New Bottles, Old Wine: Hidden Cultural Assumptions in a Computerized Explanation System for Migraine Sufferers

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New Bottles, Old Wine: Hidden Cultural Assumptions in a Computerized Explanation System for Migraine Sufferers

Sophisticated computer programs known as "intelligent systems" have been developed for use in medical settings for over two decades. Such systems explicitly encode information about task domains, problem attributes, and problem-solving strategies. They also embody tacit assumptions held by those who build them, reflecting meanings taken for granted in particular cultural and disciplinary arenas. This article examines assumptions built into the design of a patient education system for migraine sufferers, drawing upon extended participant-observation of the development process. Its designers view the system as neutral, but observation reveals that it embodies a physician's point of view. While intended to support migraine patients by offering useful information not given them by physicians, the system in fact offers information characterized by the same assumptions and deletions as that provided by neurologists. Thus, although intended to empower migraine patients, this system may actually reinforce rather than reduce the power differential between doctor and patient. [migraine, patient education, medical informatics, medical computing, intelligent systems]

Computers have now been in use in medical settings for several decades. Since the early 1970s, computer systems incorporating artificial intelligence have been developed with the goal of providing decision support for clinicians and (more recently) patients. Both builders and users of such systems tend to think of them simply as technical tools or problem-solving aids, assuming them to be value-free. However, observation of the system-building process reveals that this is not the case: the reasoning embedded in such systems reflects cultural values and disciplinary assumptions, including assumptions about the everyday
world of medicine. The processes by which such values and expectations come to be inscribed in new computerized technologies are largely unexamined.2

This article draws upon my eight years of full-time participant-observation in the world of intelligent systems. I focused upon software design in medical informatics, a rapidly growing field at the intersection of computer science and medicine.3 Presenting material from a project to build a computerized patient education system for migraine sufferers, the article addresses two themes. First, how do values and expectations come to be embedded in technology? As I will show, software developers do not necessarily intend to do this, and indeed are often not even aware that they do it. This raises the problem of agency. Second, what are the implications of this state of affairs? I argue that the embedding of tacit values in biomedical technologies raises issues of importance for both practitioners and consumers of medical care. These issues include questions of knowledge and power between doctors and patients. Some of the assumptions inscribed in knowledge-based systems are contested in the world of medicine and/or in the wider society. Designed into software, however, they become invisible to the user and thus unlikely to receive much scrutiny (Forsythe 1993a, 1993b).

These points are grounded below in specific examples from the system-building project. First, however, I present some background on anthropological studies of computing and on the migraine project.

Background

Locating Technology

As Suchman (1994) has noted, technology is always located. Although the designers who build such systems may think of the artifacts they produce as transcending social particulars, tools are inevitably used in specific practice settings. As I will show, tools are also created in specific practice settings.

Location in Suchman’s sense is a matter of place and practice. In his analysis of the computerized medical-decision support system known as ACORN, Berg elaborates the notion of location, addressing “localization” in space, scope, and rationale (in press:ch. 4). In this article I argue that technology is located in another sense as well, in terms of the origin and nature of the ideas it embodies. The attempt to unpack intelligent systems conceptually, from a cultural and disciplinary standpoint, is a central theme of my research in artificial intelligence and medical informatics.

Designers of intelligent systems tend to portray them as “objective, neutral agents” (Crevier 1993:362), thus positioning (what they see as) computerized reason outside the unpredictable social and cultural contingencies of everyday life. Anthropologists have increasingly contested this construction, however, locating such technologies instead in the social and cultural world of their designers. Ethnographic observers have documented the embedding in knowledge-based systems of a wide range of beliefs and expectations carried over from the everyday world (Forsythe 1992; Graves and Nyce 1992; Kaplan 1987; Lundsgaarde et al. 1981; Nyce and Lowgren 1995; Nyce and Timpka 1993; Suchman 1987, 1990). For example, such systems have been shown to represent beliefs about the relation between plans and human action (Suchman 1987), expectations concerning the
nature of work practice in particular settings (Suchman 1992), theories about individualism and education (Nyce and Bader 1993), and tacit assumptions about the nature of knowledge (Forsythe 1993b) and work (Forsythe 1993a).

These anthropological analyses of the system-building process and of the software thereby produced show consistently that intelligent computer systems are cultural objects as well as technical ones. Because they are often taken for granted, the assumptions embodied in system design can be invisible to those who hold them. Since such beliefs are not necessarily shared by end-users, however, their representation in a system may contribute to problems of comprehension or acceptance when the software is installed in real-world settings (Forsythe 1993a; Suchman 1987).

The assertion that designers build aspects of their own worldview into their systems in unacknowledged and uncontrolled ways has found little resonance in computer science and medical informatics. Most designers apparently do not believe that they build cultural values and assumptions into their systems. Indeed, they do not always recognize that they hold some of the values and assumptions that I and other observers have pointed out. While it is not unusual for anthropologists’ accounts of others to differ from the others’ accounts of themselves, this difference in perspectives is intriguing because it raises the problem of agency. Ideas do not embed themselves in technology, nor do I entertain the determinist notion of humans as “cultural dopes” (Garfinkel 1967:68, quoted in Suchman 1990:307). If identifiable cultural and social expectations are routinely represented in intelligent systems, just how do they come to be there?

In addressing this question, I present examples from a three-year project to build a natural language patient education system for migraine sufferers (Buchanan et al. 1995). Design involves decisions made daily throughout the long process of system building. Such choices reveal many things decision makers take for granted. In the case of the migraine project, these involved not only abstract cultural and disciplinary beliefs held by various members of the design team, but also assumptions about such things as what counts as “medical knowledge,” power relations between doctors and patients, the relative importance of nurses, the reasons for (what physicians call) patient “noncompliance,” and other characteristics of the everyday world of medicine.

The investigation reported here is highly reflexive. As an anthropologist studying a scientific community engaged in formulating knowledge descriptions, I offer my own descriptions of their knowledge. In addition, as explained below, I carried out ethnographic fieldwork not only on a system-building project, but for it. Based on that fieldwork, I also describe something of the knowledge of migraine sufferers. My attempt to describe and contrast different sets of assumptions inevitably reveals some of my own beliefs as well. In the text below I use my own reactions and experiences to help throw my informants’ assumptions into relief.

