Exploration of Ethnic Minority Patients' Experiences at XXX Medical Center

Executive Summary

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I. Purpose

This is the summary of an exploratory and descriptive study of experiences of a convenience sample of ethnic and linguistic minority and immigrant inpatients at XXX Medical Center (XXX). At the request of XXX, this summary report was prepared by the research unit of the Cross Cultural Health Care Program (CCHCP). It is intended to mirror to XXX managers what their ethnic minority patients experience; if these experiences, as reported, are in any way unacceptable to managers, they may elect to conduct more scientifically rigorous inquiries among more representative and more diverse panels of respondents, using more quantitative methods. These would help determine the prevalence of these experiences and the degree to which they might be attributed to particular units, practitioners, language groups, ethnic minority populations, or income groups.

II. Methods

The analysis and report are based on confidential face-to-face, taped, open-ended interviews with 25 recent ethnic minority inpatients and their family members, five physicians, nine interpreters, and six other XXX hospital staff; in addition, we were able to observe the interactions of some patients, family members, and XXX staff in certain units. During the brief period of time during which these interviews were arranged and conducted, we interviewed, as available and willing, a number of persons scattered throughout the many services and units at XXX and with markedly different diagnoses, severity, interventions, and lengths of stay. The interviews were conducted during February-June 2000. The patients were contacted during their stay in the hospital or by referral from an XXX staff member. Accompanied by a skilled medical interpreter when necessary, the researchers interviewed patients and family members in their homes. Patients and family members were asked to relate the story of their most recent stay at XXX; the issues that were in the foreground of their memories and assessments form the core of the findings.

III. Caveats

The ethnic minority populations represented in this convenience sample of patients included: six African Americans, one African, one Asian Indians, three Chinese, one Cuban, one Korean, one Mexicans, one Middle-Easterner, four Filipinos, one Russian, one Samoan, and three Vietnamese; they are not considered representative of any larger group. The patients themselves were drawn from different ethnic groups and varied widely by culture, language, age, gender, education,

medical condition, personal history, and so on. Interpreters interviewed were also diverse, and represented Cambodian, Cantonese, ChouJo, Eritrean, Mandarin, Spanish, and Vietnamese speakers. We interviewed an insufficient number of patients, interpreters, and staff to draw conclusive findings about specific departments, units, sites, shifts, individual practitioners, support staff, or ethnically defined populations. The authors did not interview Caucasian patients, so have no basis to compare the perceived experiences of these ethnic minority patients with other XXX inpatients.

IV. Patient-XXX Communications

In its most general sense, communication is reported to be the greatest obstacle in patient-XXX relationships, as reported by ethnic minority patients and their families. Communication issues include:

- Failure to identify race, ethnicity, and language need at admission
- Use/misuse of family members and friends
- Failure to communicate sensitive information to the correct person(s)
- Failure to observe the hallmarks of medical [as distinguished from cross cultural] provider-patient communications
- Failure to communicate information across providers and shifts
- Failure to respond to complaints and concerns
- The desire for patient advocacy
- Patients' impatience with explanations

While it is not assumed that these problems are more ubiquitous at XXX than other comparable hospitals nor that these problems occur more frequently with ethnic minority than with other patient populations, it is clear that these pose serious frustrations and problems to these patients and are exacerbated by the linguistic and cultural differences between XXX staff and these patients.

In this report, we will focus on some of the most prevalent communication issues that arose during our inquiry, including: family member involvement, informed consent, communicating information across shifts, and the provision of interpretation services.

A. Use and misuse of family members and friends for interpretation

Our field notes demonstrate that, in several instances, family members are used as interpreters, despite XXX guidelines recommending otherwise. The cases in which family members served as interpreters varied tremendously, with no indication of <u>the existence of guidelines indicating when it might be acceptable to use the family member as an interpreter</u>.

One physician reported that she does not always call an interpreter when the patient does not speak English, if English-speaking family members are present. She said her decision depends on the sensitivity of the case and the family's level of English speaking ability, both subjectively determined by her. Similarly, a social worker shared that his method of determining whether or not an interpreter was needed was dependent on 1) the nature of the patient's situation, 2) the

presence of family members, and 3) the family members' ability to interpret and understand, all subjectively assessed by the social worker alone.

