereas post-ED care was a similar proportion (39%) and diagnosis and cause was a smaller proportion (11%).

Table 5 presents the results for subjective understanding for all patients (or caretakers) and shows how these results correspond with comprehension ratings. In the first row, the table shows that study participants perceived comprehension deficits or difficulty with understanding in 21% of all scored domains. The next 2 rows divide the scored domains into 2 groups: those with complete concordance and those with less than complete concordance. The table shows that patients perceived comprehension deficits or difficulty in a similar proportion of these subgroups (22% and 20%, respectively).

Overall, our findings indicate that the majority of patients with comprehension deficits failed to perceive them. Patients perceived difficulty with comprehension for only 1 in every 5 domains (20%) that were found to have less than complete concordance. This trend was consistent across all 4 domains of the ED visit, with less than 30% of patients indicating comprehension difficulties for domains with deficiencies. Although participants receiving higher comprehension ratings (near concordance) were less likely to perceive comprehension difficulties than those with the lowest scores (minimal or no concordance), the majority of all deficiencies were not perceived by patients (or caretakers) even for the lowest ratings.

Twenty-two percent of patients (or caretakers) perceived comprehension difficulties for domains given scores of complete concordance (Table 5). Among those patients with perfect scores (ie, complete concordance for all 4 domains), 39% (12/31) perceived difficulty with comprehension in at least 1 domain.

LIMITATIONS

Our study has several important limitations. First, it was conducted at 2 teaching hospitals in southeastern Michigan, limiting its generalizability. Second, our comprehension scores may have been subject to variation across cases because the same 2 authors did not score each case. We tried to minimize this concern and standardize the scoring process by establishing a detailed set of guidelines for scoring. In addition, each case was scored independently by 2 authors and discrepancies were discussed before final scoring. Third, concordance coding (to obtain comprehension scores) was limited in some cases by the number and detail of follow-up questions asked by the research assistant during the interview. To minimize subjective judgment, we established clear guidelines on how to handle these situations. In extreme cases in which significant information was missing because of inadequate follow-up questions, a score of NA (not able to code) was given. In those cases in which the patient (or caretaker) provided incomplete answers, a score was provided according to what was available from the transcript and patients were not scored lower for information that was lacking because of inadequate follow-up questioning. This approach would, if anything, overestimate comprehension scores. Fourth, the use of telephone interviews introduced the possibility of decreased recall compared to those interviewed at ED discharge because of the delay in the interview. Although sensitivity analysis did not reveal any significant differences between these groups, the increased frequency of comprehension deficiencies for ED care in telephone interviews likely reflects rapid deterioration in recall for this information with time. Fifth, our questions about patient perception of comprehension and difficulty with understanding were likely subject to bias. Some patients (or caretakers) might have felt uncomfortable or embarrassed about reporting comprehension difficulties even if they perceived them. Because the intention of our study was to consider whether or not one can identify patients with comprehension deficits by asking them directly, this is an acceptable limitation.

DISCUSSION

In this sample of ED patients from 2 health systems, many patients have poor comprehension of multiple aspects of their ED care and discharge instructions. Seventy-eight percent of the patients demonstrated a comprehension deficiency in at least 1 domain of their ED visit. These deficits were most common for the category of post-ED care, raising significant concerns about patients' ability to adhere to discharge instructions and recommendations after leaving the ED. Moreover, our study suggests that we cannot simply ask patients to identify their comprehension deficiencies because the majority did not report difficulties in areas in which deficits were objectively demonstrated.

Despite increased concern during the past decade about the importance of communication in the ED, the high rates of deficiencies in patient (or caretaker) comprehension we found

are similar to those found in studies conducted in the 1990s by Logan et al[8] and Spandorfer et al.[9] In the former study, 153 adult patients were interviewed after ED discharge and 63% were found to demonstrate incorrect answers in at least 1 part of the patient's discharge instructions (diagnosis, home care, and follow-up plan). In the second study, Spandorfer et al[9] found that for each of 3 categories of the ED visit (diagnosis, medications, and follow-up instructions), approximately 40% of 217 adult patients demonstrated deficient understanding of discharge instructions. It is likely that the frequency of comprehension deficits was somewhat higher in our study largely because our study design considered an additional category for ED care and also included a scoring system for partial but incomplete comprehension.

