

# Using Ethnography to Build a Working System: Rethinking Basic Design Assumptions

Diana E. Forsythe  
Intelligent Systems Laboratory, Department of Computer Science  
University of Pittsburgh, Pittsburgh, PA 15260

## ABSTRACT

*The problem of user acceptance of knowledge-based systems is a current concern in medical informatics. User acceptance should increase when system-builders understand both the needs of potential users and the context in which a system will be used. Ethnography is one source of such understanding. This paper describes the contribution of ethnography (and an anthropological perspective) during the first year of a three-year interdisciplinary project to build a patient education system on migraine. Systematic fieldwork is producing extensive data on the information needs of migraineurs. These data call into question some of the assumptions on which the project was based. While it is not easy to rethink our assumptions and their implications for design, using ethnography has enabled us to undertake this process relatively early in the project at a time when redesign costs are low. This should greatly improve our chances of building a system that meets the needs of real users, thus avoiding the troublesome problem of user acceptance.*

## INTRODUCTION

The problem of user acceptance of knowledge-based systems has been identified by the medical informatics community as a major research issue for the 1990s. It has been suggested that user acceptance would be increased if problem formulation, design, and system-building were informed by reliable information about the needs and desires of potential users, as well as the settings in which systems are intended to be used [6]. Such information provides a better basis for system-building than beliefs or assumptions that reflect neither systematic investigation nor experiential knowledge [15]. One source of such data is ethnography, a research method developed by anthropologists to gather descriptive qualitative information on complex real-world settings [13]. There is growing interest within medical informatics in incorporating ethnography into system design [3][6].

At the Intelligent Systems Laboratory we have been investigating the use of ethnographic techniques and an anthropological perspective in different phases of the process of building knowledge-based systems, including knowledge acquisition [5]; problem formulation [11][4]; system evaluation [6]; and project management [7]. Believing that ethnography can provide valuable input

throughout this process, we initiated a major project building on this insight.

In 1991 we received funding from the National Library of Medicine to support a three-year interdisciplinary project to design and build a patient education system using ethnographic data (in addition to other knowledge). The domain chosen was migraine. The proposed system is described in [2]. It is intended to collect patient histories and--on the basis of those histories--to provide natural language explanation tailored to individual patients concerning migraine, their experience of this condition, the drug treatment prescribed for them, and possible side-effects of their drug(s).

Ethnography is being used in this project in several ways. First, observation of doctor-patient communication in a range of clinical settings is providing data about the information needs expressed by migraine patients, the explanations offered them by physicians, and the extent to which particular explanations satisfy particular information needs. In addition, semi-directed interviews with migraineurs outside the clinical setting are revealing concerns that may not be expressed explicitly during patient visits.<sup>1</sup> Second, analysis of the field data is providing information about the factors with reference to which explanatory material should be tailored, as well as the relative value of different explanatory strategies for particular types of patients. And third, as the system is designed, the ethnographers draw upon their understanding of this domain to help insure the appropriateness of material and approaches developed by the system designers.

Fieldwork and system design proceed on an iterative basis. Having conducted a period of fieldwork, we step back, review our data in search of patterns, construct preliminary concepts and inferences, reflect upon their system-building implications, and then return to the field to further investigate and test these ideas. Concerns of system design sometimes suggest specific issues (e.g., causal reasoning) for the fieldworkers to investigate. Similarly, the fieldwork reveals unexpected issues (e.g., patient fears) that suggest modifications in system design (see below). During the first year of the project, we have carried out about 80 hours of documented observations of doctor-patient communication in five different clinical settings. We are developing prototype history-taking and

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<sup>1</sup> The fieldworkers are D. Forsythe and M. Brostoff.

explanation systems, and are building theory about migraineurs' information needs, patient types and explanatory strategies in order to help design these systems to meet the needs and expectations of real patients.

The interrelated processes of fieldwork and system design will continue over time as the project develops. However, we have already learned some important things from the effort to incorporate ethnography into the system-building process. This paper presents some of what we have learned.

## BACKGROUND

Medical information systems necessarily incorporate assumptions about the world, some of which are explicit and some of which remain tacit [9]. Traditionally, the information built into a system stems from one of two sources: what the designer knows and/or takes for granted about the world [6], and the conscious models of the domain expert(s) involved in the design team. Both types of belief can influence decisions about system design, although they may not have been subjected to rigorous scrutiny.

