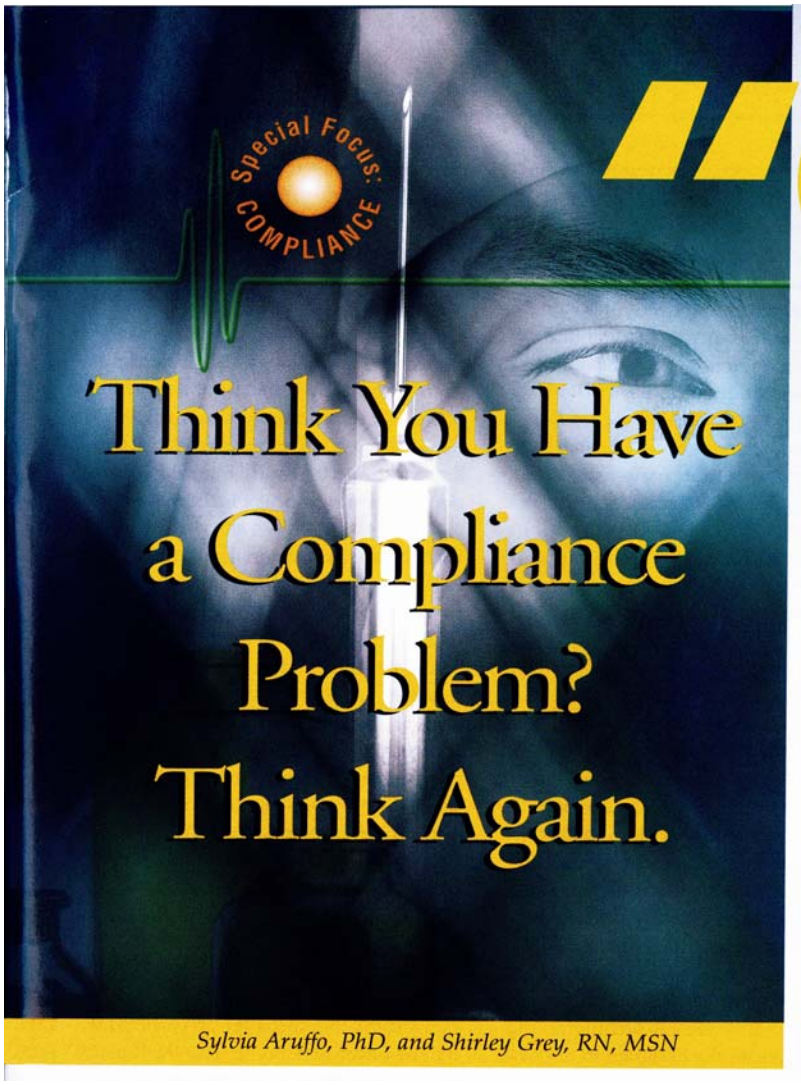
THE CASE MANAGER
*The Official Journal of the Case Management Society of America*
March/April 2005




# Think You Have a Compliance Problem? Think Again.

*Sylvia Aruffo, PhD, and Shirley Grey, RN, MSN*

"Oh, yes, I know Mrs. Elmwood very well," her case manager affirmed. "Poor thing. She just never seems to get it right on her self catheter."

Mrs. Elmwood, 97 years old, had been in the hospital 6 times in the previous 9 months with urethral infections. "We give her a set of supplies every time. We go over the instructions carefully, she even does a return demonstration, but she keeps getting infections. Even sending out a home care nurse to show her didn't help." The case manager smiled sadly and gave a shrug of hopelessness. In her mind, Mrs. Elmwood was the problem.

But a visit to Mrs. Elmwood's home turned up a handwritten hospital handout with a shopping list that included an item spelled "c-h-u-c-k-s." Mrs. Elmwood's daughter was frantic to find a retail source of sterile CIC trays, believing she must use exactly what the nurses used to teach—especially since the catheter labels read, "One time use only." And Mrs. Elmwood still didn't feel confident of the technique, because, she reported, each time she tried to do a return demonstration, at her first hesitation, the nurse interrupted and took over, doing it for her rather than letting her complete the procedure herself.