Our study builds on previous findings by assessing patient understanding across the entire ED visit, rather than just considering recall of the diagnosis and discharge instructions. It remains unclear which of the identified deficits are most clinically relevant. Future work will need to explore how the domain of the deficit and the score correspond with outcomes, such as adherence, recidivism, and morbidity.

Although we found comprehension deficits across all domains of the ED visit, it is striking that the highest frequency arose in the category of post-ED care (medications, ancillary measures, and follow-up). A similar trend has been found in previous studies that have demonstrated that patients have greater difficulty recalling information about their medications and home care than their diagnoses.[6-8] A provocative example from our study is one patient who was diagnosed with pelvic inflammatory disease and did not understand that she was prescribed an antibiotic.

Although we are not aware of studies demonstrating a direct relationship between patient comprehension, adherence, and outcomes, there are some early data to support this. In a pediatric ED study by Grover et al,[7] parents' ability to recall their child's follow-up appointment time(s) at discharge was the only variable found to be associated with compliance with these appointments. Such findings emphasize the importance of identifying why patients demonstrate the greatest comprehension deficits for post-ED care instructions. It is possible that some of the difficulty stems from the fact that much of the post-ED care information is provided at the end of the visit, when the patient is anxious to leave and may feel less inclined to ask questions. In addition, it is likely that in some instances these instructions are never discussed but simply written on discharge paperwork that the patient is unaware of, unable to read, or chooses to ignore.

Our study takes an important step in exploring comprehension difficulties in the ED by assessing patients' awareness of identified deficits. It is of great concern that only about 20% of patients reported comprehension difficulties for domains with deficiencies. Overall, it is important to keep in mind that the results for our perceived comprehension assessment are subjective. In such settings, patients' answers are heavily influenced by experience, as well as personal attitudes and standards for what they need and want to understand. This bias makes it inappropriate to place value on relative scores and limits us to using this tool simply as a means for identifying those who would be likely to identify comprehension difficulties if asked. Our findings would strongly suggest that, if we rely on such an approach, we will miss the majority of patients with comprehension deficits.

These findings are generally consistent with results of work by Crane[6] in 1997. In this study of 314 patients, comprehension rates were found to be 59% (average across all parts of the discharge instructions), whereas greater than 90% of patients reported that they had been provided adequate explanations of their instructions after an ED visit.

Overall, our study findings suggest that we need better strategies for identifying patients who are having difficulty understanding their care and instructions in the ED. One strategy might be to do what we did in this study: test patients' recall immediately after discharge, through strategies such as asking patients to repeat information in their own words. Recent research in primary care settings indicates that although physicians rarely assess patients' recall or comprehension of new concepts during outpatient visits, diabetic patients of physicians who consistently make these assessments with strategies such as "closing the loop" have significantly better glycemic control than patients of physicians who do not.[25] This technique may improve communication by making physicians aware of comprehension deficits and thereby facilitating individualized patient education.[25] This study found that physicians' assessments of patient recall did not prolong visits, perhaps because physicians immediately identified areas of poor comprehension and focused discussion.

Efforts to anticipate, identify, and address communication failures are critical to improving patient care. As part of our work, we plan to explore physicians' ability to predict patients' deficits, as well as specific visit and patient characteristics that are associated with poor comprehension. In addition, the content and organization of discharge instructions should be considered as a possible means of improving comprehension. Instructions may help to improve understanding if they clearly emphasize all domains of the visit (diagnosis, ED care, post-ED care, and return instructions).

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Author contributions: KGE, MH, DMS, and PAU conceived the study and designed the survey tools. KGE and PAU trained the research assistants. KGE supervised the research assistants and the data collection process. All 6 authors met on a biweekly basis to discuss the project's progress and to generate the coder's guidelines. At the completion of data collection, all of the authors participated in the analysis of comprehension scores and met for debriefing sessions. KGE was responsible for the remainder of the data analysis and initial drafting of the article. PAU was responsible for a preliminary revision of the article. All authors contributed substantially to subsequent revisions. KGE takes responsibility for the paper as a whole.

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Prior to beginning interview questions OR during initial encounter with patients who will participate in phone interviews,

1. Obtain informed consent. See Patient Consent Script.
2. Administer Mini-Cog mental status examination to participant to rule out dementia:

The Mini-Cog is a two-part test: 3-item recall plus clock draw test (CDT).

