Communication Problems in the Intensive Care Unit

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Hospitalization in an intensive care unit is often physically uncomfortable and socially disorganizing. The ordinary forms of conversational participation that generate and sustain a sense of agency are breached when the patient cannot communicate in socially consensual "real time." Using my own experience in an intensive care unit, I describe how delayed speech, through the use of an alphabet board, frequently leads to a host of interactional problems and mutual accusations about character. I attempt to show that the fabric of self and the perception of quality of care are achieved through "real time" communication. I also describe the differential communicative structure of those who will not and those who will use my alphabet board. Those using the board exhibit, through board employment and through the "local" topics discussed, a depth of common culture between them and me.

MONITORS AND COMMUNICATION

I was initially interested in writing about Jean Baudrillard's television screens as a displacing hyperreality of today (Baudrillard 1983, 1990). I proposed to use the idea of screens and the displacement of the person and experience in the context of the monitors in the intensive care unit (ICU). The monitor screens, in my experience as a hospital patient, seemed to constitute multiple shifting loci of the self, consonant with Fredric Jameson's description of the postmodern self and identity (Jameson 1984). I sometimes thought I had become like William Gibson's (1984) characterization of a human with cyborg parts. I had to look at the monitor

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screens to find out if I was alive, how close to death I was, and if I were making any progress to recovery. The monitors were my constant focus when I was alone. They were, as well, the focus of those taking care of me. My heart rate was monitored, as well as my blood pressure, respiration, oxygen saturation level of my blood, the other blood gases, my temperature, urinary output, the infusion rate of my medications, and my prostrate body was monitored by a television in the ceiling. I lived in and by the collective scanning of the monitors by me and by my caretakers.

Let me illustrate this point about living in the monitors. When an ICU nurse would come into my room she or he could flick a remote switch on their belt and the monitor readouts of other patients would be projected on my monitor screen. That way she or he could keep track of other patients while working in my room. I was at first unaware that my nurse routinely switched on my neighboring patient’s readout on my monitor. I would look at and listen to my monitor and become alarmed at the falling blood pressure, the irregular cardiac rhythm, the low oxygen saturation level, and the bells and buzzers that would go off to signal the other patient was in need of immediate life saving assistance. Thinking it was my readout, my blood pressure would jump to near 200, my respiration rate would increase to 40 per minute, my oxygen saturation level would sink to 80s, and my own monitor alarm bells and buzzers would go off.

It was this confusion of living in monitor screens, whether your own or mistakenly other’s, that caught my analytic attention. I proposed to write about the displacement of the self by the screens, with the added dimension that the monitor screens were not only located in my room but also at the nursing station, about 100 feet away. The displacement was not only characterological, in terms of finding the truth about who you are in the screens, but spatial, as well. Most of the monitor reading, so at least you thought and hoped, took place at the nursing station. The placement of careful and continuous reading of the monitors at the nursing station may have been a panoptic dream, but it effectively removed critical reading of factors concerning life and death, as well as televised bodily behavior, to a remote, unseen location. Additionally, the actions derived from this information were formulated in an invisible place, a site beyond personal influence.

However, when I started writing the paper on the monitor screens, I piled page after page on my communication problems with the nursing staff, physicians, and other workers on the hospital floor. I am afflicted with a neuromuscular disease and I cannot talk or communicate in anything approaching the social consensus of “real time.” I came to feel as if I had deserted my initial project of describing my uncomfortable journey in the cyberspace of the monitors. I faced a dilemma of putting aside the description of my communication problems and proceeding with the theme of the
monitor screens. The more I worked on the paper, the larger my failure at consensus "real time” communication appeared to be the source of my discomfort in the ICU, even with the monitors. The direction of the paper seemed clearer, and I eventually came to see the dislocating, self-distancing (Zola 1982) trouble with the monitors was not all that different from most nurses failing to use my alphabet board, to talk with me. The sense of loss of personal control with the monitors was roughly approximated in the refusal of most nurses to use my alphabet board. When I could not communicate I had no participation in my care or the way I was regarded and the way I came to view myself.