What professionals offer patients for selfcare is, in the vast majority of cases, **incomplete, inappropriate or flat-out wrong**. Even when written materials meet rigorous standards of health literacy, self care instructions are still either impossible to follow, or, if they *are* followed, directly cause infection, complication and deterioration. Unfortunately, evidence for this shocking assertion is invisible to professionals—until the tables are turned.

At one professional meeting, a presenter asked four case managers what their departments do to prepare patients for self care. After listening to four descriptions of impeccable discharge processes, the presenter asked, "Have any of you been a patient in the department of someone here?" Six hands went up. "And did you in fact receive the preparation that you just heard described?" Howls of outraged denial echoed through the auditorium. "They didn't give me anything!"

"No one had any time to explain." "There weren't any supplies." "The instructions weren't clear at all." "I didn't have a clue what to do—and I'm a nurse!"

Defining the problem as "compliance," something lacking in the patient, prevents professionals from seeking or seeing solutions in their own actions. Some professionals are on the right track in that they perceive the word compliance is offensive. The word *adherence* has been proposed as an alternative. But both words equally imply a flawless contribution from the professional, whether delivered whole or collaboratively developed. All a patient must do is follow. If the patient suffers imperfect self care outcomes, both words equally imply the patient is at fault. Neither word directs attention back to the standard for scrutiny as to its possible flaws.

Assuming that patients in general are unable to follow instructions is a very powerful set of blinders—and very costly. Redesigning self care training materials alone, when done according to principles in this article, has repeatedly reduced readmissions by 70% or more. However, most interventions to reduce readmission rates assume they must use expensive labor and technology to do actions for and to the patients rather than enabling patients to act independently. Clinics plan for nurses to do procedures that patients could do at home, call centers staff up, and—most insidiously—they all encourage patients to be dependent. "It doesn't matter if the handout is imperfect; the case manager will explain it."

Defining the problem as compliance allows professionals to judge their own performance as satisfactory even in the face of overwhelming contrary evidence. At Rush Medical Center in Chicago, 70% of nurses were satisfied with their materials and teaching at discharge even though their own study showed 96% of the patients could not follow them.[1] In any other industry, such a failure rate would set off alarms that the production process must be changed—in health care, however, it doesn't occur to professionals that patients fail because nurses inadequately prepare them. How could it be our fault when we are so sincere and caring? Besides, our materials are approved by a Patient Education Committee.

Committees approve patient education by using two checklists: clinical correctness and literacy. But clinical correctness is only a ticket to get on to the production floor of training design. Literacy standards are the last pass before exiting the floor. The most important component of preparing self care training, which occurs between the establishing of clinical protocols and the final literacy review, is wholly missing.

What's missing is qualitative research for evidence of what patients most commonly misunderstand, completely miss, cannot do and should not do—in other words, research that explodes professionals' false assumptions. The most important component of designing training programs for self care is overcoming professionals' false assumptions about patients. False assumptions cause preparers of self care training to:

1. Omit crucial steps
2. Organize material in non-actionable formats
3. Include distracting, irrelevant information
4. Direct patients to actions they are incapable of performing, and even
5. Direct patients to actions they **should** not perform at home—actions that may be suitable in the hospital, but cause pain, infection, complication and deterioration at home.

Hard, numerical evidence that a self care training program is comprehensible, as measured by actual reductions in utilization, should be a requirement for approval. Evidence for communicative effectiveness should be as essential as evidence for clinical correctness. Literacy standards are not sufficient to measure effective communication. A sentence can be perfect third-grade language, but if the direction itself is not appropriate, the patient will not succeed.

Patients do not have a compliance problem. Professionals have a communication problem. In the case of Rush Medical Center, the staff engaged a external, specialist team to research the patients' difficulties and had them re-write the materials. Nothing clinical was changed, yet the rate of patient success immediately rose from 4% to 92%.[1]

[1] "Discharge Kits Boost Patient Satisfaction," *Hospital Peer Review Journal,* September 2000 p. 121-2.