1. Instruct the patient to listen carefully as you name 3 unrelated objects (for example: cup, ball, flag) and then to repeat the object names.

2. Next, instruct the patient to draw the face of a clock on a sheet with the clock circle already drawn on the page. After the patient puts the numbers on the clock face, ask him or her to draw the hands of the clock to read 11:20. These instructions can be repeated, but no additional instructions should be given. Give the patient as much time as needed to complete the task.

3. Now ask the patient to repeat the 3 previously presented object names.

Scoring

- Give **1 point** for each recalled word (after the CDT distractor).
  - Points given _____
- The CDT is considered **normal** if all numbers are present in the correct sequence and position, and the hands legibly display the requested time.
  - Was the CDT normal? (yes/no) _____
- Score interpretation:
  - **A score of 0 indicates dementia (regardless of CDT results).**
  - **A score of 1 or 2 with an abnormal CDT indicates dementia.**
  - A score of 1 or 2 with a normal CDT indicates absence of dementia
  - A score of 3 indicates absence of dementia (regardless of CDT results).

If the Mini-Cog score indicates absence of dementia, continue on to the Interview.

If the Mini-Cog score indicates dementia, you should begin the Interview with Part I and attempt to continue through the interview as far as possible. If the patient has trouble understanding the questions or the response categories, then you should skip to Part 6 Comprehension. Turn on the audio-tape for this section and see if the participant can answer any of the questions. Continue as long as the patient is able to respond appropriately. At the completion of Part 6, skip to Part 10 and attempt to obtain demographic information from the patient.
After you have completed patient's interview, you should then attempt to enroll the patient's primary caretaker, if present. The caretaker interview should be done with a separate interview guide (in the interview folder), but the same Case/Consent number and audio-tape.

For Parts 1-4 of the Participant Interview, please mark the participant's answers in the spaces provided in the script.

Whenever you provide the participant with a scale card, explain that the participant can answer using either words or numbers.

Part 1

Part 1 – Intro

Thank you for participating in this study. We are very interested in learning about your experience in the emergency department today (*or* yesterday). Your answers will be kept strictly confidential and will be used for research purposes only, as we try to improve the care patients receive in our hospital.

Part 2 – Overall Satisfaction

Before I begin asking you more detailed questions, I would like to ask you about your overall satisfaction with the care you received in the emergency department today (*or* yesterday). Please rate your satisfaction from poor to excellent.

Provide the participant with a card that shows the following scale: poor, fair, good, very good, excellent.

For phone interviews, please ask the participant to refer to PAGE #2 of the interview packet given to them in the emergency department.

Please rate your satisfaction with respect to…

	Poor	Fair	Good	Very Good	Excellent
Overall Visit					
1. The visit overall	☐1	☐2	☐3	☐4	☐5

Part 2

***For phone interviews*, you should SKIP this section!**

Part 3 - Emotions

Next, I am going to start by asking you about the feelings and emotions that you have right now. I am going to name 20 emotions; please give me a number from one to five to indicate how strongly you feel each emotion, using the scale shown on this card. You may also answer using the words that correspond to each number. *Provide the participant with a card showing the scale, then read the scale aloud, as follows:*

Use the number 1 if you feel the emotion "Very slightly or not at all"
the number 2 if you feel the emotion "A little"
the number 3 if you feel the emotion "Moderately"
the number 4 is you feel the emotion "Quite a bit"
the number 5 if you feel the emotion "Extremely"

Then name the following emotions: "The first emotion is….The next emotion is…."

2.

