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# Lessons from the Field — Health Care Experiences and Preferences in a Latino Community

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*As part of Midwest Bioethics Center's PATHWAYS to Improve End-of-Life Care project, we conducted an exploratory study in the Latino community of Kansas City to understand health beliefs, practices, and values, particularly as they relate to end-of-life care. We conducted ten focus groups and interviewed more than seventeen individuals who serve the Latino community in a social service, ministry, or health care capacity. We found that people were very concerned with "barriers to health care" (our term), and very willing to reveal their preferences for health care decision making and end-of-life care treatment options. We believe that bioethicists should conduct other, similar projects because they can improve our engagement with the Latino population and help Latinos find a greater voice in health care settings.*

Cultural diversity was one of the thirteen initial strategies of the PATHWAYS project, largely as a response to two observations. Center staff had long noticed that both the issues and participants at Center-sponsored events and other bioethics-related events tend to be consistently and remarkably monochromatic. As one of our colleagues has observed, "bioethics seems to be for middle class white people and about middle class white issues."

Center staff designed the specific parameters and methods of a cultural diversity strategy using various tactics. We started by identifying the communities who, by size and cultural impact, ought to have a significant role in Kansas City health care. We then invited representatives from the African-American, Latino, and Vietnamese communities to the Center, hoping to seek their counsel about how to proceed.

The meeting was revelatory in two ways. First, we heard over and over that no single individual or group could comprehensively represent or communicate the story of an entire community.

Second, we realized that we needed to move outside our normal surroundings to new settings with new alliances or partnerships to provide the entrée. We also needed a new kind of agenda. Rather than assume our usual roles as teachers or educators, we needed to do what we had often done in situations not our own. We needed to "actively listen" and let the agenda emerge from the group.

Our next step was to invite health care colleagues from the Hispanic and Vietnamese communities to attend Ethics Committee Consortium meetings. Our intention was to hear their stories and let the Consortium decide how we should proceed. Our guests related experiences that they had had while serving as the link between the health care world and their communities. The stories were fascinating; the experiment was a dismal failure. As illustrative as the stories were, they did not go beyond the experience of the individuals involved. We fell dangerously close to the pitfall in all such experiments: the danger of stereotyping. Our failure was predictable because we ignored advice that we had already recognized as sound. We hadn't gotten out of our own backyard to really listen!

While that advice resonated with us, studies had reported that certain minority populations resist conversations regarding advance care planning (Blackhall et al. 1995; Hauser et al. 1997). The challenge was how to listen actively without imposing our own agenda, and yet elicit information that was directly on point for our project.

Anthropologists have long known that we cannot learn about others through external means or by merely inviting them into our domain. We must immerse ourselves in other cultures and learn from them. To the extent possible, we must step outside our own belief system and recognize that even simple “rights” and “wrongs” are not similarly defined by all people.

A main tenet in anthropology is that culture is taken for granted (Peacock 1986). That is, we often do not realize that we also have a culture. “Middle-class white folks” living in the United States sometimes think that they do not have a “culture”; that only others have cultural differences. As Peacock (1986, p. 7) observes, “the fish is the last to understand the water.” At this point, we realized that what we needed was to combine anthropological field methods with bioethical inquiry, and thus our project was born — we determined to do a field study in our local Latino community.

### **Participant Recruitment and Data Collection**

Our objective was to explore, through personal accounts, the health care experiences of some Latinos in our community. Our qualitative findings describe the experiences of those with whom we spoke. We were hopeful that our inquiry would provide a glimpse into the experience of some Latinos in our community to help illuminate some of the issues surrounding appropriate patient care.

We decided to explore the health beliefs, knowledge, and practices of Mexican-Americans in our city, as they related to general health care and more specifically, to health care at the end of life. However, when we began to speak with members of the community, we found that the agencies with whom we needed to cooperate to

recruit focus group participants were reluctant to limit participation in the groups to individuals with Mexican origins. These spokespersons asserted that their organizations serve Spanish-speaking persons from diverse ethnic backgrounds. We decided to heed the advice of these community “gatekeepers,” and target our efforts to already existing groups of Latinos.