Incorporating ethnography into the design process can help to reduce the extent to which design is based upon unexamined assumptions. Given a system intended for a particular population of users, we can investigate systematically the information needs of such users, making informed inferences about the characteristics that a system would need to possess in order to meet those needs. Real-world data can thus assist designers to evaluate the appropriateness of their own prior beliefs about what potential users want and need.

## USING ETHNOGRAPHY TO HELP DESIGN THE SYSTEM

The fieldwork is leading us to reassess some of the beliefs upon which the migraine project was based. Initially we made a number of assumptions concerning the information needs of migraine patients, the meaning of such concepts as "tailoring" and "explanation," and the factors that influence successful information transmission. Some of these beliefs were explicit, while others only became clear as the fieldwork made us aware of other ways of thinking about these issues. To illustrate this process, this section considers four assumptions and the ways in which we have begun to rethink them.

1. We believed (and doctors told us) that patients actively request explanatory material from their physicians. We also believed (and doctors told us) that physicians respond to such requests by providing extensive explanatory material. This was the rationale for observing doctor-patient communication: we assumed that watching this process would provide useful data for

building a patient education system.

2. We took for granted that the explanation that migraine patients want is textbook material concerning the physiology of migraine and the side-effects of particular drugs used to treat migraine.

3. Believing (as we still do) that it is useful to tailor explanation to individual patients, we conceived of such tailoring as adapting the *content* of this textbook information to individual patients. Related to this, we assumed that the "patient types" to which we would adapt this information would be defined in terms of patients' social attributes (e.g., ethnic background, educational level, age, and possibly gender.)

4. Following from Assumption 2, we believed that patients would be empowered and compliance would be increased by providing patients with more and better substantive information about the physiology and treatment of migraine and the side-effects of migraine drugs.

On the basis of these assumptions, we began empirical research to investigate just what explanatory material migraine patients request of their physicians and to identify the "patient types" in terms of which this material should be tailored. At the same time, the system-building team began to develop schemes for representing textbook material on the physiology of migraine and the side-effects of particular migraine drugs. However, as fieldwork progressed, the anthropologists on the team began to have doubts about these four assumptions.

**Assumption 1.** The patients we observe rarely spontaneously demand explanations from their doctors. Patients don't ask nearly as much as we thought they would, and physicians don't necessarily give long or coherent explanations. This is consistent with the literature on doctor-patient communication [8][12], quoted in [14], p. 108], but contradicts what we had been told by some physicians. In order to elicit information needs and other concerns that patients might not be expressing to their physicians, we began a series of semi-directed interviews with migraineurs outside the clinical setting. These interviews are providing data on matters that have seldom arisen during our observations of patient visits. For example, we are finding that migraineurs often fear that their condition may be fatal, a concern apparently prompted by the frightening nature of some migraine symptoms and by their perceived similarity to symptoms of brain tumor or stroke. This example illustrates the adaptability of ethnography as a research method. Having detected hints of such underlying fears from the observational data, we used interviews to pursue the matter, obtaining data that confirm this insight and expand our understanding of patient experience. The scope of the prospective system will be broadened to address such fears.

**Assumption 2.** When patients do ask physicians

direct questions about their conditions, those questions generally concern neither physiology nor drug side-effects. We realized that we had simply been assuming that what patients want to hear about migraine is what doctors want to explain: that is, formal, general, textbook-type information. Instead, the information needs that we collect from migraine patients through both observation and interview are much more likely to reflect concerns of the following sort:

i) Is this something major (e.g., a stroke or brain tumor?)

ii) How does this make sense in terms of what I know about my body and my life (e.g., my eating habits or menstrual cycle)?

iii) How will this affect my everyday life (e.g., my work schedule or my ability to drive)?

iv) Why is this happening to me (allergy? inheritance?)

This list reflects a hierarchy of concerns, with (i) clearly perceived as the most important. At the bottom of this list come concerns such as the following:

v) What is migraine anyway, and how does my migraine drug work?

**Assumption 3.** While we continue to believe that tailoring explanation to individual patients is desirable, the fieldwork is beginning to change our ideas about how this should be done. It seems likely that explanation generated by the system will need to be adapted to patients' gender, age, educational level, and possibly ethnic background. However, it seems certain that tailoring will be necessary in terms of the hierarchy above, that is, in terms of where individuals are in their understanding of what is wrong with them. The order of these concerns is important: patients are unlikely to take in the later information (iv, v) until they have received answers to the prior concerns (i, ii, iii). For example, a lecture on the physiology of migraine or the side-effects of a given drug (v) will not register with a patient worried about a possible brain tumor (i).