The Migraine Project

In 1991 a university-based research team received funding to support a three-year interdisciplinary project to design and build a computerized patient education system for people with migraine. The system was intended to empower migraine sufferers by providing them with information about their condition and
its treatment. In contrast to conventional design procedures in medical informatics, this project included ethnography; the latter was used not only to document project meetings but also to provide input to system design. Fieldwork included observation of 78 doctor-patient visits in neurology, informal interviews with numerous physicians and patients, and extended formal interviews with 13 migraine sufferers (Forsythe 1995). Formal interviews and most of the doctor-patient encounters were audiotaped. A detailed content analysis was carried out on the 600-page transcript of 18 of the doctor-patient visits.5

A prototype system was built and subjected to formative evaluation with migraine patients. Intended to be used by both patients and doctors (or other health care providers), the system consisted of two linked components: a history-taking module and an explanation module. The development team intended the system to be used as described in the following scenario:

A new headache patient comes into the doctor’s waiting room and is invited to sit down at the computer to use the system. First, the history-taking module presents an automated questionnaire, which takes a detailed initial history of the patient’s headaches. Based on the user’s responses, the system prints out a written summary for the neurologist to use when seeing the patient. Before subsequent visits, the system takes a shorter update history, again producing a written summary for the physician. Following each encounter with the doctor, the explanation module of the system is available for patients to use to pursue questions of interest to them. Since the history taker sends information to the explanation module, which also receives up-to-date information about the patient’s diagnosis and medications from the physician, the system is able to provide on-screen expository material that is tailored to each individual patient. This material contains information about the patient’s condition and current medications, offering further explanation as desired. In addition, it includes some general (i.e., non-tailored) information about the experience and treatment of migraine on topics seldom addressed explicitly by doctors. Several levels of explanation on each topic are offered, activated when the user clicks with the computer’s mouse on words and phrases of interest in each text screen. When the patient is finished using the system, the computer prints out a record of the expository material presented that day for the patient to take home.6

Three factors contributed to our choice of migraine as the focus of the explanation system to be built by the project. First, migraine is very common. This chronic condition inflicts severe and unpredictable pain on approximately 20 percent of the population (Lane et al. 1989). Three-quarters of migraine sufferers are women (Saper et al. 1993:93). Second, although this condition causes great discomfort (Good 1992), it is almost never fatal—a quality that attracted the research team on ethical grounds. While the goal of the system was to help migraine sufferers, the team was reassured by the knowledge that failure to help patients would be unlikely to cause them lasting harm.

And third, because diagnosis and treatment of migraine depend on effective verbal communication between physician and patient, it is an attractive domain for a system-building project. Few physical signs or laboratory tests differentiate this condition from other sorts of headache. Instead, diagnosis depends primarily on a thorough history of symptoms; treatment efficacy is evaluated on the basis of what the patient reports. Since information that humans articulate can also be requested
and provided in text on a computer screen, the research team expected migraine to be a suitable domain about which to provide explanatory material with a computer.

Locating Myself in Relation to the Migraine Project

This article is part of an extended field study in the anthropology of science and technology, focusing upon the relationship among the values and assumptions that practitioners bring to their work, the practice that constitutes that work, and the tools they construct in the course of their work. I take an interpretive approach (Geertz 1973, 1983), attempting to understand what events mean to the people involved. From 1986 to 1994 I was a full-time participant-observer in five software development laboratories in the United States. Four of these were located in academic settings; one was in an industrial setting. The unusual length of this fieldwork reflects the complexity of the technological and social processes under investigation; systems typically are produced collaboratively and take several years to develop.

The migraine project took place during the last years of my fieldwork. In the beginning of the project, at least, I was a full participant. I wrote substantial portions of the funded proposal, which explicitly proposed the use of ethnography to support system design. Paid by the project as a co-investigator, I took an active role in group meetings and coordinated the ethnographic fieldwork and analysis.

As the project progressed, however, I found it increasingly difficult to reconcile my roles as both participant and observer. The paradigmatic differences between informaticians and anthropologists that I had documented in my previous work (Forsythe 1993a, 1993b) took on practical as well as epistemological significance as we attempted to find ways to reconcile relativist understandings of ethnographic data with the positivist expectations and procedures of normal system-building. As the project developed (in the steps outlined below), I became less of a participant in and more an observer of the system-building effort. Despite our shared initial intent to undertake an innovative design effort, despite the rich ethnographic data on migraine that we collected and analyzed for the project, and despite some anthropological contribution to the explanatory content and overall direction of the prototype system (Forsythe 1995), the migraine system that was actually built reflected much less ethnographic input than we had originally envisioned. Some of the reasons for this outcome will become apparent in the following sections.

Designing Values and Expectations into an Intelligent System

The design team included people from computer science, cognitive psychology, medicine, and anthropology. In the course of the three-year project, these people met in various combinations for dozens of project meetings. During these meetings, and during informal discussions between them, team members made decisions that affected the design of the system. The design decisions described below were the outcome of negotiations to which individual team members sometimes brought divergent points of view. In order to protect their privacy, I refer to team members collectively and omit details of how particular decisions were made.
Design decisions reflect different levels of intentionality. Some are made explicitly. Others occur as a sort of side effect of other, explicit decisions, while still others can be said to occur by default. (It may be inappropriate in the latter case to use the word "decision.") To convey a sense of these three possibilities, I will give examples of each.

1) Explicit design decision—"hanging" explanatory text on the patient summary: The migraine system was designed to engage in an explanatory dialogue tailored to the specific needs of the user. In order to initiate the dialogue, the system builders needed to present users with something to ask questions about. For this purpose, they chose to use the so-called patient summary—a two to three page text presented on the computer screen that details the neurologist’s recommendations during his or her most recent visit with the migraine patient. This text averages about ten paragraphs in length and is adapted to each patient around a basic topic structure. A sample text begins as follows:

Today you were seen by Dr. _____, who diagnosed you as suffering from migraine. The most common symptom of migraine is a moderate to severe headache. Migraine patients also frequently experience visual symptoms, nausea, sensitivity to light, sensitivity to noise and confusion. Your head may feel tender and sore when you have a migraine headache. Much of the pain in a migraine headache is thought to be due to the stretching of blood vessels in the scalp and the head. Your symptoms included flashes, light-spots, double-vision, blurred-vision, photo phobia and painful-eye-movements which are all consistent with typical cases of migraine.