THE ILLNESS

This paper is based on three and a half months of hospitalization, most of it in the ICU.¹ This fieldwork is not recommended. I have had a neuromuscular disease since 1985 and an acute episode of pneumonia in 1991 suddenly brought me to the hospital in an ambulance. My lungs had filled up with fluid; I was having extreme difficulty breathing. The emergency medical service crew of the ambulance stuck a tube in my nose and down to my lungs and pumped air in with a bag. I was air bagged for the twenty minute ride to the hospital. Attached to the bag was a cylinder of oxygen. When I arrived at the emergency room, I was rushed inside to a room where seven people began to work on me. I was reintubated. a new tube stuck in my nose, down my throat, and into my lungs. The fluid was suctioned out of my lungs. The suctioning of my lungs would become a permanent feature of life.

I cannot talk. I can communicate by forming individual letters with my lips. I could emit some vocal sounds before the hospitalization but I did not have enough muscle strength and control to articulate words. I spoke by spelling out words by moving my lips. This is a slow process and does not match the real time order of natural conversation. Moreover, the number of people who can read my lip movements is highly limited. My lip movements are restricted, due to weak lip muscles, and it takes intensive training and exposure to be able to read my lips. The students who work for me as research assistants can read my lips, as can my wife, daughters, and my mother-in-law. Otherwise, I have to communicate by using an alphabet board, an even slower process than lip reading. Most of the time when I was in the hospital I had to use the alphabet board, with nurses, nurses’ aides, and respiratory therapists. Occasionally, a student research assistant would work with me on a book, and for that time I could communicate more rapidly by lip movements. My wife spent most nights with
me in the room and she could read my lips and tell the staff what I was saying.

I found not having a real time voice was the equivalent to not having any defense to what was done to my body, and once my body was touched I had no control over the intensity or the painful effects of the procedure. I came to visualize having a voice as having a defense of making assertions about myself, making threats, and counter threats, and otherwise carving out and maintaining an interfunctional space for myself. Not only could I not control what was happening to my body, I found I could not control the interactions which largely made up my person. I could not even communicate simple information about my condition to my doctors and most of my nurses. It was very difficult to gain people’s attention and maintain that attention through a course of conversation. The physicians, operating under tremendous subjective time pressures, would limit their visits to my room to fifteen minutes, time enough for only a few, if any, of my laboriously formulated sentences. The physicians would suggest that I formulate what I had to say before they came. This suggestion left out the possibility to respond to any emergent conversation while they were in the room. It also assumed that I would remember what I wanted to say in conversational contexts long after the conversation had passed. Some physicians made decisions in the room about treatment, including surgery, and I could not respond, besides giving a simple yes or no with head movements. If I wanted to enter a qualified answer, it was impossible and many times the physician would leave the room while I was trying to spell out a reply. Often the physician would not see himself being addressed by my reply, the time lag was too great and his attention had switched to a new task, and the person interpreting what I was trying to say was so concerned about reading my lips or using my alphabet board that she or he forgot to signal the physician that I was saying something to him.

Not being able to conversationally influence most aspects of my experience in the hospital generated frustrations, resentments, and attributions about my intelligence, my motivations, and, equally from my perspective, about the intelligence, motivations, sensitivity, and the irrationality of the entire health care delivery system.

**FLYING NURSES**

The communication problem with most nurses was the same as with physicians. Most of the nurses in the ICU were visiting nurses from the U.S. mainland. In my experience the visiting nurses were uniformly Caucasian or haoles, as they are known in Hawaiian. These nurses call them-
selves "flying nurses." Flying nurses sign short term contracts to work three months to a year. Most of them worked on three to six month contracts. Most worked three twelve hour shifts a week and would have four days off to enjoy Hawaii. The hospital paid roundtrip airfare to Hawaii and subsidized the apartment rent of flying nurses. The flying nurses lived in the same large apartment building (appropriately named the Marco Polo) and mainly socialized with each other. It is not too strong to say the visiting nurses lived an Anglo-like colonial compound existence. Many of these nurses had worked in major medical center ICUs on the U.S. mainland. The national need for ICU nurses was so severe that some were able to spend years making the circuit of resort areas in the United States.