Patients' information needs seem to start with the self and with major life/death worries, and to work from there outward. Note that the list begins with specific, personal concerns and moves toward more general ones that nevertheless still are personal. Formal, general concerns come at the bottom of the list. Thus, textbook descriptions of migraine are of much less immediate concern to patients than "what is going to happen to me."

**Assumption 4.** We initially saw tailoring explanation as a way to increase patient compliance, assuming that compliance can be increased if information flow increases. Thus, our initial discussion of tailoring explanation focused upon the *content* of the explanatory material presented by the system. But the fieldwork shows that the effectiveness of physicians' explanatory messages

depends in part on the *style* in which material is presented: this reflects both the tone with which the doctor approaches the patient, and the way in which the doctor frames what he says to the patient. In other words, how doctors say what they say is at least as important as what they say to patients. A fact-filled explanation that is delivered in a way that a patient cannot "hear" is not a good explanation in reality.

Some of the factors of relevance here have to do with non-verbal aspects of the physician's self-presentation, such as tone of voice, gaze, and touch. These variables do not correspond in any obvious way to attributes of a knowledge-based system. But other factors do imply things about designing the explanation facility of a system--things to which we did not initially pay much attention. For example, the field research has led us to focus upon the process we call *enlistment*. Although we assume that all of the physicians we observe offer explanations that are technically correct, some doctors consistently word their explanations in ways that seem to get through to patients more successfully. One relevant factor that we have identified in this connection is the language in terms of which physicians frame their explanatory messages. Enlistment of the patient by the physician is promoted by the use of inclusive language, that is, language that explicitly recognizes patients' competence and thus treats them with respect. We believe that such language increases the physician's (and thus the prospective system's) chances of having the patient hear the diagnosis and treatment recommendations. Given the importance of the doctor-patient relationship for patient education [1], as well as the links between doctor-patient communication, patient satisfaction, and compliance [10], it seems likely that successful enlistment of the patient by the doctor through the use of such language helps to promote compliance.

The following examples illustrate the use of inclusive language for patient enlistment. Text in italics is verbatim material spoken by physicians; text in brackets summarizes physicians' utterances as recorded in the fieldnotes, but is not verbatim.

**Example 1.** *I'll take a look in your ears, just to be sure. As you know, your ears are connected to your throat, and sometimes a sore throat can cause an ear infection.*

**Example 2.** *The chances are pretty good that this is a virus, the flu. As you know, there are two kinds of germs, virus and bacteria.* [further explanation follows]

These explanations contain some information about anatomy and germ theory. However, in each case, that information is presented after the phrase "You know," a phrase used quite consistently by this particular doctor. This wording allows the doctor to give patients information that they may or may not know without

appearing to lecture them. This wording is inclusive because it treats the patient with respect, as someone who shares knowledge with the doctor. The explanation is presented as a reminder rather than as instruction. **Example 3.** [The patient is a nurse with occasional migraines who has come to the doctor because of recently developed tension headaches. The narcotics that have worked occasionally in the past for the patient's migraines are not working now that she is taking a lot of them for the continuous tension headache. The physician urges the patient to get off the narcotics, saying approximately: As a nurse you know all about drugs and have easy access to them. But we medical people need to watch out and realize that we too are subject to some of the problems with these drugs.]

In this example, a different physician uses the fact that this patient is a nurse to frame the message as a reminder between colleagues. The device "we medical people" is used to make more palatable the presumably unwelcome message that the patient has become habituated to the narcotics she is taking for migraine.

## DISCUSSION

Our use of ethnography has called into question some of the basic assumptions on which this project was based. Initially the fieldworkers set out to discover the relation between migraine patients' information needs and their social and educational characteristics. Conceiving of these characteristics as defining patient "types," we assumed that these "types" would provide an appropriate framework in terms of which to tailor educational information about migraine and drug side-effects. Underlying this approach was a further belief that our goal was to construct a tutoring system to convey in appropriately tailored language some version of the same basic textbook material to all migraine patients. This framing of the problem assumed the patients' information needs to result from a lack of formal, general information about migraine, that is, precisely the sort of knowledge in which physicians are trained.