In one instance, a family member gave hospital staff her home telephone number and stayed at the hospital to allow communication between the patient and provider at all times, thus ensuring 24 hour availability.

> So my husband stayed in emergency room and then I had to stay, especially after [the surgery] because she cannot say 'drink' or where is pain, it's important…They did not ask about interpreter…During the day, I know how hard it is for the nurse, so I gave telephone, 'call us, sometimes night, anytime,' because I left. 5 o'clock, early morning, they called me, she want to ask something. We asked them to call us if they need help because she couldn't speak English.'

It is unknown why the AT & T language line was not used for short-term, immediate needs such as this. It was also unclear why the institution would shift the burden of interpretation to the family and itself become reliant on the family, rather than on institutional, resources.

Time and timing also influenced whether/when a family member was used by XXX staff in lieu of a professional interpreter.

> In the interest of time, I think most of the time they (doctors) don't call for an interpreter if there's a family member present who's capable of interpreting for them…doctors don't want to set a specific time that they have to be there, so a lot of times they use family members.

Under what circumstances (e.g., simple acts such as eating and cleaning versus complex actions of expressing significant discomfort) and how to use family members as occasional interpreters may require XXX to provide more detailed and uniform guidelines. Lack of guidelines about when to use a family member as interpreter leads to inconsistency across and conflicts within staff.

> I see that happening inappropriately in both directions. Meaning that people will often use a family member because it's convenient and not think about the fact that this person may not convey all the information or may not have a medical background. Or they will try to go by the letter of the law and say 'it's illegal to use a family member,' and maybe not be as inclusive as they should, because the translator's not going to be there with the person when they get home…people don't really know how quite to use critical thinking skills in the use of a translator. We lay down guidelines and then they're [staff] very, very literal.

Providing guidelines and their underlying principles may help staff make more appropriate decisions for their patients and themselves.

One consequence of the relatively constant presence of family members in the hospital is a resulting XXX over-reliance on family members, not only for communications, but other tasks.

> How much does XXX depend on family members? Do they **expect** me to be there? I'm concerned. Of course, I like to be involved, but it's not **my** job. In June, my brother and I took turns to be with her 24 hours a day, we were wiped out. Then my mother knew less

> English because she didn't have English-speaking caregivers. She was walking hallways. Doctor asked me, ‘Could you talk to her, tell her not to walk hallways?’ But talking to her wouldn't help, because of her stroke she was incoherent. It didn't make a difference if a sitter was Cantonese speaking or not, she just needed someone with her all the time to watch over her and so she could communicate her needs, signing or however. She was capable of communicating her needs in spite of language barrier.

Providers have an obligation to do more than transmit information in a form that patients and family members can understand; they need to ensure that the information is received and understood. This is particularly crucial when confronting the role of informed consent in procedures of medical care.

B. The need for truly informed consent

Informed consent is one of the most complex issues in cross-cultural health care. In many cultures, advanced directives to constrain future events are inconsistent with religious and other beliefs. The literature on this topic is large and growing, but, in general, many cultures do not countenance the more Western stance that one can or should attempt to control the future.

These beliefs run counter to the humanist and legal arguments underlying current hospital practices and procedures in seeking and obtaining informed consent for near-term and long-term eventualities. They also run counter to the power difference between physicians and patients.

> Sometimes the doctor sees the medical part only, and they're [patients] worried about 'is this going to cost me? Is the insurance going to cover this?' and they're worried about other things. Many times I think it has happened that, Hispanics sometimes, they come especially from lower classes, they're more accustomed to being told by the doctor what to do. And sometimes they feel like what the doctor is saying, it is going to be done. They don’t know that they have the right to say no, or they have the right to ask more questions.

The arguments, practices and procedures, and consent are all foreign to many ethnic minority patients and their families. For example, we observed one physician-family member encounter.