It was my feeling the flying nurses were almost impossible to communicate with. I had a much easier time talking with local nurses. Unfortunately the number of local nurses in the ICU was small. By local nurses I mean nurses who lived in Hawaii, whether they were immigrants to Hawaii or were born and raised in Hawaii. The flying nurses knew little of the social structure, culture, and history of Hawaii. They knew the Hawaiian pidgin English word for urine (shi shi) and the Hawaiian word for finished (pau), but little else.

It was not by intention, but the flying nurses could not locate me in their conversations. The "me" they could locate was a generic person, but not the "me" that lived in Hawaii, had friends, worked, had a history in Hawaii and the Pacific Islands. The flying nurses could talk about where they were from, where they had gone to nursing school, where they had worked, and where I had lived and worked on the U.S. mainland. When the Dean of the School of Nursing at the University of Hawaii would visit me the flying nurses did not recognize her. When clinical instructors in the School of Nursing would visit me they would be unrecognized. The local nurses would quiz me about my relationship to nursing faculty. When my research assistants would come to work with me they had to fight being hurried out of the room. I was treated as a standard sick person, someone too sick to be working and in command of his circumstances. It appeared to me that the flying nurses could not conversationally formulate me except as a sick person. I had no local personality. I felt as if I were one more sick person, equivalent to countless others in their experience. It was not that the visiting nurses wanted to treat me in crass, generalized ways but hardly one of them inhabited the particulars that illuminated my social circumstances in Hawaii.

The relevance of describing the context of interaction with flying nurses is that the commonplace, generalized methods of treating me appeared to not include a personal status whereby I could get them to use the alphabet board. None of the flying nurses would use the alphabet
board. A few would try but they would become frustrated and stop the effort. The most common problem is that the nurses could not remember the letters of the words as I selected them from the alphabet board. They would not write the letters and words down. They would reverse letters, forget the last letter of the sequence, and would quickly lose all sense of progression through words, sentences, and paragraphs. Frequently when we would move from the first word to the second and third, the first word would be forgotten.

I discovered that when most nurses correctly spelled out the words without writing them down, they could not recognize the word, even after repeatedly saying each letter in the word. I learned that spelling out words is not equivalent to word recognition, especially among native speakers of English. This would happen for short words such as “what,” “is,” “the,” or for longer words like “responsible,” “routine,” “medication,” “procedure.” A nurse would stand before me and spell “W-H-A-T” over and over again without recognizing the word.

I had a hard time separating words, many would run the words together as in “Iwanttocallmywife.” This was completely unintelligible. I got as lost as the nurses when they would spell out run together words. I would have to start over again from the first word. Separating words became a paramount problem. I would try to stop after spelling out a word to indicate a separate word had been completed. But, as I came to learn, most people could not recognize a word even after they had spelled it correctly and had repeated it several times. I would try jerking my head to the right to indicate a word had been completed but this was too easily mixed up with saying no by shaking my head from side to side. Indicating the stops between words was and is a continuing problem, even for those who write down the letters as I sequentially spell them.

These communication troubles were encountered or anticipated by most flying nurses. Many would say, “I am not even going to try the board.” Others would say, “It is no sense in trying to communicate. I know what needs to be done and I am going to do it.” Some few would say, “I have a job to do, so don’t give me any trouble by trying to talk.” The most memorable nurse told me the first time I met her, “I am the nurse from hell and do not try any of that communication shit with me.” Working with a patient in my condition, it was thought, could be accomplished without any communication with the patient. I was made aware that “most” patients in the ICU could not communicate by any means and I was using up critical time from the care of other patients by using an inefficient communication process. There was a flutter of talk about outfitting me with a speech prothesis, as if such an instrument would cure my communication problems. There was a naive belief that a speech prothesis would operate in real time of normal
conversation. My insistence in talking and being heard, expecting what I said to influence behavior, lead to a spiral of mutual antagonism between myself and the flying nurses. Communication with flying nurses was a lost cause. I quickly came to think of them as nearly anonymous parts, universally interchangeable, mirroring what I thought they thought of patients.

