Clues to Patients’ Explanations and Concerns About Their Illnesses

A Call for Active Listening

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Most patients who experience illness symptoms develop an explanatory model. More frequently than physicians realize, these attributions involve serious and potentially life-threatening medical conditions. Only a minority of patients spontaneously disclose or “offer” their ideas, concerns, and expectations. Often patients suggest or imply their ideas through “clues.” Active listening is a skill for recognizing and exploring patients’ clues. Without this communication skill, patients’ real concerns often go unrecognized by health care professionals. Qualitative techniques including videotape analysis, postinterview debriefing, and interpersonal process recall were used to identify types of clues. We propose a taxonomy of clues that includes (1) expression of feelings (especially concern or worry), (2) attempts to understand or explain symptoms, (3) speech clues that underscore particular concerns of the patient, (4) personal stories that link the patient with medical conditions or risks, and (5) behaviors suggestive of unresolved concerns or unmet expectations. This clue taxonomy will help physicians recognize patients’ clues more readily and thereby improve their active listening skills. A deeper understanding of the true reasons for the visit should result in increased patient satisfaction and improved outcomes.

Decades of research have richly documented the discrepancy between physicians’ clinical orientation toward disease and patients’ experiences of illness. Patients often organize symptoms into a construct of possible meanings, interpretations, and explanatory models, which results in a unique set of related concerns and expectations—the patient’s perspective on illness (PPI).9

While it is often obvious that the perspectives of patients and physicians differ, both parties may erroneously assume that mutual understanding exists during their dialogue about symptoms. Unfortunately, patients do not overtly express their true concerns in up to 75% of acute care visits.8,10-12 When these concerns are explored, there is improved satisfaction, adherence, and disease outcomes.13-17 A group of international experts on patient-physician communication developed the Toronto Consensus Statement, recommending active listening for eliciting the PPI.18

The patient’s perspective may be elicited via nondirected facilitation techniques, direct questioning, or active listening. Nondirected facilitation skills, such as “tell me more” or “what else,” encourage patients to share ideas and concerns.10 Direct questioning, for example, asking the patient, “What do you think may be causing your problem?” results in greater sharing of patient’s ideas, concerns, and expectations.10 Unfortunately, many physicians do not use this approach after initial responses from patients like “I don’t know. That’s why I came to see you.” The third approach, active listening, focuses on attending to patients’ clues, ie, utterances and/or behaviors that are not explicit but may have special meaning and suggest unshared ideas, concerns, and expectations. Skill in active listening is required to recognize and explore these clues.
It should be noted that active listening for the PPI is distinct from active diagnostic listening (hypothesi- deductive processing) for biomedical information. In fact, physicians’ intense clinical gaze directed at symptom description, time line, modifying factors, and associated symptoms so focuses clinical attention as to make it difficult to recognize clues to the PPI.20,21 This distracting effect, which can interfere with caring physicians’ hearing the patient’s effort to be understood, was described as being “off in differential-land” by one of our standardized patients after working with a medical student who had failed to explore a set of repeated clues. Clearly, the skill of active listening is challenging in the face of such strong professional counter-currents.

The intent of this article is to (1) summarize what has been previously published on clues and active listening, (2) describe additional clues identified in our work, and (3) present a clue taxonomy to help physicians recognize opportunities for active listening and thereby facilitate a clearer understanding of the patient’s meaning (Table).

**CLUES TO THE PPI: A BRIEF HISTORICAL SUMMARY**

Balint22 used the term “offers” to describe patient expressions that implied or stated the meaning of their illness and purpose of the visit. Without specific training these go unrecognized, and the physician typically returns to further diagnostic questioning.28 The University of Western Ontario group24 have begun to operationalize the variety of communications that serve as clues to the PPI. They define statements that are repeated or out of context as “prompts.” For example, a mother presenting with her infant provides an example of “prompts” when she repeats the word “lethargic” 3 times. When asked to elaborate on the meaning of the word “lethargic,” her ideas and concerns (ie, dehydration as a life-threatening illness) becomes clear.