	V. slightly Not at all	A little	Moderately	Quite a bit	Extremely
a. Interested	☐1	☐2	☐3	☐4	☐5
b. Distressed	☐1	☐2	☐3	☐4	☐5
c. Excited	☐1	☐2	☐3	☐4	☐5
d. Upset	☐1	☐2	☐3	☐4	☐5
e. Strong	☐1	☐2	☐3	☐4	☐5
f. Guilty	☐1	☐2	☐3	☐4	☐5
g. Scared	☐1	☐2	☐3	☐4	☐5
h. Hostile	☐1	☐2	☐3	☐4	☐5
i. Enthusiastic	☐1	☐2	☐3	☐4	☐5
j. Proud	☐1	☐2	☐3	☐4	☐5
k. Irritable	☐1	☐2	☐3	☐4	☐5
l. Alert	☐1	☐2	☐3	☐4	☐5
m. Ashamed	☐1	☐2	☐3	☐4	☐5
n. Inspired	☐1	☐2	☐3	☐4	☐5
o. Nervous	☐1	☐2	☐3	☐4	☐5
p. Determined	☐1	☐2	☐3	☐4	☐5
q. Attentive	☐1	☐2	☐3	☐4	☐5
r. Jittery	☐1	☐2	☐3	☐4	☐5
s. Active	☐1	☐2	☐3	☐4	☐5
t. Afraid	☐1	☐2	☐3	☐4	☐5

Part 3

In the emergency department, patients typically are cared for by a team of health care providers, including doctors, nurses, technicians, etc. During the interview, I may use the words "medical team" to include all of these people.

Part 4 - Satisfaction

Next, I would like to again ask you some more detailed questions about your satisfaction with the care you received in the emergency department today (*or* yesterday). For each question, please rate your satisfaction from poor to excellent.

Provide the participant with a card that shows the following scale: poor, fair, good, very good, excellent. For phone interviews, participants should continue to refer to PAGE #2 of the interview packet.

Please rate your satisfaction with respect to the following items…

	Poor	Fair	Good	Very Good	Excellent
Time					
3. The amount of time you spent waiting to be seen by the doctor	☐1	☐2	☐3	☐4	☐5
4. The amount of time you spent waiting in the emergency department after you were seen by the doctor	☐1	☐2	☐3	☐4	☐5

Now again, please rate your satisfaction with respect to the following items…

Communication Process					
5. The medical team explained information to you in words that you could understand	☐1	☐2	☐3	☐4	☐5
6. The medical team spoke at a reasonable rate of speed	☐1	☐2	☐3	☐4	☐5
7. The medical team gave you enough time to say what you thought was important	☐1	☐2	☐3	☐4	☐5
8. The medical team listened carefully to what you had to say	☐1	☐2	☐3	☐4	☐5
9. The medical team took your concerns seriously	☐1	☐2	☐3	☐4	☐5
10. The medical team gave you enough information about your medical problem	☐1	☐2	☐3	☐4	☐5
11. The medical team made sure you understood what they told you about your medical problem	☐1	☐2	☐3	☐4	☐5

Finally, please rate your satisfaction with respect to the following items…

	Poor	Fair	Good	Very Good	Excellent
Interpersonal Style					
12. The medical team treated you in a friendly and courteous manner	☐1	☐2	☐3	☐4	☐5
13. The medical team made you feel welcome in the emergency department	☐1	☐2	☐3	☐4	☐5
14. The medical team seemed to care about you as a person	☐1	☐2	☐3	☐4	☐5
15. The medical team helped you to feel less worried about your medical problem	☐1	☐2	☐3	☐4	☐5
16. The medical team treated you in a compassionate and caring manner	☐1	☐2	☐3	☐4	☐5

Part 4

Please tell the participant that you will turn on the audio tape for next part of the interview (Parts 5-9). When you turn on the audiotape, state the case consent number and your name (the R.A.'s name).
REMEMBER CONSENT NUMBER and RA NAME!

Part 5 – Self-reported Comprehension
Many patients find it difficult to understand everything that happens during a visit to the emergency department. The next few questions will ask you about your understanding of the care and instructions that you received today (*or* yesterday). We will be using two different response cards for these questions.
Indicate appropriate response cards (poor to excellent AND not at all to extremely).
For phone interviews, patients should refer to PAGES #2 and 3 of the interview packet.

DIAGNOSIS
This first series of questions is about your diagnosis; in other words, what the medical team thought was wrong with you today (or yesterday).

	Poor	Fair	Good	Very Good	Excellent
17a. Using the poor to excellent scale, how would you rate your understanding of…*underlined above*?	☐1	☐2	☐3	☐4	☐5

	Not at all	A little	Moderately	Quite a bit	Extremely
17b. Using the second scale from not at all to extremely, how difficult was it for you to understand…*underlined above*? *See follow-up question.*	☐1	☐2	☐3	☐4	☐5

EMERGENCY DEPARTMENT CARE
The next series of questions is about what was done for your medical problem in the emergency department.