> The physician asked the daughter if she were familiar with an advanced care directive, what would she want the hospital to do should her mother's heart stop? The daughter said, ‘Of course, do everything, CPR, whatever it takes.’ The physician asked, ‘But what would your mother want? Would she want that?’ The daughter responded ‘Of course!’ then she looked at the researcher and asked, ‘Oh, I see, so they need permission for that kind of thing?’ Upon exiting the exam room, the physician mentioned that that wasn't a proper advance directive and that was a great example of when the presence of an interpreter would have been helpful.

Hospitals and their staff are often comforted by a kind of proceduralism, an assumption that by going through the legal and institutional form, the basic ethical requirements have been met.

> In some cases, they're gonna understand enough to know what's going on, <u>and everybody's comfortable with that</u>. And if they're not, they can say ‘no.’ <u>Of course, they may not be comfortable doing that</u>. I'm sure that there are people that <u>end up getting stuff</u>

> that they don't understand or that they may not agree to. But things that are sensitive, we have a huge formal consent procedure for those kinds of things, surgery, things requiring informed consent. So, those things are protected by law. So, there's nothing grave happening without their knowledge.

In this condition of relative powerlessness for the patient, it is worrisome what is meant by “getting stuff,” “things that are sensitive,” "formal consent," “protected by law,” or “nothing grave”, as well of the consequences of such assumptions.

C. Failure to communicate information across providers and shifts

Ethnic minority patients, like their non-minority counterparts, expect their care to be managed – that is, in pursuit of a plan coordinated with and by their doctor and communicated through all services, physicians, nurses, and shifts. Some have learned this expectation through their experiences with their primary care physicians in managed care settings. Others have learned this expectation through prior experiences at XXX or other hospitals.

Overall, patients seemed somewhat distressed that so many doctors were following up on patient care, due to different specialties and different shifts. They were pleased that hospital staff seemed to be responding quickly to medical issues, but there were a lot of providers to deal with. For some patients, and perhaps in some locations, the numbers of people were not seen as disturbing because the members appeared to operate as a team --- coordinated, synchronized, professional. One friend of a cancer inpatient noted

> I followed the sequence with the radiation, the surgery, the chemotherapy, and I could see that these are the same doctors, they work as a team. Everything was coordinated, everything was synchronized.

However, many of our respondents expressed concern at what appeared to them to be **scattered services and approaches across XXX staff and shifts**. One new mother stated this experience clearly.

> I was really frustrated because my own doctor at this point, went out of town, and her partners, she has five partners, who are each on call for one day a week, so then I had a different doctor every day, so I was communicating with different doctor. The second time it was really stressful and quite miserable because each doctor really had a very different philosophy, very different experience with pregnancy. One of them had very, very different advice for me than the second person and the third person and so on and so forth. And the person that induced me clearly meaning to push to the end until I delivered. But, by the time he went off call, the next doctor who came on call said, ‘There's no reason to keep on inducing you, you obviously just need to lie down and rest, we're not going to push this.’ But the doctor before felt like he really should induce me, and he was saying, ‘This is miserable, you really shouldn't be pregnant, this is awful, it's gonna be really hard, it's amazing that you've made it so far.'

This patient attributed some calm in the midst of this confusion and division to her nurses.

> I think it was positive that, in the changing of my doctors and the different philosophies and the confusion, it was really the nurses that made it comfortable and explained, ‘This is

> why your doctor's saying this, and this is why this is happening and this is why this doctor feels differently than the last doctor.' It was a lot easier to have them explain things to me.

But then divisions appeared within that same nursing staff itself.

> The nursing staff there was pretty wonderful, except that now things got more complicated. Because there was me to take care of as well as two babies. And there were a couple of nurses that had very different philosophies about taking care of babies. Overall, everybody was very, very open to what was my philosophy. But it was like a few times, I think just a couple of people, like one person who was absolutely crazy about breastfeeding and no other alternative. And when she saw that I was having such a hard time breastfeeding, she just drove me crazy. She was really, really pushy with me, way too pushy. And another person, in the other extreme, very pushy. Because she saw that I was having a very hard time breastfeeding and decided that they should be fed formula without discussing it with me, without getting my opinion. And took them to the nursery and started bottlefeeding them, which I did not want and I had specifically asked her not to do it.