Neighbour25 recommended that physicians train themselves to identify various forms of speech censorship as indicators of unspoken, highly charged ideas, concerns, or needs. For example, when a patient pauses for a long moment and/or appears to be struggling whether to respond, this may represent a clue that significant problem solving, self-censoring, or reflection is occurring.

Butler23 described the “maternal grimace,” an example in our taxonomy of a nonverbal feeling clue. Barsky3 noted that a routine visit “without cause” or a patient’s expression of dissatisfaction with previous medical care may be a signal that the real reason for the visit has not yet surfaced.

Realini et al26 explored “inter- ruptions” as indicators that the patient may have additional information to share and found that when patients successfully interrupted, new information was contributed more than 70% of the time, with 39% of the interruptions contributing new, unsolicited information. White et al27 noted that “Oh, by the way . . . ” statements at the close of the visit (White et al27) in our taxonomy. Patient interrupts physician (Realini et al26) “By the way . . . ” statements at the close of the visit (White et al27)

**BEHAVIOR CLUES INDICATIVE OF UNIDENTIFIED CONCERNS, DISSATISFACTION, OR UNMET NEEDS**

- “Routine visit” without specific expressed concern or expectation (Barsky3)
- Presence of other people during the visit
- Patient interrupts physician (Realini et al26)
- “By the way . . . ” statements at the close of the visit (White et al27)
- Reluctance to accept recommendations
- Seeking a second opinion or an early return appointment
- Expression of dissatisfaction with prior care (Barsky3)

**METHODS: PROCESS OF ADDITIONAL CLUE DELINEATION**

Over the past 20 years, one of us (F.L.) has videotaped interviews between his patients and students. Follow-up interviews with these patients led him to suspect that certain patient utterances and behaviors were associated with their underlying ideas, concerns, and/or expectations. Later, after reviewing a variety of interviews, we developed a preliminary list of such clues.

One investigation that helped confirm and modify our original list involved videotapes of a convenience sample of 55 patients presenting with new symptoms to the family practice centers in Kingsport and Johnson City, Tenn. A postinterview questionnaire modified from Korsch et al25 focused attention on the PPI and explored for ideas and concerns that had not been explicitly communicated. All videotapes were reviewed initially by one of us (F.L.) to identify additional potential clues to the PPI. Then, we collectively reviewed the videotapes and information elicited from the patients’ postinterview questionnaire, comparing these attributions to the identified clues. An initial taxonomy of clues was developed and refined.

The relationship between identified clues and the PPI was further explored with 15 additional patients using a modified interpersonal process recall technique described by Kagan and coworkers.29 After securing patient permission, patients with new complaints were videotaped during their office visit. Immediately following the visit, the videotape was
reviewed with the patient by one of us or a research assistant trained in the interpersonal process recall technique. The videotape was stopped either by the patient when he or she felt their ideas and concerns were not being fully appreciated, or by the researcher after a possible clue was presented. At these points the patient was asked to recall unspoken attributions, concerns, and/or expectations; this review process was recorded on videotape.

RESULTS: ADDITIONAL CLUES TO THE PPI

A number of verbalizations and behaviors take place regularly during medical interviews that, if recognized, can prompt physicians to explore the explicit meaning of these clues.

In the sections that follow, dialogue examples are provided that illustrate a variety of patient statements (clues) and physician responses. Unless otherwise noted, all patient statements are essentially verbatim. Differences are contrasted between a traditional medical-diagnostic approach that focuses on “establishing a diagnosis” vs active-diagnostic approach that focuses on exploring the explicit meaning of these clues.

EXPRESSION OF FEELINGS

Direct Expression of Feelings

One of the most frequently observed clues was the expression of feelings (usually concern, fear, or worry) arising from the patient’s conscious but unspoken attributions of the cause of symptoms. Statements such as “I am concerned . . .” or “It has me worried,” or “That really bothered me” commonly serve as cues for the clinician to acknowledge and legitimize feelings (empathic response). Equally important, an active listening response may also uncover that which is yet unspoken, ie, the meaning underlying the feeling.

Situation: A 45-year-old woman complaining of weight gain.
Patient’s statement: “I’m real, real concerned about this weight gain. I’m getting so puffy.”