	Poor	Fair	Good	Very Good	Excellent
18a. Using the poor to excellent scale, how would you rate your understanding of…*underlined above*?	☐1	☐2	☐3	☐4	☐5

	Not at all	A little	Moderately	Quite a bit	Extremely
18b. Using the second scale, how difficult was it for you to understand…*underlined above*? *See follow-up question.*	☐1	☐2	☐3	☐4	☐5

For each series of question above, please follow-up with the appropriate questions depending on the participant's response (questions should be asked if answers to either question above fits the conditions).

*Reponses less than Excellent **OR** more than Not at all*
What types of things made it difficult for you to understand this?
Is there anything that might have helped you?

*Good or Very Good or Excellent **OR** Not at all*
Is there anything that the medical team did that helped you to understand this?
What types of things did the medical team do that helped you to understand this?

Part 5

Part 5 – Continued

HOME CARE

The next series of questions is about <u>what you have to do to take care of your medical problem</u> at home.

	Poor	Fair	Good	Very Good	Excellent
19a. Using the poor to excellent scale, how would you rate your understanding of…*<u>underlined above</u>*?	☐1	☐2	☐3	☐4	☐5

	Not at all	A little	Moderately	Quite a bit	Extremely
19b. Using the second scale, how difficult was it for you to understand…*<u>underlined above</u>*?	☐1	☐2	☐3	☐4	☐5

See follow-up question.

RETURN INSTRUCTIONS

The next series of questions is about <u>which symptoms or changes should cause you to return</u> to the emergency department.

	Poor	Fair	Good	Very Good	Excellent
20a. Using the poor to excellent scale, how would you rate your understanding of…*<u>underlined above</u>*?	☐1	☐2	☐3	☐4	☐5

	Not at all	A little	Moderately	Quite a bit	Extremely
20b. Using the second scale, how difficult was it for you to understand…*<u>underlined above</u>*?	☐1	☐2	☐3	☐4	☐5

See follow-up question.

For each series of question above, please follow-up with the appropriate questions depending on the participant's response (questions should be asked if answers to <u>either</u> question above fits the conditions).

*<u>Reponses less than Excellent **OR** more than Not at all</u>*

What types of things made it difficult for you to understand this?
Is there anything that might have helped you?

*<u>Good or Very Good or Excellent **OR** Not at all</u>*

Is there anything that the medical team did that helped you to understand this?
What types of things did the medical team do that helped you to understand this?

After completing questions 17-20 with appropriate follow-up questions (as above), continue with #21.

21. Now I would like you to continue to think about things that may have affected your understanding of your care. *Hand the participant the laminated list or <u>for phone interviews</u> ask the patient to refer to PAGE #4 of the interview packet.*

Please look at this list of things that may have been part of your experience in the emergency department today (*or* yesterday). Please tell me how each of these may have made it easier or harder for you to understand what happened during your visit.

Encourage the participant to address each of the topic areas on the list. If the participant points to something when he or she makes a comment, please be sure to repeat it out loud so that it is heard on the tape!

22. Is there anything else that you would like to share with me about your visit in the emergency department today that you think might help us to as we try to improve the care of patients in our hospital.

Part 6

Part 6 - Comprehension

Next, I am going to ask you some questions about what the medical team told you about your medical problem today (*or* yesterday). You may refer to your discharge instruction sheet in answering these questions.

23. What did the medical team tell you that they thought was wrong with you (your diagnosis) today (*or* yesterday)?

    If necessary, follow up with: Why do they think this happened? What was the cause of your symptoms?

24. What test(s) did you have today (*or* yesterday)?
    a. Why did you have this test(s)?
    b. What were the results (what did the results show)?
    c. Was there anything else?

    If necessary, prompt with examples of tests: x-rays, blood tests, EKGs, etc.

25. What treatment(s) did you get in the emergency department today (*or* yesterday)?
    a. Why did you get this treatment(s)?
    b. Was there anything else?

    If necessary, prompt with examples of treatments: For example, did you get any medicines, IV fluids, or breathing treatments?