Patient summaries go on to mention that migraine is hereditary, that migraine attacks may be frightening but are rarely life-threatening, and that they are likely to get better with age (a comment offered only to women who are premenopausal because of the frequent connection between migraine and the menstrual cycle). They describe migraine triggers and address the treatment and possible side-effects of medications prescribed for the particular patient using the system. The designers considered the decision to "hang" the system’s explanatory texts on the patient summary to be straightforward. However, this choice had a significant tacit consequence for users that the system builders either did not notice at the time or simply took for granted.

2) Tacit consequence of an explicit design decision—excluding explanatory material from the system: Because explanations are displayed when the user clicks on words or phrases in the patient summary, the prototype system cannot explain anything that does not fit into the scope of this text. The system design thus excludes patient questions on topics that were not addressed by doctors during patient visits. This prevents the system from answering most of the questions we picked up from migraine sufferers during fieldwork, which were unanswered in the first place because they involved topics not generally addressed by doctors during patient visits. Even though the design team never actively decided to ignore patient questions that lay outside the scope of what doctors prefer to talk about in the office, in effect they did just that.

3) A default design decision: A third type of design "decision" is not a conscious decision at all, but rather an unplanned reflection of the designers’ worldview. Like everyone else, software designers make assumptions about the
everyday world; these may affect their work practice. For example, an unconsidered omission by the migraine system designers prevents the history taker from collecting potentially important information about the user’s possible experience of domestic violence. The question below is from the section of the automated questionnaire intended to establish the user’s headache history:

Did anything happen to you at about the same time you started having this kind of headache?
___ accident
___ illness
___ started or stopped some drug or medication
___ other
___ don’t know
___ not applicable

If the user checks “accident,” a pop-up window appears on the screen and offers three further options:
___ head injury
___ injury other than a head injury
___ car accident

This question sequence categorizes physical injury under “accident.” The questionnaire thus does not allow for the possibility of headaches caused by intentional violence, a significant omission given that 75 percent of migraine sufferers are women (Saper et al. 1993:93). Physical trauma is a relatively common cause of migraine (Weiss et al. 1991), and domestic assault is a form of trauma to which women are particularly vulnerable. On the basis of observations and transcript analysis, the project ethnographers had noted that several of the women in our study appeared to be victims of domestic violence; this point had been mentioned repeatedly at research team meetings. Nevertheless, because of a particular, perhaps gender-biased view of the world, the men who wrote the above question for the history taker did not make the connection and overlooked a possible cause of post-traumatic migraine that mainly affects women.

I have illustrated the fact that system builders’ tacit assumptions can affect the design of an intelligent system in a variety of ways, reflecting different degrees of intentionality. The next section describes how particular assumptions were inscribed in the prototype migraine system at different stages of the development process.

Assumptions Expressed in the Design of the Migraine System

Some design decisions affected the user interfaces to the history-taking and explanation modules (i.e., what appeared on the screen). Others affected the way the system worked and what it could address, but remained backstage from the user’s standpoint. Decisions of both types were influenced by designers’ cultural and disciplinary assumptions.

The sections below provide examples of both types of decision. I organize them sequentially, in order of the major stages of system-building: (1) assembling the project team, (2) problem formulation, (3) knowledge acquisition, (4) writing the code to build the system, and (5) evaluation. Obviously, assumptions made by
designers in one stage of system construction are likely to be made in other stages as well. For reasons of convenience, I discuss particular assumptions in the context of design decisions that reflect them especially clearly.

Stage 1: Choosing the Project Team

The stated goal of the migraine project was to develop a patient education system for the benefit of migraine sufferers. The research team assembled for this project was large, containing half a dozen faculty members, two programmers, a research assistant, and about six graduate students.

Two aspects of the composition and interaction of the team are of note. First, the team contained two physicians but no nurses. In view of the fact that nurses often have a great deal of contact with patients and consider patient education to be one of their most important jobs, their absence from the project is noteworthy. It reflects the characteristic muting of nurses' voices in medical informatics in relation to those of physicians.9

Second, the voice of migraine sufferers was muted as well on the project, though for somewhat different reasons. Although four nonphysician members of the research team (including two senior members) actually suffered from migraine, they spoke in meetings only in their professional roles; they never spoke in their private personae as migraine sufferers. This was especially striking because in private interviews, they had eloquently described to me the pain and fear of their migraine attacks, and the failure of biomedicine to provide them with significant relief—a story heard over and over again in the course of the study. Yet for three years, they remained silent about these experiences at project meetings, allowing the physicians (neither of whom had migraine) to speak for patients. Although these migraine sufferers' private stories diverged from the project physicians' accounts of what migraine patients know and want to know, they never publicly contradicted these physicians. I see their silence as reflecting the power differential between doctors and patients in the world of medicine. Their choice (in public, at least) to privilege "expert" medical knowledge over their own experiential knowledge may also reflect the stigmatization of migraine to which several of our interview respondents referred.

Insofar as it affected the work that produced the migraine system, this disparity of voices between doctors and nurses, and between medical experts and laypeople, is inscribed in the system design. What migraine patients know and say in private about their condition is present in the system only as it was represented on their behalf by physicians and anthropologists. And whatever nurses might have had to say about migraine and its treatment is completely absent from the system.

Stage 2: Problem Formulation

Intelligent systems are intended to solve problems. Problem formulation, the initial design stage, involves deciding what problem a prospective system should address. This decision in turn influences the type of system to be built.

The project team made a series of assumptions that led to the definition of the problem that the migraine system was to address. These assumptions were not all explicit; indeed, as beliefs taken for granted in medical informatics, many remained
completely tacit. I recapitulate below the basic argument made by the project team during problem formulation, considering several of the assumptions on which this argument rests.