Patient’s true concern: She would become like her mother who was obese and who died of a stroke.

Actual diagnostic response: “When did you first notice the weight gain?”
Recommended active listening response: “You’re worried about your weight gain. What has you concerned?”

Projected or Denied Feelings or Concerns

Patients occasionally deny concern, or attribute fears to other family members when they feel anxious about a perceived threat. Such expressions should be seen as variations of direct emotional expression. Examples of this category included: “My wife’s been bugging me to see you about my headache. She gets worried about every little thing” or “I’m not worried about this rash but I felt it would be good to check it out.” Again, the clue “worried,” and exploring that will often yield the patient’s underlying concerns.

Symptoms Described With Vivid Intensity

Patients also revealed their concerns by vividly describing symptoms; for instance, “these headaches have been torturing” or “gobs of the vilest green material that you ever wanted to see.” Often words like “prolonged,” “severe,” or “worsened,” are indications of patient beliefs about potential serious illnesses or death.28 When patients use affect-laden adjectives and phrases, the meaning behind these charged descriptors may be explored by asking, for example, “Tell me what it means to you when sputum turns ‘vile.’”

ATTEMPTS TO EXPLAIN

Another frequently encouraged clue to the PPI is an effort by the patient to understand new symptoms through a self-diagnostic process.

Statements Revealing Attempts to Explain

A statement that the patient has been considering causation is an example of a patient’s problem-solving clue.

Situation: A 66-year-old man described a skin lesion.
Patient’s statement: “You look at it, and you wonder what it is.”

Actual diagnostic response: “How long has it been?”
Recommended active listening response: “Wondering? What sort of things have crossed your mind?”

Other examples of active problem-solving attempts included: “Whatever it is, I’d like to get to the bottom of it,” “I guess it could be anything . . .,” “I don’t know what it is,” “Something must be causing my . . .,” and “When I first felt this way, I thought it might be . . . but . . .”

Description of Unnamed Disease

The patient’s explanatory hypothesis at times surfaced when the symptoms were clustered and organized into recognizable constellations of some “dreaded” disease.

Situation: A 60-year-old nonsmoking woman spontaneously described her cough.
Patient’s statement: “. . . it’s not that it is that bad but, it’s back. It started to get better with the cough medicine, but now it’s back. The phlegm that I’m coughing up is clear, except recently there has been some blood mixed in.”

Patient’s concern: Familiar with the American Cancer Society’s 7 warning signs of cancer, the patient was concerned about possible lung cancer.

Actual diagnostic response: “Have you had any trouble waking up short of breath?”

Recommended active listening response: “The way you describe your cough, I wonder if you have a specific concern?”

Typically, when physicians ask specific closed-ended questions, patients’ yes/no or brief responses reveal little about how they have tried to organize and make sense of their symptoms.

Loaded Questions or Statements

Some patients indirectly addressed underlying concerns by asking apparently factual questions.

Situation: A 55-year-old man with poorly controlled insulin-dependent diabetes mellitus.
Patient's statement: “I’ve heard that hypoglycemia can damage the brain. Is that true?”

Patient’s concern: Having recently experienced an episode of dizziness, which he attributed to hypoglycemia, and having had several episodes of misplacing his car keys, this patient was worried that he might be developing dementia.

Actual response: Initially, the medical student explained the brain’s unique carbohydrate metabolic needs.

Recommended active listening response: “Before I explain about diabetes and hypoglycemia, I wonder if you have experiences or concerns about hypoglycemia?”

During the attending faculty’s exploration of the PPI, this patient disclosed a fear of medication-induced brain damage, which led to nonadherence and frank hyperglycemia. The medical student’s factual explanation deflected the patient from expressing his actual concerns.

SHARING A PERSONAL STORY

A personal story frequently served as a clue to either the clinical diagnosis (describing genetic or exposure links) or the patient’s etiologic explanation of her or his illness, for example:

Situation: A 55-year-old woman with arthritis.

Patient’s statement: “You know my mother lived to 85. I cared for her right to the end. She always said she didn’t want to suffer. She got her wish. She was pain free till the end. And I took care of her all the time.”