LOCAL NURSES

I had more success with the few local nurses serving in the ICU. But this success was not general to all local nurses. Some local nurses are military dependents, working here for three or four years and then moving on to the site of the new assignment. Another but small portion of local nurses are the newly arrived. They are usually Caucasian, dependents of business people or professionals who have just moved to Hawaii. A few of the newly arrived are nurses that have been recruited from the mainland. The military dependents and the newly arrived cannot be seriously considered authentic local nurses.

What I mean to indicate by the term local nurse is either locally trained nurses or long time residents of Hawaii. Local nurses need not have been born and raised in Hawaii. Many authentic local nurses are from the Pacific Islands and the Philippines or are Caucasians from the U.S. mainland who went to college in Hawaii. But most local nurses were born, raised, and educated in Hawaii.

Authentic local nurses could by glances, gaze, facial expression, vocabulary, syntax, cadence, dialect, body language, and topical reference conversationally locate themselves and the patients as members of and constrained by the same local culture and social structure. We could exchange information about neighborhoods, schools, places of employment, local and national cultures, food, life histories in the context of Hawaii, or, in short, the conversational formulation that we belonged to this place, something which pervades and appears as essential in social interaction among "local" residents. I had a personality with local nurses, to the extent that I could use my knowledge about Hawaii and the Pacific to locate them specifically. There was a reciprocity of highly detailed knowledge which located me and them. I felt that they knew me as a unique situated individual. I felt I knew them as situated individuals. We did not deal with each other in generic, universal categories.

Not all local nurses could communicate with me. No male nurses even attempted to use my communication board. This experience is consistent with my extra-hospital experience. Males, in general, appear not to have the patience or the multiple communication rhythms to be able to use alternative
means of communication. There were three nurses and one respiratory therapi
tist who would consistently use my communication board. One nurse was a
local Chinese, whose first language was Cantonese. Although she spoke En
glish without any accent, she only spoke Cantonese till she entered elementary
school. The other nurse was a Chamorro from Guam. Her first language was
Chamorro. The third nurse was a Hawaiian from Hilo. She did not speak
Hawaiian or any other language except English. All three nurses were trained
at the University of Hawaii. The respiratory therapist was a Caucasian from
Indiana. She had lived in Hawaii for fifteen years.

Interaction with local nurses began much the same as it did with flying
nurses but it progressed much faster in getting into biographical particulars.
Both kinds of nurses would enter the room the first time and introduce
themselves and say “I hear you are a professor at UH.” I would nod my
head. The next question would be what department was I in. This was the
first hurdle. The flying nurses would guess and would almost never get it
right. The flying nurses would not usually use my alphabet board, even
though it was lying next to my bed and they had been shown how to use
it. The local nurses would begin to use my board, perhaps because they
had the knowledge and motivational culture to conversationally formulate
themselves as members of the same social space. Hawaii has a strong cul-
ture of differentiating those who belong and those who are visitors or just
passing through. Once my department was identified the local nurses would
know where my department was located, “You are in Porteus Hall.” Then
there would be statements like, “I took a sociology class from Ikeda or
Sakumoto.” I could then ask “Who did you have for medical-surgical nurs-
ing?” We could progress quickly to a conversational exchange of person-
alities, “What did you think of X?, How did you like the class?, Where
did you go to high school and where did you grow up?” I could tell the
local nurses I lived in Kailua and they would immediately ask me what
neighborhood. They would know a lot about me from the neighborhood.

The local nurses had the conversational moves which both indicated
the detailed knowledge of place and the motivation to use this corpus as
the basis of formulating co-membership in the social topography with me.
This shared body of knowledge was identical with who, with substantial
variation, we were. We, me and the local nurses, could be called out and
motivated by these deep attachments.