**Basic Argument.**

1. Physicians know a great deal about migraine.
2. Migraine sufferers need this knowledge in order to manage their condition better. In the language of medical informatics, migraine sufferers have unmet information needs.
3. These information needs contribute to (what physicians see as) the problem of poor patient compliance: if patients knew more about migraine, their compliance would improve.
4. Improved patient compliance would promote successful treatment of their condition, which in turn would empower them.
5. Physicians do not have time to provide patients with lengthy explanations, and are likely in future to have even less time for explanation.
6. The problem to be solved, then, is migraine patients’ insufficient access to medical information, which in turn is caused by the time shortage of physicians. Since information needs can be met by delivering more and better information, and since intelligent systems are well suited for information delivery, there is a clear need for an intelligent system to provide patients with explanatory material about migraine.

**Assumptions.** To some, this argument and its conclusion may not seem to rest upon assumptions at all, but upon obvious truths. As the foundational assumptions of medical informatics, these “truths” are so thoroughly taken for granted that they are invisible to people within the field. But as the fieldwork with migraine sufferers made clear (Forsythe 1995), the steps in this argument can be viewed from other points of view. I recapitulate below the assumptions enumerated above, pointing out some issues of perspective.

1. The project team assumed that knowledge about migraine means biomedical knowledge, that is, formal, general information of the sort found in medical textbooks (Forsythe et al. 1992).
2. Because the project team interpreted “knowledge about migraine” to mean what doctors know, they believed that migraine sufferers who are not physicians lack knowledge about migraine. As I began interviewing migraine sufferers in private, it became clear that this assumption is wrong. People with migraine tend to know a great deal about the condition and about some of the drugs used to treat it. They may have different knowledge than physicians. For example, people with migraine have experiential knowledge of what happens to them during migraine attacks, which they often exchange with fellow sufferers. In addition, they may have medical knowledge. Some of our informants read medical literature about their condition and were extremely well informed. In relation to physicians, then, migraine sufferers may have alternative knowledge but certainly do not lack knowledge about migraine.
3. The migraine team assumed that the information needed by migraine sufferers was biomedical information. They expected patients to want physiologi-
cal information about migraine and about the side-effects of drugs used to treat it. In other words, the research team simply assumed that what patients wanted to know about migraine is what neurologists want to explain. In actuality, however, migraine sufferers expressed a desire to know about a broad range of topics involving migraine, beginning with the apparently universal secret fear, “Do I have a stroke or a brain tumor?” (Forsythe 1995). Much of what they said they wanted to know about their condition was informal and/or specific knowledge (Forsythe et al. 1992) rather than textbook material. Of particular importance to people living with migraine was the problem of translating formal medical knowledge about migraine and its treatment into information that they could apply in their own lives, a factor that seems related to patient compliance (Hunt et al. 1989).

(4) The migraine team assumed that a lack of time prevents physicians from explaining more to patients. However, our observation of patient visits suggested that time is not the main factor constraining explanation to patients. In fact, a great many questions are asked and answered during patient visits, but almost all of them are asked by the doctor and answered by the patient. This finding is consistent with the literature on doctor-patient communication (Frankel 1989; Wallen et al. 1979, quoted in West 1984:108). We found that neurologists provide relatively little explanatory material, and that patients are given little chance to request it. We also found that when patients attempt to bring up concerns that neurologists do not see as strictly medical, physicians often appear not to “hear” them or attempt to pass the matter off as a joke. Such patient concerns include veiled references to death (presumably prompted by the secret fear mentioned above [Forsythe 1995]) and questions about how they can carry on normal life and work in the face of unpredictable disability. Clearly, migraine patients do have unmet information needs, but they are not necessarily due to a lack of physicians’ time. On the basis of our observations, I would attribute such unmet information needs as well to the power of physicians to control doctor-patient discourse and thus to avoid topics they may not be prepared to address.

In the problem formulation stage, the migraine team framed the problem of patients’ lack of knowledge as technical in nature. Given this view of the problem, they proposed a technical solution: development of a computer system to deliver to migraine patients the information they were assumed to need. As I have tried to show, the team’s construction of the problem took for granted a series of assumptions and expectations about the medical world. These included the privileging of biomedical knowledge over the knowledge of patients, and a tendency to overlook the power of doctors to avoid patients’ questions. Not only were the research team’s assumptions and expectations embodied in their problem formulation; as I show below, they were also built into the system.

**Stage 3: Knowledge Acquisition**

The proposal to use ethnography in support of system design was innovative. I was convinced that concepts and methods from anthropology could make a useful contribution to software design and evaluation (Forsythe and Buchanan 1989, 1991, 1992). Although a handful of social scientists have applied ethnographic and survey methods in medical informatics since the 1970s (Anderson and Jay 1987; Kaplan 1983; Kaplan and Duchon 1988; Lundsgaarde et al. 1981; Nyce and Timpka 1993),
social scientific contributions to design are still viewed as experimental by most people in medical computing. Perhaps because writing code is seen as the “real work” of software development (Forsythe 1993a), ethnographic research tends to be subordinated to the conventions of “normal” software design. In the present project, for example, senior physicians and computer scientists were unwilling to have fieldwork with migraine sufferers begin before the writing of code for the migraine system. Instead, it was decided that fieldwork and system building should run in parallel.

The anthropologists began systematic fieldwork at the start of the funded project. We observed interactions between patients and neurologists and conducted private interviews with migraine sufferers and physicians. At the same time, the system builders began to think about how to represent the knowledge that they expected the fieldworkers to present to them. However, tensions arose over the issue of timing. Accustomed to a “rapid prototyping” model of software production, the designers wanted to start building the system long before the anthropologists felt ready to generalize from the early field data. In order to have something to code, the designers began conventional knowledge acquisition in parallel with the ethnography. Their intention was to build results of the ethnography into the system as they became available.

Elsewhere, I have written about what conventional knowledge acquisition entails (Forsythe 1993a, 1993b; Forsythe and Buchanan 1989). In the migraine project, it involved debriefing a single neurologist (designated as “the expert”) about migraine drugs, treatment strategies, drug side effects, and so on, and then incorporating his conscious models into the knowledge base as “knowledge about migraine.”