The set of research techniques the team used, specifically designed to discover false assumptions and accurately target the end user, is ethnography. Ethnographers go where a subject lives and observe. Ethnography thoroughly describes the subject's point of view and context of use for a given product, process or service. Ethnography applied to patient education gives us the patient's perspective on patient education. Ethnographic research is the science behind effectively preparing materials for self care.

Ethnography is well-known in other industries where engaging the end user effectively is a high priority: the PT Cruiser, the Ford Focus and Maytag appliances are all designed using ethnography. The makers of Gatorade hired ethnographers to redesign their bottle. The researchers went out to construction sites and sporting events and videotaped hours of people drinking. They measured hand spans and mouth sizes. The result is a bottle that perfectly fits the fingers, a mouthpiece that allows a runner to drink comfortably without stopping, and an opening that releases the exact amount of fluid to match the flow rate of swallowing. When the bottle hit the shelves, sales jumped 23%. At the New Product Development and Marketing Association, the use of ethnography is one of the criteria for making its annual award, "Corporate Innovator of the Year." Intel, according to its head of R&D, does not bring a new product to market without using ethnography for the design. General Motors, Microsoft and many others employ ethnographers full-time.

Health care has never heard of ethnography. Health care professionals are familiar with focus groups. Focus groups, however, are subject to limitations and distortions. For a focus group, patients are taken out of context and brought into a deliberately unstimulating environment. Discoveries, then, are limited to what participants are specifically aware of, what they can remember, what they can articulate, what they are willing to share with an authority figure and what they are willing to say in front of their peers. What they do say will be highly influenced—if not determined—by the questions the leader asks, and by the reactions of others around the table.

The father of a child with cancer forcefully claimed to other focus group participants that he never had any trouble flushing his daughter's catheter. He said the process was simple and obvious. He had no patience or sympathy with others who reported struggling. Then an ethnographer visited his home to meet the girl. Her mother came in, gushing to the husband, "Oh, honey! Do you remember how hard it was for us to learn how to flush it? They sent out one home care nurse after another. It took us weeks to get it!"

Ethnography bypasses those pitfalls. Toyota, in designing its next generation SUV, could choose to convene a focus group of soccer moms and ask them, "How should we change the Highlander for next year?" Instead, Toyota is sending ethnographers with video cameras to shopping mall parking lots to record what happens when mom tries to load up the van with kids, stroller, packages, coffee cup, purse and dog. Those videos are where the richest, most reliable data exist to redesign the product.

By contrast, the top two marketing executives at a major ostomy appliance manufacturer, who had each been with the company for over ten years, were asked if they had ever observed a real patient change a bag. "No," they replied. "We've never actually watched anyone use our product. But we've done focus groups." It is sadly ironic that ethnography in industries that make cars and fruit drinks is trumpeted as the "state of the art" for engaging customers in successful product use, but in our industry, where the user's level of engagement and success can mean life or death, ethnography is virtually unknown.

Ethnography sends the researcher to the patients' homes to observe self care efforts. The patients demonstrate to the researcher exactly what they do. Researchers use a series of highly crafted questioning techniques to minimize the influence of the researcher and uncover the patient's priorities, vocabulary and attitudes. For example, an ethnography may begin with a technique called The Grand Tour.

The patient walks from room to room, describing what difference it makes in that room to have their particular condition.

In an environment rich with cues, without authority figures or peers to influence, the feedback is far more complete, spontaneously revealing the patient's perceptions and level of understanding. Rather

than a short-answer questionnaire, an ethnographic observation lasts 3-5 hours and may even be repeated with the same subject another day, in the same place or in another significant context. Part of the observation is always to actually DO the self care procedure(s): not simply to "demonstrate" by pretending or "describe" by talking, but to do a real dressing change, glucose test or blood pressure reading. Ethnography drives to a level of excruciating detail to reveal false and inadequate assumptions.

For example, one cancer clinic at a well-known Southern hospital had given up teaching chemotherapy patients to change their dressings. The infection rate was unacceptably high. The payers' case managers agreed with the staff that patients were simply incapable of properly changing the dressings. When the new policy was announced, patients were relieved and appreciative, since they, too, believed they were incapable.