For different doctors to recommend different courses of action, and to do so without consulting with the patient directly gave the patient the impression that she was being experimented on, with no method of care clearly seeming to be the most appropriate. The apparent discontinuity of medical care took this patient back and forth between different recommendations and procedures of care. If different providers had different philosophies, patients had no indication whether they consulted with each other and proceeded with one method of care, rather than changing recommendations every single day. Such changes are confusing to the patient, demonstrate a lack of continuity within staff, and do not support the best interest of the patient.

> I think that all of the number of doctors who were caring for me should have consulted, should have had a conference, consultation, decided how they were going to proceed with me as a group and to take that one route, as opposed to everybody taking me in a different direction and absolutely driving me crazy. One of them would give me hope, one of them would take me back, one of them would give me hope, one of them would take me back. It was too much. It was really hard.

Therefore, even if patients knew that several providers would be involved in their care, due to a lack of communication among staff, they were confused and frustrated by discontinuities in service. We do not have enough information to draw conclusions about where and when team and non-team relationships are observed.

While it may not always be possible for all staff involved with a particular patient's care to meet and discuss the course of treatment, at the very least, patients expect them to document and regularly consult information in the patient's chart since this is their primary, immediate means of access to all information pertaining to the patient. However, documenting and referencing patient charts is not always adequate to address all of a patient's immediate needs.

> It's hard because, they have paper [the patient chart] they read, but it's not enough explain every time, because one does not know she cannot drink this, she cannot drink cold, she cannot drink water with ice like everybody. Because it's hard to say to everybody the same about her.

In this case, the patient's daughter felt compelled to stay with her mother in the hospital, to prevent miscommunication and ensure that all of her mother's needs were met.

D. Interpretation Services

With some pieces of a system in place, but not a strategic and rationalized process, XXX's meeting of language needs appears scattered, ad hoc, and driven by convenience, rather than procedures and standards.

> If the patient has a crisis and needs to communicate immediately, I think the patients do the best they can to express them, basically. Or they may have a relative there. So, in that kind of situation, you might communicate through a relative. I have occasionally used AT&T language line, and I know that we do, too, for a daily telephone update. So we'll use them also. We usually wouldn't use them for kind of impromptu questions, I think that would more likely be dealt with through a relative. Unless they've used it, they're probably a little intimidated by it. I think in this organization, if a manager ever says, 'that's very expensive,' the staff takes that very much to heart, and they think they're being forbidden to ever use it. And so you need explicit permission and description of when it's appropriate to use such a thing…Many floors share an educator. What that means is that their orientees don't all come through one person, they're delegated through different RNs so there might not be as much consistency in exactly what people are told. And even when it is through one person, still you have other people…you have the informal communication at work, that, 'Oh no, I heard at a staff meeting years ago that we weren't supposed to do this.'

1. Patient awareness of language interpretation at XXX

When patients come to XXX Medical Center speaking a language other than English, their level of familiarity with interpreter services varies. Some XXX staff believe that most patients would request an interpreter if they felt that they need one.

> I would imagine patients would request interpreters. I think the older patients are less assertive about that, or would even know that that would be an option. I think people that are younger would figure that, oh yeah, there must be an interpreter or somebody around.

One patient was aware that interpreter services did exist, but because of his experiences at other health care facilities, expected them to be automatically provided. As explained by his interpreter during our conversation,

> I don't know why they didn't have an interpreter. When they come to PacMed, the same chart in the computer says this patient needs an interpreter. They said, 'we don't have to request it.' So they expected kind of the same thing from XXX, and apparently it didn't happen.

When asked why he didn't request an interpreter upon discovering that one was not already present, he replied,

> How could I tell them? I didn't have anyone to interpret for me!

There does not appear to exist an established system to signal to the patient that an interpreter is being called, will arrive shortly, and how long will it take. We recommend either the immediate use of the language line or the provision of small signs in every language with some basic messages to communicate with the patient prior to the interpreter's arrival, including conveying the fact that the interpreter is on the way.