The plan to combine the results of this knowledge-acquisition process with the results of the ethnographic investigation reflects the system designers’ assumption that knowledge is neutral. In computer science and related fields, knowledge is generally viewed in positivist terms. It is assumed that one can understand and evaluate it in decontextualized fashion without attention to the identity or position of the knower (Forsythe 1993b). In medical informatics, knowledge is conventionally described in terms of transfer and flow. “Information needs” are seen as “out there,” stable (at least in the short term), inherently ordered, characteristic of and shared by groups or categories of people, and knowable by others. Thus one task expected of the anthropologists on the migraine project was to “find” the information needs of migraine patients and to report them (in a prioritized list) to the system builders. Seen from this reifying perspective, knowledge should be additive. It made sense to the designers to begin building the system’s knowledge base by representing material supplied by the physician-expert, with the intent of incorporating the ethnographic findings later on.

In contrast, anthropologists see knowledge as inherently contextual (Geertz 1983). To consider knowledge “needs,” “transfer,” or “flow” without addressing the matter of who wants, knows, or shares this knowledge is (for an anthropologist) to delete an essential part of what it means to know. Furthermore, because all human beings are positioned in a social order, their knowledge is seen as positioned as well. To an anthropologist, knowledge always incorporates a perspective (Rosaldo 1993). Given this view, knowledge is neither neutral nor necessarily additive.
It turned out to be difficult to combine the results of conventional knowledge acquisition with the insights from fieldwork. The material obtained by the conventional method embodied a neurologist’s point of view. It privileged the knowledge and categories of formal medicine, and incorporated the assumptions and expectations characteristic of medical informatics. In contrast, the ethnographic findings treated physicians’ and patients’ perspectives on migraine as different but equally valid. While the designers were willing in principle to encode such material in the system, in practice it just did not seem to fit. The ethnographic material was inconsistent with design elements to which they had committed in the early stages of conventional knowledge acquisition with the physician-expert. Later on, material based on the ethnography was difficult to incorporate into the system because it did not take for granted the centrality of medical events (e.g., the doctor-patient visit) or a physician’s point of view.

Stage 4: Building the System

In addition to the general epistemological and disciplinary assumptions discussed thus far, the migraine system also embodied more specific assumptions and expectations of the research team. Below, I illustrate specific assumptions that were built into the history-taking and explanation modules.

**Design of the History-Taking Module.** The history taker is an automated questionnaire that inquires about the user’s headache and medication history. Each patient’s responses are compiled to create a printed summary for the physician. The responses are also passed to the explanation module, which makes use of them to generate explanatory text tailored to the gender, age, symptoms, medications, migraine triggers, and other attributes of each individual user (Buchanan et al. 1995).

The migraine team included several social scientists who were experienced in constructing and piloting questionnaires. However, the job of developing the history taker was given to a computer programmer, who approached the assignment as a system-building task. Rather than first developing and refining a set of questions, as a social scientist would have, the programmer built version after version of a computer system that generated questions—a much more difficult undertaking. The questionnaire produced by each version of the system was criticized by fellow team members, after which yet another version of the entire module was slowly and carefully built.

Eventually, perplexed at the seeming irrationality of constructing successive versions in code instead of in simple text (which would have been much faster), I asked the computer scientist in charge why the social scientists had not simply been asked to construct a questionnaire, pilot it, and then give it to the programmer to code. The response highlighted different disciplinary assumptions concerning the nature of the work in question. From my standpoint, the automated history taker was a questionnaire. I saw its construction as a social science task that happened to require some programming to represent the final product. From the computer scientists’ standpoint, in contrast, constructing the history taker was a technical task because the material was to be represented in code. To them, it was a coding job that happened to involve a questionnaire.
This distinction expresses a significant difference in perspective. To computer scientists, the “real work” of constructing the history taker was writing the code, that is, producing the computer program that generates what the user sees on the screen and that processes information supplied by the user. This stance reflects the centrality of coding work in computer science (Forsythe 1993a). For computer scientists, “getting the words right”—their understanding of the social science contribution to both questionnaire and system design—was merely “frosting on the cake.” To an anthropologist, in contrast, constructing a good questionnaire raises epistemological issues about the categories into which human experience is divided. From this viewpoint, resolving such issues was an important part of the “real work” involved in constructing the history taker. This contrast in perspectives reveals conflicting assumptions about the relative importance of technical work and epistemological work (or alternatively, about which part of the work should be seen as technical.)

The design of the history taker also reflected a second kind of assumption, the belief that migraine sufferers categorize their headaches as a physician would. The wording of certain items in the dynamic questionnaire generated for each user privileged medical categories and a physician’s perspective. For example, at the beginning of a history-taking session, users are asked: “How many types of headache do you have? Answer the questions about the type that brings you to the doctor today.” This question reflects the assumption that headache patients classify their headaches according to the same “types” that neurologists use. Therefore, one of the types is expected to be migraine. However, this assumption was not borne out by our field data, which showed that headache sufferers may categorize their experience quite differently from neurologists. For example, a patient diagnosed as suffering from both migraine and tension headache, or from two different types of migraine, may understand herself to be suffering from one fluctuating or unpredictable “type” of headache. In this case, her responses to the history taker would “lump” information about what a neurologist would see as two different types of headache.

Design of the Explanation Module. As with the history taker, the interface design for the explanation module reflected the assumed centrality of medical perspectives and events. As noted above, all explanatory material in the prototype system is “hung” on a summary of the doctor’s recommendations during the patient’s latest visit. The prototype system is restricted to explaining items that can be worked into the context of this text. This is a severe constraint. Our observation showed that neurologists rarely bring up issues outside the formally medical (e.g., lifestyle questions), and tend not to respond to patients’ attempts to bring up such issues (e.g., concerns about whether particularly severe attacks may be fatal). Based on the fieldwork, I compiled a list of about 200 queries to which migraine sufferers wanted to know the answers. The restriction of the system’s explanatory frame to the patient summary made it impossible for the system to address most of these questions. Instead, members of the project team made up questions for the system to answer. In effect, then, they worked around the ethnographic data in order to revert to conventional design procedures.
The system reflects in several ways the assumption that patients are passive and physicians are active and powerful. For example, as illustrated above, for more than a year the prototype patient summary began, “You were just seen by Dr. _____, who diagnosed you as having migraine.” This language frames the user as object in relation to the physician. Late in the project, it was finally changed to “You just saw Dr. _____, who diagnosed you as having migraine,” thus removing from the explanation module one small symbolic representation of the power differential between physicians and patients.