Patient’s concern: This patient feared that she would live a long life with overwhelming arthritic pain and physical limitation.

Actual response: “You were a good daughter.”

Recommended active listening response: “Sounds like you really took good care of her. What’s most important for me to know about your experience with her?”

BEHAVIOR CLUES

Certain overt behaviors can serve as clues to unexpressed ideas and concerns.

Presence of Other People

For the very young, the reason of additional persons during visits seems obvious. For other patients, the presence of additional persons may be a clue about some unexplained concern. As a way to better understand the reasons for the visit, clinicians are encouraged (with the patient’s permission) to engage the accompanying person(s) in a discussion of their input into the visit.

Reluctance to Accept Recommendations

At times patients are hesitant to accept diagnostic or treatment suggestions.

Situation: Patient with a cough, runny nose, and sore throat for which the physician prescribed a cough medicine with codeine for an upper respiratory tract infection.

Patient’s statement: “This cough medicine never seems to be enough.”

Patient’s concern: Last winter, the patient saw a physician for a bad sore throat like this one, was prescribed a cough medicine, then 3 days later was diagnosed as having a tonsil abscess. He was afraid that if he hadn’t come in, the abscess could have burst and pus might have gone into his lungs.

Actual response: “Your lungs are clear and...”

Recommended active listening response: “You sound worried that the cough medicine might not be enough. What are your concerns about that?”

The patient’s reluctance may have derived from unstated beliefs about causation or expected treatments that were never addressed. Such reluctance can lead to feelings of defensiveness or frustration on the part of the physician. Active listening is a helpful step to reaching common ground on a treatment plan.

Seeking a Second Opinion or an Early Return Visit

Unscheduled follow-up visits is another behavior that suggests that patients’ true concerns have not been adequately addressed. For example, a mother returned with her infant after having been seen at the first visit 2 days previously for a viral syndrome. The clinical situation had not changed, but the return visit was prompted by a previously unaddressed concern, namely, the fear of dehydration. Our clinical experience also supports that requests for second opinions, at times, reflect a concern or expectation that was previously not identified or adequately addressed.

In addition to identifying a number of additional clues, this review process confirmed the frequent occurrence of several previously recognized clues, for example, repeated statements, “by the way...” statements, and nonverbal emotional clues.

COMMENT

Patients present to health care professionals because of symptoms and concerns that they often indirectly express through clues. The taxonomy of new and previously referenced clues (Table) attempts to improve communication by helping clinicians recognize many ways that patients introduce their ideas, concerns, and expectations into the encounter. Feedback from our study participants using the interpersonal process recall technique confirmed the association of identified clues with specific, previously unexpressed ideas, concerns, or expectations they had about their illnesses. While we have described a number of patient clues, this list is certainly not exhaustive. Future research is needed to identify how people from a variety of backgrounds indirectly communicate their concerns to clinicians.

The classification of clues roughly parallels the patient’s process of evolving meaning from symptoms. Patients interpret symptoms in the context of personal, family, and life experience. Spontaneously shared personal stories may provide input into this contextual background.31-33 The patient’s attempts to understand symptoms often generate a series of hypotheses or explanations, which may result in problem-solving statements, as reflection of this self-diagnostic process. Many of these self-generated hypotheses create concern and anxiety. Patients’ emotionally charged expressions may provide an avenue into broader issues of the patient’s perspective. Several authors have described the tension that patients experience between wanting to share
their perspective and their embarrassment and reluctance to verbalize frightening ideas and feelings. It is our belief that this tension can produce the speech clues first identified by investigators at the University of Western Ontario and frequently observed in our study.

Identifying patients’ clues and exploring their underlying meaning can be an efficient means to bring together patients and physicians. The physician’s focus on the patient’s symptoms in an effort to correctly diagnose the underlying disease reduces attention and/or response to patients’ clues. This focus probably best explains why clinicians frequently follow such clues with additional questions about the characteristics of presenting symptoms. Developing and utilizing active listening skills and being patient centered requires that clinicians maintain their diagnostic orientation while concurrently seeking the PPI. Once the PPI is expressed, it is possible to address the concerns in an explicit way relevant to the patient’s real reason for the visit.