Preliminary analysis of our first year of field data has led project members to rethink this approach. First, although migraine patients exhibit a range of social and educational backgrounds, it remains unclear at this stage whether there is a relationship between these characteristics and patients' information needs with respect to migraine. Thus, our initial notion of patient "types" needs to be modified. Second, patients do indeed express information needs with respect to migraine, but these needs seem relatively infrequently to involve textbook-type information. In other words, what physicians and cognitive scientists define as "expertise"--formal, general information about anatomy, physiology, and pharmacology--is not necessarily what patients want to

know. Instead, the primary information need of the migraineurs we observe and interview seems to be to discover some meaning in their condition and to understand the implications of that condition for their own lives.

As is illustrated in the preliminary hierarchy of concerns presented in the previous section, the "top-level" question for migraine patients is, "What will happen to me?" Since migraine patients often fear that they have a brain tumor or have had a stroke, this is understood as a question of life or death significance. Lower down on the hierarchy are questions about the triggers, treatments, and causes of the condition. Useful responses to these questions may make use of textbook information, but will need to focus upon helping patients to translate this information into implications appropriate to their own particular circumstances. We hypothesize that every migraine patient perceives something like the hierarchy of concerns (i-v) laid out above. We do not yet know how long it takes patients to move through the hierarchy, or the extent to which individuals vary in this progress. However, each step of this hierarchy is associated with a particular set of information needs. In offering information to migraine patients, then, we need to provide explanation that meets the information needs that they currently experience. This implies that instead of tailoring information in terms of patients' social characteristics, we should tailor that information to their current concerns. This may make our task more difficult: although patients' social attributes remain fairly stable over time, their concerns about migraine can be expected to change as they move through the hierarchy.

The type of rethinking described in this paper is a predictable consequence of the systematic comparison between assumption and observed reality that constitutes an important part of ethnographic research. Experienced anthropologists expect that part-way through a field project, they may discover that they have been asking the wrong questions. Fortunately, the same analysis that leads to this realization also helps to suggest what the right questions may be. However, since the use of ethnography is quite new in medical informatics, researchers in this field may be less used to changing their major assumptions in mid-stream. During the first year of the migraine project, our system-building colleagues eagerly awaited the "results" of the ethnography. They expected these "results" to help them build the system they expected to build by providing data on how patients phrase their requests for textbook knowledge, as well as how best to word the textbook information offered by the prospective system. Instead, one of the first major results of the ethnography has been to call into question our original problem formulation. Observation of what migraine patients actually do and say suggests that we

have been thinking of building the wrong system.

It is not easy to rethink basic assumptions and their implications for design. For example, we may need to reconceptualize the proposed system as something other than a conventional tutoring system, that is, a system whose primary purpose is the explication and transmission of formal, general information. Given what we now know about the information needs of migraine patients, however, it seems likely that the system we had planned to build would have encountered major problems of user acceptance. We were planning to build a system intended to meet information needs that do not seem to be the most important ones from the standpoint of migraine patients. Fortunately, our observations are providing considerable information about what migraine patients do want to know. Thus, the ethnography provides some guidance in terms of which to redesign the prospective system. In addition, this rethinking is being accomplished relatively early in the design process, at a time when we can easily reorganize our approach to system-building. This contrasts with the more usual situation in medical informatics, in which inappropriate assumptions about users may not be discovered until a system is fielded and encounters the well-known problem of user acceptance. The ethnography has therefore enabled us to circumvent mistakes that would have been far more time-consuming and costly if discovered at a later stage.

Finally, the situation described in this paper brings up a theoretical issue for medical informatics. In an earlier paper, we pointed out that medical information varies both in its degree of specificity and in its degree of formality. Crossing these two dimensions produces a matrix of types of medical information [4]. We also noted that medical informatics has concentrated its system-building efforts upon meeting information needs that are formal and general in nature. Little attention has been given to the problem of facilitating access to formal, specific information or to informal information that is either specific or general in nature. In the project described here, our initial approach reflected this convention: we simply took for granted that a patient education system in migraine should provide formal, general information about migraine and the drugs used to treat it. As we have seen, however, data on the information needs of migraine patients have led us to realize that while migraineurs do need access to textbook-type information on migraine and its treatment options, they also need information that is specific in nature. This includes both specific, formal information (e.g., CT scan results) and specific, informal information (e.g., experiential findings about their migraine triggers and about drugs and dosing schedules that work for them). We now face the challenge of investigating whether and how our patient education system can facilitate patient access to a much broader

spectrum of information.

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