However, other potentially more disempowering aspects of the system design remain unchanged. As is conventional among computer scientists who design natural language systems, the developers saw the purpose of the explanatory dialogue produced by the explanation module as persuading the user to believe certain things. This stance is reflected in their description of the system’s text-planning architecture, excerpted below:

The explanation planning process begins when a communicative goal (e.g., “make the hearer believe that the diagnosis is migraine,” “make the hearer know about the side effects of Inderal”) is posted to the text planner. A communicative goal represents the effect(s) that the explanation is intended to have on the patient’s knowledge or goals. [Buchanan et al. 1995:132, emphasis in original]

The system selectively presents information to headache patients in order to try to persuade them to believe certain things deemed appropriate by the designers. For example, the initial paragraph of the patient summary (see above) defines migraine in the general case for a given user by listing the specific symptoms selected by that user while taking the headache questionnaire. Thus, if Mrs. Jones experiences flashes, light spots, double vision, blurred vision, photophobia, and painful eye movements in connection with her headaches, the patient summary subsequently constructed for her by the explanation module will list these as typical symptoms of migraine. Symptoms of migraine that Mrs. Jones does not select on the questionnaire do not appear in the general description of the condition shown to her. This design feature is intended to “make [Mrs. Jones] believe that the diagnosis is migraine.”

In short, the system has been designed to persuade patients that the physician’s diagnosis of their headaches is correct. This aspect of the design takes for granted two major assumptions. First, it assumes that the physician’s diagnosis is in fact correct, although no test exists to verify a diagnosis of migraine. Second, the suppression of typical migraine symptoms not experienced by a given patient from the general description of migraine implies that it is more important to persuade patients to believe their physician’s diagnosis than it is to present them with information that might serve as a basis for doubting that diagnosis. Although such assumptions were never explicitly raised at project meetings, their incorporation into the system design seems more likely to empower physicians than patients.

Finally, the explanation system embodies a physician’s perspective not only in what it explains to patients but also in the way in which concepts are explained. Despite our data about what migraine patients want to know, the explanatory material actually offered by the prototype system largely reflects the physicians’ assumptions about what patients need to know. It also reflects physicians’ notions about what constitutes proper explanation. Examination of some of the explanatory
text produced by the system suggests that such assumptions can be wildly inappro-
priate on both counts.

The three pieces of text below were all drafted by a physician for the
explanation module and encoded in the prototype system. The first contains
especially no explanation at all, the second offers an explanatory image likely to
disturb any user, and the third consists of textbook-type language so inaccessible
that it offers little illumination.

(1) Material intended to address the experience of headache:

Well everyone has a tender or sore head at some time. If you bump your head on
a wall you would expect it to be sore. On the other hand if it is sore as part of your
migraine, then it may be part of the migraine symptomatology.

(2) Material intended to address the question whether an individual’s migraine
triggers will always cause a migraine attack:

Triggers in the case of migraine can be likened to the trigger on a gun. When
pulling the trigger on a gun there will sometimes be misfires when the gun does
not go off. This also seems to be the case in migraine. A trigger is therefore a
physical or mental action that OFTEN causes the onset of headache, but not
necessarily always.

(3) Material intended to explain the causes of migraine:

The precise causes of recurring headache as in migraine are not known. There is
a belief that the pain originates from structures of the brain, specifically the nerve
systems which travel to and from the spinal cord. It is believed that there is a
disturbance of transmission system. This means that there is a problem in the way
the nerve impulses travel to and from the brain. No specific personality type has
been implicated. It is not thought to be a neurosis or a psychosomatic disorder.
The conventional view of the cause of classic migraine, dating from the early
observations of Wolff and his colleagues, has been that vascular narrowing
accounts for the neurological symptoms and the dilation of the vessels for the
headache and tenderness. The pulsatile character of the headache seem to indicate
a vascular factor. More recent theories place greater emphasis on the role of
sensitized nerve endings in the blood vessels, which release a chemical substance
called substance P, this causes the vasoconstriction or narrowing and therefore a
regional reduction in blood flow. Another hypothesis favors an initial disturbance
of the hypothalamus and limbic cortex, the latter are two centers in the brain. None
of these hypotheses explains the periodicity of migraine.

Stage 5: Evaluation of the System

Researchers in both medical informatics and anthropology devote consider-
able attention to questions about information and knowledge. However, as we have
noted, they understand these concepts rather differently. During the evaluation of
the prototype migraine system at the end of the three-year project, the questions
that the computer scientists and anthropologists wished to ask of users of the system
reflected these different views of knowledge. The specialists in medical informatics
focused upon the quantity and utility of the information offered by the system. One
of their concerns was to demonstrate that the system offered patients more inform-
ation than their doctors had in the past. This goal is reflected in the following
question contributed by a computer scientist to the interview schedule for the evaluation of the prototype system: “Did the program ask for less or more information than doctors you have talked to about your headaches?”

In contrast, my questions focused upon the perceived meaning and appropriateness of the information offered to the user. As the interview schedule developed, I contributed questions such as the following: “Did the information presented make sense to you?” “If not, what didn’t make sense?” “Was anything presented that seemed confusing or inappropriate to you?” Such divergent questions about the system reflect different views of knowledge.

**Discussion**

Koenig has described the tendency for expensive new technologies to “diffuse into widespread clinical practice before evidence is available about their actual usefulness” (1988:467), a phenomenon that reflects what Fuchs called the “technologic imperative” in medicine (Fuchs 1968, 1974). Medical computing does not fit this pattern. Although medical information systems are being developed at a rapid rate, it is common for technically sound systems to be rejected by their intended users and not adopted into clinical practice (Anderson and Aydin 1994:6). In medical informatics, this phenomenon is known as “the problem of user acceptance” or “end-user failure.” As these labels imply, when computer systems are not accepted into clinical practice, system developers tend to blame the users (Forsythe 1992).