26. What medications, if any, were prescribed for you to take at home?
    a. Why do you need to take this medication(s)?
    b. Was there anything else?

27. What did the medical team tell you to do (besides taking medication) to take care of your medical problem?
    a. Why do you need to do these things?
    b. Was there anything else?

    If necessary, prompt with examples: For example, are you to do anything like applying hot or cold compresses, avoiding certain activities, or wearing a splint or brace?

28. After you leave (*or* left) the emergency department, are you supposed to follow-up with any doctors about this problem?
    a. Who?
    b. When?
    c. Why do you need to see another doctor?

29. What symptoms or changes should cause you to come back to the emergency department?
    a. Why do you need to come back for these symptoms or changes?
    b. Was there anything else?

Part 7

Part 7 - Plans
Next I am going to ask you about your plans when you leave (*or* now that you have left) the emergency department.

30. What do you plan to do to take care of this medical problem when you get home (*or* now that you are home)?
For phone interviews, what things have you already done since you got home?
31. Do you feel that your discharge instructions are something you can do? If not, why?
32. What are the chances that you will do everything the medical team recommended? Which things do you think you won't do and why?

Part 8 - Pain
Now I am going to ask you about any pain and discomfort you have from your medical problem.
Please rate your pain, with 0 being NO pain or discomfort and 10 being the WORST pain or discomfort of your life.
Provide the participant with a card that shows the above-described scale. For phone interviews, ask the participant to refer to PAGE #5 of the interview packet.

33. *For ED interviews*, what is your pain/discomfort right now?
For phone interviews, what was your pain/discomfort when you left the emergency department yesterday?
34. What was your pain/discomfort level when you first came to the emergency department today (*or* yesterday)?

Part 9 - Experience
Now I am going to ask you some more questions about your overall experience in the emergency department today (*or* yesterday).

35. While you were in the emergency department today (*or* yesterday), approximately how many times did someone caring for you have to stop and leave the room to do something else? In other words, how many times was your care delayed due to an interruption?
If participant is unsure, ask the following:
    a. Do you remember it ever happening today (*or* yesterday)?
    b. Did it happen more than once?

36. While you were in the emergency department today (*or* yesterday), approximately how many people (including nurses, doctors, technicians, etc) helped to take care of you?
If participant is unsure, ask the following:
    a. How many people do you remember coming into your room to care for you?
    b. Was it more or less than 5?

37. While you were in the emergency department today (*or* yesterday), did you have a family member or close friend present with you for more than half of your visit?

Please state the case consent number and your name (RA) again. As you turn off the audiotape, tell the participant what you are doing. Please mark down the answers to Part 10 directly onto the script.

Part 8

Part 10 – Personal Information

Finally, I would like to ask you a few questions about yourself.

38. This is an optional question. Please tell me your Race/Ethnic background. Are you:
    a. Black, African American
    b. White, Caucasian
    c. Hispanic or Latino
    d. Asian or Pacific Islander
    e. American Indian or Alaskan Native
    f. Indian sub-continent
    g. Multi-ethnic

39. Please tell me the highest level of education you have completed or are currently enrolled in. Is it:
    a. Less than 9th grade
    b. Between 9th and 12th grade
    c. High School Graduate or GED
    d. College
    e. Graduate School

40. Before today (*or* yesterday), how many times have you visited our emergency department in the last 12 months, as either a patient or with family/friends? _____

41. In general, would you say that your health is poor, fair, good, very good, or excellent?
Again, provide the participant with a card showing the following scale: poor, fair, good, very good excellent. For phone interviews, participants should refer to PAGE #2 of the interview packet.

Poor	Fair	Good	Very Good	Excellent
☐1	☐2	☐3	☐4	☐5

Part 11 - Literacy

Administer REALM literacy test to participant. For phone interviews, ask the patient to refer to PAGE #6 of the interview packet.

REMEMBER, at SJMH, please xerox a copy of the consent and give it to the patient!

If necessary, turn the audiotape back on and dictate any additional information that may help the transcriptionist. For all cases, where a caretaker was interviewed, please state this fact. In addition, if the patient was interviewed, but a relative was in the room and made some comments while the tape was running, please note this.

REMEMBER, if you forgot to give the consent number and RA name on the tape, do it now!

Part 9

Appendix E2. Concordance scale.