Then an ethnographer visited the home of a 24-year-old leukemia patient. On the Grand Tour, she entered the bathroom and demonstrated what she had been taught about washing her hands. She scrubbed with soap and water, lathered up her wrists, and rinsed. She shook the excess water off as she turned to leave the bathroom—and wiped her hands on her skirt. No focus group, no telephone interview, no written questionnaire could have revealed this error. Only direct observation of real hand washing in the patient's home could uncover the false assumptions.

Can nurses or case managers do ethnography? Certainly health care staff trying to do it is better than not doing it at all; home care nurses have insights into self care their hospital counterparts lack. But their discoveries are not likely to be sufficient to produce measurable reductions in utilization. A far better investment of time and money is to hire professional ethnographers. James Spradley, the first to apply ethnographic techniques to subsets of our own society (rather than primitive cultures) explains the reason through a story:

A cheerleader decided to do an ethnography of football players for an anthropology class assignment. She tried to interview a fullback on the college team. He wanted to cooperate, walking her around the field before and after practice, but felt foolish. He would start a sentence and then cut it off, "You know this." Very little information was exchanged. Later, the football player was in Japan. On an airplane, a Japanese businessman saw him reading the sports page of an American newspaper. He asked "Do you play football? I do not understand the game. How is it played?" The fullback launched into a detailed explanation of teams, field layout, goals, plays and penalties: Just what the coed wanted him to say, but could not elicit, because the subject believed that she already knew. The key to the success of the second interview was that the "subject" was the undisputed expert and the "researcher" completely unable to pass judgment of any kind as to the quality of the information delivered.[2]

One nurse who tried to play an ethnographer got as far as the bathroom on a Grand Tour with a back surgery patient. The patient was demonstrating differences in bathroom activities with a drain hanging out of her back. "To take a shower," explained the patient, "I just loop the drain up over my neck." The nurse gasped, "No!" –and blew her cover. The interview was over.

Another nurse promised she wouldn't let on. She didn't get beyond the front door. The patient described coming home with a healthy baby despite having diabetes. "My babies have all been a good size," she beamed. "The last one was even bigger than the first." Unable to stop herself, the nurse blurted out, "Yes. Progressively oversize babies are often the case with gestational diabetes." The patient was dumbstruck. What she had regarded with satisfaction was suddenly exposed as defect. The interview was over.

To elicit a meaningful body of information, the researcher must honestly tell the subject, "I am not a doctor or a nurse. I do not have your health condition. Tell me about it. Show me." Nurses simply cannot pretend not to be nurses: when they see incorrect technique, they correct it. When they see correct technique, they praise—which reveals their expert status just as definitively as a correction. An ethnographer is an utterly neutral learner, incapable of either praising or correcting. The patient is the "expert." Further, one of the ethnographer's main tasks is to find out what patients do that is different from the instructions and what vocabulary patients use to describe their conditions, devices and procedures ***when nurses are not there.***

An elderly CABG patient, a frail and polite white-haired lady, was

[2] Spradley, James. *The Ethnographic Interview*. Thousand Oaks, CA: Sage Publications, 1979

showing an ethnographer how she used a spirometer. However, she didn't refer to the device by name and stumbled several times, avoiding sentence constructions that would have required her to use the name. The ethnographer said, "The nurse has a special name for this thing, but I suspect you do, too. What do you call it?" The lady belted out, "I call it the Motherfucker!" This discovery led to identifying a pattern: the majority of patients do not want to refer to a device as "my" monitor, catheter, or meter. Without being aware, patients resist nurses who stress (sincerely believing they are encouraging patients to "take responsibility): "That's your oxygen tank, your nebulizer, your this, your that." Patients actually take responsibility more readily if they are allowed to keep psychological distance between themselves and the devices: "the" drainage bag, not "my" drainage bag. The device is something I must use, but it is not part of me. It is unlikely that this CABG patient would tell a nurse the real name she uses for the device—nor would a nurse have thought to ask.

Discoveries made through ethnography can be simple, but they are not obvious. At a large, well-respected Midwest teaching hospital, 92% of prostate surgery patients were coming back to the ER with infections within thirty days of discharge. The hospital staff leapt to the conclusion that clinicians were doing something wrong while the patient was still in the hospital.