My research on system design in medical informatics reveals another factor relevant to the so-called problem of user acceptance: the fact that systems embody perspectives that may not be meaningful to or appropriate for their intended users (Forsythe 1995). As I have tried to show in the case of the migraine system, the dozens of design decisions made by different members of the project team embodied some assumptions and expectations characteristic of medical informatics in particular and of biomedicine in general. The composition and interaction of the project team reflected the muting in American medicine of the voices of nurses and patients. The formulation of the problem that the system is intended to address, and the choice of an intelligent system as a solution to this problem, reflected foundational assumptions of medical informatics. The organization of the work of system building reflected characteristic assumptions about the importance of “technical” in relation to epistemological work. And the restriction of the system’s explanation capability mainly to facts about physiology, drugs and drug side-effects reflects the bias in American medicine toward formal, biomedical knowledge—despite the ethnographic data gathered for the project that showed migraine sufferers to have pressing concerns of a less formally medical nature (e.g., how to live with a condition that can cause unpredictable and incapacitating pain).

These assumptions will not startle anyone familiar with the everyday world of American medicine. However, it may be startling that such assumptions should be built into a “neutral, objective” piece of technology—especially one intended to empower patients. Whatever the good intentions of the builders (and I do not believe they set out to embed these assumptions in the system), the result is a piece of technology that is anything but neutral.
In a domain in which a careful observer can discern several valid points of view, the migraine system embodies only one: that of a neurologist. The content of the knowledge base and the language and categories generated by the user interface all reflect a neurologist’s approach to the doctor-patient encounter and a neurologist’s view of what counts as relevant medical knowledge. These biases are nowhere pointed out to users of the migraine system—not because the designers have consciously decided not to do so (to my knowledge, they never considered it), but presumably because they do not see either themselves or the system as biased. This situation raises important questions about what end users—in this case patients—have a right to know about technology used in clinical care.

As the migraine system illustrates, software may embody values and assumptions that users might wish to question—if they were aware of them. For example, I am troubled by the fact (noted above) that the designers of the migraine system intentionally but covertly try to persuade users that their diagnosis of migraine is correct.

Unfortunately, medical diagnoses are not always correct. It may be that the user actually has a brain tumor instead of migraine, or that (like the first patient to use our system experimentally in a headache clinic) she has both migraine and a brain tumor. By omitting from the description of migraine those symptoms the user does not experience, the system withholds information that might conceivably help an incorrectly diagnosed patient to realize that the physician has made a mistake. Similarly, the system fails to inform users that it has been designed to make them believe their diagnosis. Indeed, the introductory screen states that “This system has been designed to help you understand your condition and suggested treatment better,” implying that the system is neutral. These omissions pose ethical problems.

In these and other instances, use of the system may actually increase the power differential between physicians and their patients, a situation that is even more likely in the future if members of the research team carry out their plan to expand the system. The designers intend to adapt the migraine system to individual neurologists by encoding in its knowledge base each doctor’s personal preferences in medication and treatment. While one might assume such preferences to be “strictly medical,” in fact some of them seem distinctly cultural. For example, one physician we observed consistently recommended one particular migraine drug to male patients and another to females. When queried about this, he said that the medication he suggests to men is his true drug of choice for migraine. But because the drug can also cause weight gain, he does not recommend it to his female patients. Believing that women either should not or would not wish to gain weight, he makes a choice on their behalf that they might prefer to make for themselves.

The designers intend to replicate such preferences in personalized versions of the system’s knowledge base, justifying this plan as the only way to induce physicians to put the system in their offices. Biases in the material presented will not be pointed out to users. For example, medications that particular physicians prefer not to prescribe, or not to prescribe for particular classes of patients, will simply be deleted from the list of possible items about which users can obtain information. This, too, poses ethical problems. Furthermore, while the designers believe that physicians need to be induced to use this new technology, patients are not seen as requiring inducement to use the system. The designers seem to take for
granted that patients can be made to use it by virtue of their reliance on physicians for pain relief. This pragmatic assumption reflects—and seems likely to reinforce—the power imbalance between doctors and patients in the social world of medicine.

This article was inspired by a question of agency: how do cultural assumptions come to be embedded in complex computer programs even when system designers do not intend this? The answer I offer treats cultural and disciplinary assumptions as interpretive resources. It attributes agency neither to a reified notion of culture nor to the technology itself, but solely to the human actors. At the same time, it acknowledges that human acts do not always bring about the intended consequences.¹²

This study bridges the concerns of two newly converging research traditions within anthropology and sociology (Casper and Berg 1995; Star 1995): the study of medicine and the study of science and technology. The idea that biomedicine is characterized by hidden (and not-so-hidden) cultural assumptions is well known to medical anthropologists (e.g., Gordon 1988; Kirmayer 1988). Equally familiar are the assumptions about power and knowledge that I have attributed to neurologists and shown to have been replicated in the migraine system (e.g., Lindenbaum and Lock 1993). That the practice of science invites cultural as well as social analysis is still rather new within science and technology studies, however (Hess and Layne 1992). Similarly, the extent to which contested cultural assumptions are routinely inscribed in supposedly neutral technologies is becoming familiar within the anthropology of science and technology, but may not yet be so well known to medical anthropologists.

**Will the System Help Migraine Patients?**

It is worth considering whether use of this new biomedical technology is likely to help migraine sufferers. I have argued that many of the expectations of medical practice that were used to motivate development of this system in the first place are represented in its design. In a sense, then, the system itself replicates these conditions: it addresses patients as passive, determines (through its menu-based user interface) what questions the user may ask, offers explanation on the same narrow range of topics neurologists do, and avoids the sort of awkward “nonmedical” questions that we observed doctors themselves avoiding in face-to-face interaction.

Although the system is intended to be used by both patients and physicians, its definition as a patient education system incorporates the assumption that patients can learn from physicians but not vice versa. The system presents to patients aspects of physicians’ knowledge about migraines, but does not explain to physicians anything about the knowledge or experience of migraine sufferers—although we learned much about the latter during the fieldwork that could be incorporated into such a system to help educate neurologists about the experience of migraine.