In a number of instances in our study, patients and family members reported having interpretive services at some points in care and not at others. Our observations and conversations did not make apparent any one mechanism for determining where, when, how and by whom interpreter service need is determined and requested for patients. Respondents indicated different points at which need was identified (for example, emergency room, admissions, once admitted), different staff people responsible for making the interpretation request, and so on.

2. Establishing the need

In addition to different points of stay at the hospital at which the need for interpreter services is identified, there also seem to be varying factors that contribute to the decision to seek the assistance of interpreter services. We observed a few factors that arose repeatedly in patient, interpreter, and XXX staff accounts of determining the need for interpreter services.

a) "As needed" basis

Many patients and staff reported that interpreter services were sought "as needed," for example, when staff members determined that a crucial communication required interpreter assistance. It is open to question whether this determination is intended to serve and protect the institution, the patient, or both.

One patient reported,

> I know that every time it was necessary to call an interpreter, they would call it. X [patient's partner] thinks about four times. By 'necessary,' I mean when *I needed* them to explain something to me, something that they needed to do, or some procedure, or bring in the machine or make an x-ray, or explaining the medicines I was going to have to take, something like that. [emphasis added]

While this patient and her partner felt that their language needs were adequately met by XXX staff members, it is unclear whether there is a guideline or procedure in place to direct staff in the identification of those circumstances that warrant the need for an interpreter.

At times, interpreters are called at the end of a patient's stay to assist with discharge.

> Quite often what'll happen is, I'll get called to assess if it's safe for somebody to go home, and they don't speak English, and there's no family there, 'cause I'm guilty of using family [as interpreters] as well. *I have to call an interpreter.* [emphasis added]

Treating interpretation as a limited resource, to be used very sparingly, may produce false savings in the care of the patient and the protection of the institution's interests.

b) Last-minute requests

Surprisingly to us, interpreters repeatedly reported that inpatient interpreter services were typically last minute calls, requested immediately as they were needed, rather than being scheduled.

> Inpatient are usually add-on calls, very seldom given to us in advance. The nature of the inpatients will vary from babies in incubators to hospice patients, people on their deathbeds…sometimes it's kind of consultation that the doctor's about to carry out that requires the presence of an interpreter. Sometimes it's just the discharging instructions for an interpreter to relay to the patient. Or sometimes, it is an interpretation between the baby's mother who was already there and the obstetrics nurses.

c) Reducing exposure

When assessing a patient's need for assistance from interpreter services, XXX staff members occasionally considered hospital liability issues.

> Discharge instructions. If family member does it, and any mishap happens, then the nurses will be blamed, you did not talk to the right kind of people. Also medical imaging. They will put off the medical imaging, X-ray, scanning will be put off until interpreters arrive. Even sometimes like hold your breath, inhale deep and hold it back, they cannot communicate. Even a simple instruction like this.

3. Overcoming medical terminology issues

Even in cases where the patient is proficient in English for daily purposes, it is often necessary to seek the assistance of interpreter services to ensure that both the patient and XXX staff members are satisfied that they understand each other *in medical matters*. Many ethnic minority patients speak English but, because it is not their first language, they feel more confident communicating via interpreter services in their native language. They also have the opportunity and time to hear the messages twice, once in English and once in their first language.

> Sometimes, I don't even get a chance to interpret. The patient just responds. Sometimes, it makes the doctor uncomfortable, not sure that the patient understands everything. Some patients speak quite a bit of English but they'd rather wait for interpreter and speak in Cambodian back to me and interpret.

Often, patients communicate directly with XXX staff members, but the interpreter remains present to assist with misunderstandings. However, it can be challenging for an interpreter to assess what the patient does and does not understand.

> The difficult part is when the patient speaks quite a bit of English and, so, they like to talk to the doctor, and sometimes they don't know and they don't say anything. They don't understand the terminology, but they won't say anything. Sometimes, it's very hard for me to jump in, because they don't let me know what they don't understand.