First, we identified a list of possible sites for inclusion in our study, all of which primarily serve Latinos. Our list included churches, several social service agencies, health clinics, a homeless shelter, community organizations, senior centers, and one retirement housing complex. We met with more than seventeen community leaders — priests, physicians, social service organization leaders, a refugee support center facilitator, a long-term care administrator, an assertiveness training leader, and others. We spoke to many individuals within these organizations and ultimately, interviewed seven community “gatekeepers,” leaders of different types of health, community, and social service groups, who would eventually help us conduct focus groups with the people they serve.

In addition to those interviews, we also interviewed nine prenatal patients in the waiting room at a sliding-scale community health clinic that primarily serves Latinos.

We conducted ten focus groups, and most of our data comes from these groups. We held focus group sessions with men at a homeless shelter for recent immigrants; with seniors at three community centers; with young mothers in a parenting skills class; with women in an empowerment group; with younger women (girls in the sixth through twelfth grades) in a youth leadership group; with women in a Spanish-language only, general support group; with seniors at an independent living facility; and with professional women in a cancer support group.

When developing questions for the focus groups (see Appendix), we kept the following issues in mind: How have these individuals been affected by their experiences in health care settings? What meanings did they glean from these events and in

what ways are these meanings representative of their community and culture? What can these experiences teach us about the health care system and about how we care for patients in our health care facilities, specifically when they are seriously ill or dying? And finally, how do these individuals subjectively understand their experiences?

**Analysis and Findings**

We used a thematic analysis approach to our findings. We audiotaped all focus group sessions, and wrote extensive field notes on interviews and observation exercises. We began our analysis by transcribing the tapes, then translating them from Spanish to English. We then read through the transcripts exhaustively, looking for themes — that is, for concepts, ideas, or responses that were repeated more than once. Once we had identified a preliminary list of themes, we met with a local

Latino coalition of social service providers (several of whom we had interviewed) to discuss our findings. Thus we were able to validate some of our findings and clarify others.

As with any study centered around the use of focus groups and interviews, our findings are based on the perceptions of the participants, the interviewees, and on our own research questions. In many cases, what we asked is what we heard about. However, we also found many themes in the transcripts that were completely unsolicited.

In the following charts, we list the themes that occurred most frequently in the interviews and focus groups. “Frequency of Occurrence” refers to the number of times the particular theme was mentioned by different individual participants, in all groups. “Number of Groups Reporting” refers to the number of different focus groups (we had eleven groups in

**Chart 1 — Unsolicited Themes in Focus Groups and Interviews**

Theme	Frequency of Occurrence	Number of Groups Reporting
No insurance	33	8
Discrimination	26 (experienced: 22)	6
Interpretation/language problems	19	6
Lack of knowledge of healthcare system	17	7
Importance of family/friend involvement in healthcare	15	9
Deference to God's will — <i>fatalismo</i>	18	10
Good experiences in healthcare	17	9
Negligence in healthcare	26	10
General insensitivity	16	10
Cultural insensitivity	6	5

all) and/or interviews in which the theme occurred at least once. In Chart 1, we list the themes that were completely unsolicited by the focus group leaders; in Chart 2, the themes that were solicited.

### Discussion of Findings

We have organized the themes that appeared most frequently in our focus groups and interviews into the following categories: barriers, health-care decision making, and end-of-life care.

#### Barriers

We did not ask our respondents about the barriers they encounter to effective health care. Therefore, the frequent occurrence of these barriers in our discussion was notable. Specifically, focus group participants shared many of these experiences: having no insurance, discrimination and perceived negligence, language interpretation problems, general and cultural insensitivity, and (their) lack of knowledge about the health care system (see Chart 1).

*No Insurance.* The majority of respondents had either a personal or vicarious experience that involved lack of treatment or discrimination on the basis of insurance. In addition to perceiving the need for health insurance as an unfortunate barrier to receiving adequate health care services, many participants felt that they were discriminated against because they either did not have insurance or were assumed, based on their race, not to have it.