OTHER INTERACTIONAL PROBLEMS

There are a number of routine interactional problems I encountered
with flying and local nurses and with other direct care providers. I call the
first two problems "Not Now," and "Out of Context." "Not now" would occur when I either indicated I wanted to say something or when I was in the middle of formulating a sentence. I would be told "not now" as a way of breaking the interactional focus, rearranging the interaction to permit something else to happen. I would be interrupted from speaking when the portable x-ray machine crew would appear in my doorway, when my physicians or residents would enter the room, when any new machine would be set up, when my medications would be administered and when I would be fed. Even when I was speaking about the procedure underway or about to begin, I would be cut off. Frequently I was trying to tell personnel how to handle my body in the procedure. I had gained a lot of experience about what worked in these procedures in the positioning of my body. Certain positions would cause coughing spasms and delay or abort the procedure. "Not now" would happen every morning at seven when the x-ray crew would reposition me for a chest film and I was interrupted from telling them how to position me. Ignoring what I was trying to say, the crew would begin to move me and I would invariably go into a muscle and coughing spasm, ruining the x-ray. I found little collective memory among x-ray crews, or among hospital staff about what worked and what did not work, belying the fiction of nursing notes and staff conferences. I felt it necessary to direct each staff away from problem areas in the handling of my body but because I could not overlay my speech with on-going action, and the attention to my speech required such a focus, I was usually unsuccessful in using my speech to guide the interaction.

"Not now" is directly related to "Out of Context." "Not now" can take three avenues. The first is simply saying "Not now" when I am trying to speak. The second is when the party I am speaking to cuts me off by attending to another task, usually walking away in mid-sentence. The third possibility is when another interrupts my conversation, taking over the interactional focus. "Not now" does not occur only when I am about to start a treatment or a procedure. It can happen anytime when I am trying to speak.

"Out of Context" happens when I am able to resume speaking to the topic that I was addressing when I was interrupted with a "Not now." Usually the interaction has moved along so far that when I address an old topic my conversants have a hard time seeing the relevance of what I am saying. It takes so much effort to spell out what I am saying I could not easily recycle the topic by saying "You know what we were speaking about a little while ago, the X topic." I could only, because of time and energy, speak directly to a former topic. This speaking out of context would generate many complaints and confusion. It would often break off further communication. Speaking out of context would be like an ethnomethodological
experiment, producing comments like "Are you crazy?", "What the hell are you talking about?", and so on. The local nurses came to learn that this was a standing problem with my speech and would try to remember the course of our conversation. But it was often problematic whether they could remember and it was an opportunity for closing the conversation, much to my frustration.

I found I could not do the constant reparative work that goes on in normal conversations. I did not have the temporal dimension to say, "You know what we were talking about before," as a method of reintroducing a topic I was talking about. I could not layer my speech with the body gestures and differentiations in pitch, volume, tone, stress, or pace of voice to keep my present turn at talk, keep from being cut off, and keep from having my sentences completed by others. Some people would anticipate the spelling of words as I was progressing through spelling them, unintentionally giving me words I had not thought of. The more common problem was and still is that people finish my sentences, usually making me say what I had not intended. This has caused many sharp disagreements. Because I could not talk while my translator was reading what I said, I frequently experienced gross editing of what I said. Sometimes the translator would refuse to say my thoughts. More frequently the translator would not be assertive and translate my thoughts at the proper spot in the conversation, choosing to wait, delaying my participation and leading to further out of context remarks.

Another trouble I had was that it was difficult to tell when my turn at talk was coming to an end and without the paralanguage of intonation it was difficult to know when I had actually ended a turn. This was so disassembling to the conversation that my conversant could not remember what I had just said and we had to start all over again spelling out the sentence.