Many clues are not subtle. Physicians, in our experience, frequently perceive patients’ verbal and behavioral clues and act on them without confirming their interpretation of the patient’s expectation. For example, patients’ implied interest in receiving antibiotics best predicts prescription dispensing. We advise, however, that clinicians explore the meaning of these clues, allowing patients to disclose their meaning, which often is different from the clinician’s.

As an alternative to active listening, PPIs can be explored by physician-initiated queries such as “Tell me what you think is causing your symptoms.” However, eliciting the PPI via active listening has additional benefit. Noting the clue and exploring its meaning demonstrate that the physician is carefully listening and wants to fully understand the patient’s experience as well as symptom chronology. When feelings are expressed, active listening helps the clinician understand the PPI that is usually the source of such feelings. Merely acknowledging or normalizing a feeling does not necessarily identify its source. Consequently, we recommend using active listening to encourage patients to express their implied concerns.

While the general benefit of eliciting the PPI has been documented, decisions about when and how to explore patients’ concerns may vary. For example, how should the physician respond to an elderly smoker complaining of hemoptysis and weight loss and asking the loaded question, “I wonder what could be causing this?” If the clue is explored, the patient may express her overwhelming fear of cancer, which will have to be acknowledged, inappropriately denied, or ignored. Failure to address the meaning of the loaded question may leave the patient dissatisfied from not being heard. Alternatively, the clinician could respond, “I realize your concern and want some answers. Let’s get some tests to get to the bottom of the problem. How does that sound?” As with other clinical skills, judgment is required in the use of active listening.

Another debatable situation for clinicians concerned with office efficiency is whether to ask a patient with chest pain whether he or she is worried about a heart attack. We discourage this approach for several reasons: patients’ explanations can be unpredictable and quite different from what the clinician might predict, and patients frequently interpret physicians’ verbal, nonverbal, and behavioral clues. The clinician mentioning heart attack can increase concerns for the patient. Therefore, we encourage having the patient mention the concern through this process of clue identification and exploration, ie, active listening, and then acknowledging the concern and describing an approach to address it.

How persistent should the physician be in searching for the PPI? Frequently, when a clue is explored, a patient may initially deny any particular significance. The patient’s initial explanatory hypothesis may generate considerable anxiety and embarrassment, possibly resulting in denial or projection of its source to someone else. However, persistent active listening often results in new sharing of important ideas and concerns as patients may reflect on something they originally denied or minimized and then reveal new information either immediately or at a later time. In our experience, even when patients initially attribute the concern to someone else, they usually will share their concern if given the opportunity. Certainly, there are situations in which persistent exploration may appear as a lack of respect for a patient’s right not to explicitly reveal personal concerns. Research needs to determine the appropriate limits to repeated unsuccessful exploration of clues.

It remains to be determined how easy or difficult it is for clinicians to learn to identify and respond to clues. Stewart et al have documented the ability of residents to learn to identify repeats or prompts. Over the past several years, the categories of clues described herein have become part of our teaching of active listening in the patient-centered interview. We have demonstrated these clues on trigger tapes to audiences of students, residents, and practicing physicians and created standardized patient experiences with scenarios designed to challenge active listening skills. Through this process, we have witnessed an impressive improvement in active listening skills in follow-up interviews with real and standardized patients.

While the use of active listening carries certain challenges, identifying the patient’s real concerns usually results in a new level of understanding of the patient, increased satisfaction for both patient and physician, and improved medical management. Recognizing additional types of expressions and behaviors will expand our ability to explore more fully the meaning of the patient’s illness experience, bringing the worlds of patient and physician closer together.

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Walking to Prevent Heart Disease in Women

In the Nurses’ Health Study, increased physical activity (energy expenditure) was associated with lower rates of heart disease in a dose-response fashion. Women who walked at a pace faster than 3.0 miles per hour for 3 hours a week had about one third fewer coronary events. (N Engl J Med. 1999;341:650-658.)