ED Discharge Study

August 2004 / Final

Coding scale

Each case is to be coded for four categories:

Diagnosis and Cause
ED care (Tests and Treatments)
Post-discharge care (Prescriptions, Ancillary measures, and Follow-up)
Return to ED instructions

1. **Concordance scores**
   Complete concordance
   Near concordance
   Partial concordance
   Minimal concordance
   No concordance

   NA = Not able to assess

2. **Discordant information**
   YES vs NO

3. **Omitted information**
   YES vs. NO

Primary goals

1. To assess the extent of concordance/agreement between what the patient reports and what the health care provider (PA or MD) documented during the visit
2. To distinguish between discordant information and omitted information by the patient

General assumptions / limitations for coding

1. Assume that what the patient knows is what is said in the interview. Avoid judgments about what is said in the interview versus what might be known by the patient. This issue is clarified further with specifics in the next section, "Specific guidelines for coding".

2. Assume that information from chart review is correct. This information has been transcribed directly from the official medical record. Avoid judgments about clinical management or instructions.

Part 10

Specific guidelines for coding

1. **Consider the amount/depth of follow-up questions asked in assessing concordance**.
    a. Although the RAs are encouraged to ask multiple follow-up questions, some patients may not provide some information that they know because they were not asked about this, so one should be sure to take this into account with the coding. If the RA did not ask a follow-up question, then you can not be sure whether or not the patient knows this information or not. For cases that seem equivocal, additional detail about how to handle this issue is provided in the next guideline (#2).
    b. Examples
        i. **Case 1058** – Diagnosis and Cause; when the RA asks about the diagnosis, the patient does not answer the question, but provides different information. The RA does not follow-up with additional questioning and so one can not assess what the patient actually knows about their diagnosis. In this case, it is appropriate code NA (not able to assess), rather than coding a low level of concordance.

2. **When making a judgment of whether or not to code something as NA (not able to assess), consider the worst case scenario.**
    a. In other words, if the patient had been adequately prompted with follow-up questions and did not provide the information (either omitted or discordant info), how significant would this be to their overall score. This is a bit of a subjective judgment, but is clarified with the examples below.
    b. Examples
        i. **Case 1266** – ED Care; the patient mentions that she had a pelvic exam and ultrasound, but no follow-up question is made to assess the patient's knowledge of the results of the tests. In addition, the RA does not ask the patient if there were other tests done (i.e. give the patient the opportunity to mention the blood tests). In this case, the patient clearly does know some of what happened during the visit, but the pelvic exam, ultrasound, and blood test (high pregnancy level or BHCG) reflect significant results. If one considers the possibility (worst case scenario) that the patient does not know or misunderstands these tests and their results, then this would significantly affect the score given (i.e. complete concordance vs. perhaps a minimal or partial concordance). For this reason, it is appropriate to code this as NA.
        ii. **Case 1275** – ED Care; similar to the patient in Case 1266 this patient is not asked adequate follow-up questions to ensure that all the information is elicited regarding testing. However, there are two important contrasts to this other case: first, what the

Part 11

patient does say reflects an unclear understanding of the blood tests done (causing a score of no greater than near concordance for this category) and second, the information that we are unclear about is not as significant. If we consider the worst case scenario (patient does not mention the EKG even with a follow-up question about what other testing was done) this would not lower the score significantly. In this case, it is appropriate to code near concordance and not NA because the code of near concordance provides us with good information about what the concordance is and, if anything, overestimates it only slightly.

3. **Assess concordance only**.
   a. The goal of this coding scale is to assess the extent of concordance between what the patient says in the interview and what is written in the chart/discharge paperwork. We are not intended to judge what communication may or may not have occurred OR whose fault it is in the case of a lack of concordance.
   a. Examples
      i. **Case 1001** – Diagnosis and Cause; the patient reports no diagnosis or cause, while the MD does report a possible cause. Although the patient's interview suggests some question of whether or not the MD communicated this to the patient, the goal here is to assess concordance and NOT the communication process. Concordance is scored near concordance in this case.
      ii. **Case 1083** – ED care; the patient does not report having a urinalysis (UA) although this is documented on the chart. The patient may never have known that this sample was obtained because a catheter was placed; however, the goal here is to assess concordance, not communication. Concordance is scored near concordance in this case.