*Discrimination and Negligence.* Stories about discrimination were most common among people who did not have health insurance. We heard over and over again that people felt they would not be treated without health insurance — even at the public hospitals. Respondents felt that Latinos were perceived to be indigent, even if they were not.

One woman also connected discrimination with medical negligence. She said the negligent “care” her husband had received had ultimately caused

Chart 2 — Solicited Themes in Focus Groups and Interviews

Theme	Frequency of Occurrence	Number of Groups Reporting
Medical care decision making	26 (relational: 15)	9
Attitudes about advance directives	27	11
Views on life support	58	12
Who to go to for support/help	37 (family: 13, God: 9)	10
Truth in diagnosis	22	6
Attitudes towards nursing homes	9 (negative: 6)	4
<i>Caring Conversations</i>	8	7
Views on hospice	10 (positive: 6, neutral: 4)	6
Preferred location for dying	15 (home: 9, hospital: 6)	8

him to lose a limb. Her perception was that this outcome would not have happened if they had not been discriminated against. She asserted:

They didn't give him any care. I told them, "I want to leave here because you are not treating us well. This is discrimination. This is strange." It's because we are Mexican. It happens a lot. They don't respect you. There is still a lot of discrimination.

In addition, we found that fear of discrimination ending in negligence leads some people to turn to traditional Mexican healers, *curanderos*. When asked why she would choose a *curandero*, one woman replied:

Trust. At least I know what they are going to do. In hospitals, they have their own ideas. Due to the simple fact that I'm Hispanic or that I speak Spanish, they think they can treat me badly. I heard of a [Latino] man who went in for a simple cold and he left there dead! How is it possible? It gives me fear that the same thing could happen to me. So the *curandero* is better.

*Language Problems.* Being able to communicate effectively with health care providers was another area of great concern to the focus group participants. We heard stories of daughters or young children being used as interpreters and having to tell their mothers or other family members that they had a terminal diagnosis. We also heard that those who can only speak Spanish are limited in their options for treatment because they cannot use clinics in which their language is not understood.

Language problems can also be nonverbal. It is very difficult to give written informed consent if you cannot read what you are signing. Respondents reported that they were forced to sign consent forms even without knowing what they were signing because they wanted the hospital to treat them. A woman in the Spanish-speaking women's support group explained:

In the hospitals they sometimes give us papers to sign. But in English. And since we want to be seen [by the hospital staff], we

sign the paper. But we don't know what we're signing! One signs it with closed eyes because what one wants is to be seen. If one side is English, why can't the other side be Spanish? Because we all need the same thing — we are human beings. We need to know what's going on.

Even when interpretation services are available between a Spanish-speaking patient and an English-speaking health care provider, it is sometimes not enough. Some patients cannot fully express themselves through an interpreter. One participant, a woman in one of the senior groups, said:

People that don't speak English, they can't express themselves. They can't tell the doctor exactly how they feel. Because when you speak through an interpreter, sometimes you lose things. And a lot of people think they know how to translate and they don't.

*Cultural and General Insensitivity.* Participants frequently (twenty-two times) reported perceived cultural and general insensitivity as a barrier in their health care experiences. For example, one interviewee, a young woman who leads the Spanish-speaking women's support group, stressed the importance of a cultural connection in the healing process. She felt that not only are health care providers generally insensitive to cultural differences, but also that this insensitivity leads to ineffective or suboptimal healing. She said:

This makes me think of the importance of our cultures having a connection — a feeling that we share familiarity with the people who are taking care of us. This faith affects our ability to be able to recuperate. Perhaps the American culture doesn't want or hope for this connection. But in our culture, this connection, the respect, the familiarity, these are more important. And without this, sometimes, perhaps, it affects how much we recover.