But an ethnographer found a different cause when patients demonstrated how they changed and rinsed drainage bags. They explained that the nurses had showed them how to hold and twist the catheter tips in ways that older, arthritic hands simply could not do. So they were improvising, holding the end of the catheter in the bathroom sink to rinse it. Their trembling hands caused the tips to touch the underside of the faucet. Once the problem was identified, nurses and researchers brainstormed and tested alternate techniques until they hit a workable one. Immediately on distributing new instructions, the ER return rate dropped to zero.

Ethnography at times even discovers instructions that should instead be labeled, "don't try this at home." A large medical center in the Southwest engaged an ethnographer to research post breast surgery patients—not because they were dissatisfied with the readmission rate, but because they wanted to create a better discharge program as a marketing tool. Like virtually all other clinics in the US, patient instructions said to pin the drains to their underwear.
What the ethnographer saw were patients who, when needing to go to the bathroom, had to balance a drain in one hand while wincing in pain as they pulled and pushed on their underpants. Patients who balanced the bulb on the back of the toilet could be painfully startled by its rolling off and jerking on the exit site. Worse, patients told of walking around the house with a loop of tubing hanging out, catching the loop on a doorknob, and yanking the drain completely out! And yet, so powerful is the assumption that professional instructions are above criticism, case managers did not immediately perceive that a pin, so useful in the hospital, was entirely wrong for the new home context.

Ultimately the hospital began to give patients an inexpensive, disposable belt bag instead—ER returns disappeared, and letters of appreciation from the patients poured in. Kaiser Permanente in California later adopted the same set of instructions. "The first benefit you notice" about ethnographically-designed patient instructions, affirms Pat Sloman, RN, Department Administrator at Kaiser Fontana, "Is that the phones go dead."

It is important to note that the sentence "Pin the drain to your clothes" would pass any literacy review. It is the instruction itself that is wrong. Correctly following this instruction—that is, being fully compliant—caused the patients pain, unnecessary calls to the clinic for help and anxiety-crazed returns to the ER. Literacy standards are a *development tool*, a final review after well-researched instructions are drafted. Literacy standards are not a measure of quality. The only valid measure of the quality of patient instructions is reduction of utilization. Reducing utilization is the goal of self care and is its only meaningful method of evaluation. Get a baseline on utilization today. (What is the readmission rate? Most professionals don't even know.) Conduct ethnographic research. Redesign the program. Measure utilization again. From this process, health care organizations have achieved reductions of 38% to over 74%.[3]

It is also important to point out that the problems with patient instructions in the examples above could never be discovered with telephone surveys, mail-in questionnaires or focus groups. Only ethnographic research in the patients' homes will find these inadequacies in self care patient

[3] "Breakthrough Results," *Disease Management Association of America Conference Proceedings*, October 2004

instructions. Francis Fullam, a consultant with the Blackstone Group, reviewed ethnographic patient training at the University of Chicago and observed, "I know of no other systematic program that brings about this much immediate improvement…while lowering the cost of health care."

Patients don't have a compliance problem; professionals have a communication problem. Redefining the problem from "compliance" to "communication" means if patients are not successful, we change how we train them.

We don't beat patients to be compliant, we beat ourselves to communicate effectively. Placing the responsibility for the problem in our laps means we can fix it. If we use ethnography to root out false assumptions and discover the subtleties of communication that engage and equip patients for success, we eliminate the majority of returns, readmissions and phone calls.

Bob Barger, Executive Director, Continuum of Care at Northwest Community Hospital in Illinois, affirms that ethnography "really does change behavior."

At the University of Alabama, the Director of Health Services of the VIVA Health Plan, Karen Chambers, RN CCM CDMS, agrees. Ethnography "has a great impact on patients. They finally understand what to do."

What happened with Mrs. Elmwood? An ethnographer visited her home in February. Research uncovered a full list of misunderstandings, errors and omissions. Her instructions were re-written. As of October, Mrs. Elmwood had not been back to the hospital.

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