4. **Give appropriate consideration to the specificity of information provided.**
   a. A patient may provide information that is not inconsistent with what is documented in the chart, but does not provide the same level of specificity (even with appropriate follow-up questions) for significant information regarding their visit. In these situations, the category should be coded as a lower score to reflect this lack of specificity.
   b. Examples
      i. **Case 1275** – Diagnosis; the patient states that they were told they had a high heart rate and this is in fact what is written on the discharge paperwork, but the physician documents that the cause of the high heart rate was PSVT (an abnormal arrhythmia). The patient is not aware of this cause and so the category is coded as near concordance in this case.

Part 12

5. **In the event of two unrelated diagnoses, give a single score for each category.**
    a. For a case with two unrelated diagnoses, assess concordance by considering both issues / diagnoses together. Take into account both the volume and relative importance (somewhat subjective) of the information given for each issue / diagnosis and decide on a single score.
    b. Examples
        i. **Case 1146** – The patient only mentions shoulder pain as a diagnosis while the chart review reflects an additional diagnosis of urethritis. The patient's interview indicates partial concordance with the information from the chart review for the first diagnosis and omission of the second diagnosis (complete lack of concordance). The concordance for the category of Diagnosis and Cause in this case is scored as minimal concordance.

6. **Extra information provided by the patient should not lower the concordance score**.
    a. Any information provided by the patient during the interview that is not present in the chart/discharge paperwork, but potentially consistent with the diagnosis and emergency medical practice, should not be scored as discordant. This will avoid inappropriately assigning a low concordance score for situations when the information may have been provided verbally without written documentation.
    b. Examples
        i. **Case 1146** – Return to ED instructions; the patient in this case states that he is to return to the ED if he "runs out of medications". This is not concordant with what information from chart review and is not consistent with emergency medical practice (i.e. patients should return to their regular doctor for medication refills). The concordance is scored as near concordance in this case with a YES noted for discordant information.
        ii. **Case 1198** – Post discharge care; this patient reports that he/she was told to "avoid light" after a presentation for an eye injury. While this information is not reflected on the chart review, it is consistent with the diagnosis and therefore the concordance is scored complete concordance in this case.

7. **Patients are not expected to mention instruction sheets.**
    a. In some cases, patients will be provided instructions sheets specific to their diagnosis. Whenever possible these sheets will be provided to the coder so they may be reviewed. Although the chart review will list this as part of the discharge instructions, it is not expected that the

Part 13

patient mention this sheet. The coder should review this sheet and make sure that none of the information provided by the patient is discordant with the sheet, but the patient is not expected to state everything on these sheets (i.e. do not count minor omissions of information provided only on this sheet).

Coding instructions

For each case, use a new coding sheet to record three codes for each of the four coding categories (Diagnosis & Cause, ED Care, Post discharge care, Return to ED instructions). Consider both the volume and relative importance of information, when assigning a single score for concordance for categories with more than one subset (i.e. ED care = tests and treatments). The two coders should score each case independently, but subsequently will meet to discuss and potentially resolve discrepancies in scoring. NOTE: Even if the actual score is the same, all categories with a score less than complete concordance will need to be discussed to consider differences in reasons for a score.

1. **Concordance scores**

   Complete concordance
   Near concordance
   Partial concordance
   Minimal concordance
   No concordance

   NA = Not able to assess

Complete concordance – no discrepancy between information reported by the patient and that documented in the ED chart; by definition, this means that there is no discordant or omitted information.

Clarification – a patient who states that they "got complete blood work" and did get extensive blood work should be coded as complete concordance provided that no additional follow-up of the type of blood work was probed in the interview.

Partial concordance – the patient reports some of the information documented in the ED chart, but significant information is discordant or omitted.

No concordance – the patient has no (or completely discordant) recall of the information documented in the ED chart.

Not able to assess (NA) – the coder is not able to assess the extent of concordance between the patient's report and the information documented in the ED chart due to poor tape quality or inadequate follow-up questions.

Part 14

Substantiating notes: For all codes of less than complete concordance, the coder should provide brief notes to indicate how/why they came to their decision. Line numbers are provided for reference to specific lines of interview text.

2. Discordant information

YES vs NO

3. Omitted information

YES vs. NO

Part 15