Most important, the system does not allow patients to speak for themselves. Even in a condition diagnosed through patient history, the system compels users to fit their diverse personal stories (Good 1992; Good et al. 1992) into neurological categories. As Berg notes in the case of ACORN, such disciplining of real-world complexity to the formalisms embedded in a computer system is required to enable
the tool to work (in press: ch. 3). The designers of the migraine system could at least have created special boxes in the interface for users to type free text into the system on designated topics, to be read later by the physician. However, they chose not to provide this feature.

One might wonder, then, if use of the system in a clinical setting would ameliorate or exacerbate the problems it is intended to solve. At this point it is too soon to tell, since the system is still in prototype form and has only been used experimentally in a neurology clinic and in the development laboratory. Shortly before the end of my fieldwork, however, I took part in the first round of evaluations of the system. Interviewing three volunteers who had spent several hours talking with a neurologist and using the history-taking and explanation modules, I asked each one (among other things), “How did you feel about having a computer give you this type of information? Would you rather get such information from a human being or a computer?”

Despite my own expectation that users would not—or perhaps should not—like the system, these three people did like it. They justified their views with precisely the reasoning given in the migraine project proposal. One user commented that doctors do not have time to answer questions but that the computer never got impatient; another noted that while she sometimes felt stupid asking questions of the doctor, she felt free to question the computer. When the system made errors (e.g., “forgetting” what a user had just told it about factors that triggered her migraines; or referring in error to the tyramine-free food list that “your doctor just gave you” when he had not), these users forgave it.

But brief experiment is not the same thing as normal use, and three is much too small a number from which to generalize about users’ reactions to the prototype system. The system would have to be more fully developed and many more people would have to use it before conclusions could validly be drawn about any effects of its use. Nevertheless, this initial step in evaluation does serve as a reminder that not only designers but also anthropologists bring assumptions to their work: end users may see a piece of technology differently than a critical observer.

Conclusion

Where should we locate the migraine system? Most of the project team would probably place it in some neutral scientific space, far from the disorderly world of the everyday. While they are aware that they have embedded some assumptions in the system, they consider these to be minimal, necessary for system-building, and appropriate to the domain.

In contrast, I locate the system in the disciplinary and cultural worlds of its creators. I am struck by the extent to which they have built assumptions from their respective worlds into the system. In decisions about work practice and system design, they have expressed a wide range of tacit and sometimes explicit expectations concerning themselves as doctors and patients, as specialists in “hard” “technical” work, as knowers and dispensers (but not recipients) of medical information, and as people in a gendered world that systematically overlooks the skills and experiences of nurses and victims of domestic violence. The migraine system is in no way a neutral technical object. Rather, it is a kind of collective
self-portrait of its designers, revealing little about its intended users but much about those who built it.

In closing, I return to the notion of the technological imperative in medicine. The tools of medical computing have not been adopted into clinical settings as readily as the treatment technologies described by Koenig (1988). While technology adoption in medical informatics has been slower than expected, however, technology production in this field is escalating rapidly.

The decision to build the migraine system certainly reflects a technological imperative. Practitioners in medical informatics take for granted the benefits of automation, including computerizing doctor-patient communication that might otherwise take place face to face. In medical informatics, intelligent systems technology is treated as a solution in search of a problem. "Research" in this field means building a system; "problem formulation" means finding a real-world justification for the system one wishes to build. Left aside here are important questions about the broader costs and benefits of this approach for defining and sharing medical knowledge. Whose assumptions and whose point of view are inscribed in the design of technical systems? Who will benefit from adoption of a given system, and who stands to lose? As the case of the migraine project demonstrates, the answers to these questions are not simple nor are the questions themselves necessarily even apparent to users. If designers do not ask such questions, and users are not always in a position to do so, who will monitor the hidden cultural assumptions built into computerized tools for medicine?

**Notes**

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1. The development of MYCIN, the first intelligent system for medicine, is described in Buchanan and Shortliffe 1984.

2. The title of this article reverses the New Testament warning against putting new wine in old bottles (Mark 1:22). It is meant to draw attention to the distinction between the character of particular technologies (which may be highly innovative) and the nature of the knowledge represented in them (which—as I show in this paper—may not be innovative at all).

3. In some institutions, this field is known as medical information science. For an overview of medical informatics as seen by its practitioners, see Shortliffe et al. 1990.
4. In computer science, “natural language” denotes normal, everyday language as opposed to a specialized programming language. The migraine system is designed to generate explanations comprehensible to any adult English speaker.

5. Myra Brostoff and Linda Purinton (graduate students in anthropology) and Nancy Bee (research assistant in psychology) took part in and made important contributions to our ethnographic study of migraine sufferers and neurologists.

6. Taken from an unpublished project paper, this is one version of the narrative produced by research team members to explain what the migraine system was for.

7. The hyphenation in this text is necessitated by technical attributes of the computer software used to generate the material and adapt it to each individual user.

8. For discussion of the invisibility of female bodies and female experience in medical informatics, see Forsythe 1994.

9. Most systems developed in medical informatics are designed by physicians to support their own work; the field might more accurately be called physician informatics. Not surprisingly, nurses are now developing a parallel field of nursing informatics (Forsythe 1994; DHHS 1993).


11. A different set of assumptions could have led to a different problem formulation and thus a different migraine system. For example, the team could have envisioned a system that would—without privileging either perspective—have supported the exchange of information between physicians and migraine sufferers by explaining to each some things likely to be taken for granted by the other. Such a system would surely have made more use of our ethnographic findings than the system actually built.

12. The case of the migraine system raises broader issues of agency and intentionality that deserve fuller treatment on their own in relation to this material. Perhaps the most interesting from a science studies standpoint is the extent to which one might want to treat the system itself as an actor (or “actant,” to use Latour’s term) in relation to its users. To the builders of the migraine system, for whom the notion of machine intelligence is commonplace, the idea of computer programs as intelligent agents is unproblematic. In contrast, among social scientists, at least some of whom view “machine intelligence” as an oxymoron, the attribution of agency to technology is subject to debate (Amsterdamska 1990; Latour 1987).

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