The last example of trouble in this brief sample of interactional difficulties in the hospital was the absence of redundancy. Normal conversations are filled with countless restatements and qualifications of topic and its predicates as the conversants continuously negotiate and resplicate meaning. My spelling out sentences was too labor intensive and focused to be context sensitive to the need to rephrase and reinterpret what I meant. Tied down to looking at the spelling as it was written, I was usually unaware of behavioral signs of the need to resplicate and was at a loss in formulating a proper interpretational context. Sometimes it seemed as if my statements came out of the blue, obscuring the interactional fit and meaning of what I said.
CONCLUSION

This paper started out with the intention of describing the ontological insecurity experienced in personal absorption into a complex of monitor screens in the ICU. I had been interested in the fragmentation of the post-modern personality, described by Jameson, and Baudrillard's hyperreality of TV monitor screens as a site of the shifting postmodern personality. I thought my experience in the ICU was a good example of fragmentation and ontological insecurity in the context of remote monitoring and my own viewing of the monitor screens.

When I started writing I entered the qualification that I cannot talk. I thought this colored my experience, making a difficult time even harder. However, when I began to think of how my body and my person was fragmented by the monitors, I could not get beyond the thought that there was a learning process of me looking at the nurses looking at the monitors and talking about what they saw. I was directed to look and read the monitors from their attention to them. It became a coordinated looking and reading. Because I was alone much of the time and could not talk to ask questions about the monitors and what they meant, I tended to spend a lot of time looking at the screens and trying to figure out what they meant. When I tried to communicate with the nurses I was unsuccessful most of the time. Ninety percent of my nurses were flying nurses. I could not tag them with my face, gaze, or my identity, pulling them into conversations.

As much as I was attracted to the notion of monitor screens, I came to doubt the source of my trouble was in the monitors. Further, I came to see that postmodern social theory, at least as represented by Jameson and Baudrillard, has no sense of social interaction (Tucker 1993). If the social is dead, as Baudrillard would have it, this common culture truth is an interactional achievement of talk, writing, film, TV, broadcasting, drama, teaching, and other forms of discourse. The source of my difficulties in the ICU was in the daily social interaction with nurses, physicians, and technological people and in the meaning this interaction generated for the social and physical environment, including machines in the room. The absorption into monitor screens was produced, in large part, by the comparative isolation and inability to get information about the monitors and their read out values.

I have described some of the communication problems I experienced in the ICU. I have come to see interaction, from its earliest phases of glancing and starting to talk, as the site of personal integration or fragmentation, security, power and powerlessness, anger, patience, memory and context relevance in my attempts to talk in the hospital. The institutionalized, natu-
ralized, socially consensual order of conversation has a time order, a rhythm, that assumes an intersubjective coordination of physical human bodies. Having a body which could not inhabit this time order was a breach of the normalized conversational environment every time I tried to talk. Yet, as I learned from the local nurses, there are a few people who demonstrated the normal time order is but one among many time orders and structures for communication.

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ENDNOTES

1. This paper explicitly uses the self as the primary source of data. I have long ignored this experience in doing sociology. I feel like Irving Zola (1982) when he wrote in the first paragraph of his book, Missing Pieces, “Yet for over two decades I have succeeded in hiding a piece of myself from my own view.” While I have suffered this illness since 1985 and have been in a wheelchair since 1988, I have felt constrained from consulting this experience until this paper, written in 1993. I implicitly regarded personal experience as a “forbidden pool” of knowledge, used but never acknowledged (Fine 1992). This diffidence toward describing my experience of disability is also shared by the late disabled anthropologist Robert Murphy (1987), in his book The Body Silent.

This reluctance is, in retrospect, strange for someone trained as an ethnographer. The “unique adequacy requirement” (Garfinkel 1984; Schutz 1967) for beginning a study of a social setting states that the analyst must be a recognized member of the practices he or she is describing. However, most ethnographical studies after assuring the reader they are proficient practitioner of the setting described, quickly turn into third person accounts. The use of the “I” as the subject of analysis is an embarrassment for many. It remained for Dorothy Smith (1987) to explicitly theorize the self as the source of both analytical knowledge and the subject of official research.

I was encouraged to use the experience of my disability as a broad sociological topic by Irving Zola. He gave a colloquium in Honolulu in the spring of 1993. In his talk and in personal conversation after, he used his disability to open up broad issues of social order, for both the able and disabled.

2. I know of no computer assisted speech device that speaks in real time. I have made a thorough investigation of the synthesized speech market.
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