*Lack of Knowledge.* Another barrier to effective health care that our participants reported was that of confusion about the health care system. We heard

frequently that individuals do not know how to get the help they need. Some participants also reported that they were confused about payment options and costs of treatments. One woman, in the Spanish-speaking women's support group, felt that the cost for treatment was more expensive the longer you had to wait to be seen. She said:

One thing I have noticed is that the longer they keep you waiting, the more it will cost. I took a child into [the hospital] and had a three-hour wait. The bill was \$420! And it turned out that he didn't even have an infection. Two months ago, he did have a fever and [I brought him in again] and they cared for us quickly, and the total only came to \$72.

An interviewee, the woman who leads the parenting skills group, summed up the problems that women in her group, primarily recent immigrants, face because they lack knowledge of the health care system. She explained:

I have been in this country for twenty-three years and it's still very difficult for me to understand the health system. Can you imagine how it is for these people? They have the language problem. In the countries they are coming from they have the public health system. Here, they can't understand the clinics. We are not used to making appointments.

### *Health-care Decision Making*

As factors that affect health-care decision making, our respondents expressed their feelings about informed consent, the importance of family involvement in the decision-making process, and the importance of faith in God.

*Informed Consent.* The majority of participants wished to be fully informed about their illness and treatment options. Many participants, however, do not expect to be fully informed, and others would prefer that their families be kept in the dark regarding their health status. In any case, many participants expressed how important it is to them to protect one another from a terminal prognosis.

One interviewee told an illustrative story of a Mexican couple. The elderly woman and loving wife stepped away from the bedside of her terminally ill husband of many years. She closed the door to his hospital room, and in the hall, sighed, and said to her waiting friends and family, "I am so glad that Manuel does not know that he will die soon." Meanwhile, her husband turned to a companion and confided, "If there is one thing I am thankful for, it is that Rosa does not know that I am about to go."

The participants of this project fell into three general categories regarding the extent to which they wished to be informed of their condition:

- those who wanted the truth in all circumstances;
- those who would decide in the moment; and
- those who did not want to know, or at least not directly.

Although most participants wished to be told the truth regarding their condition, a significant number preferred not to know everything. A common reason for not wanting full disclosure, one woman explained, is that "[being informed] can contribute to an acceleration of the illness."

*Relational Decision Making.* Most persons we asked preferred to make decisions about their health care only after consulting with their family. When we asked who made the decisions regarding health care, a typical response was, "You have to talk with your husband and your [adult] children." Many older persons mentioned that they were dependent on their family for support, which underscores the recurrent theme of familial responsibility. In the words of one older woman, "We haven't thought about what we would do if we didn't have our daughters or our sons. That's the truth."

Many participants said that it is particularly important to have familial involvement in the health care of their loved ones in hospitals and nursing homes to prevent negligence. One woman explained that she had to take restraints from

nurses to prevent them from binding her husband. Another woman found that her husband was not well cared for in the nursing home unless she was there to supervise. She said, "You have to be with them constantly."

### *End-of-Life Care*

Because we specifically asked about issues related to end-of-life health care, several of the more frequent themes we heard were directly related to this subject matter.

*Views on life support.* Views on the use of life-sustaining treatment fell into basically five categories. Of the fifty-eight participants who addressed the issue, twenty were against the use of life support in virtually all circumstances — or rather, they were adamantly against the use of life support unless there were extenuating circumstances. They made comments such as "I would not want to live like a vegetable. Nor be a burden on anyone," or "Life support isn't any good. If God wants you, he'll take you," or "Why prolong me, if I'm going to die anyway?"

Others said that they would want to die at home to avoid life-prolonging treatment. A woman in the cancer support group said:

The thing I fear the most is being in the hospital when I'm dying. If I'm in the hospital, let me die. Do not put anything into me, and don't give me things I don't want. That's why I'd rather die at home. I'd have more control in my home than I would in a hospital.

Only one respondent felt that life support should be used unconditionally. Others (five) felt that the appropriate use of life-support depends on the age of the patient and on his or her chances of survival. A few respondents (three) also felt that life support should not be used if it is going to prolong the suffering of the patient. Still others (two) felt that the appropriate use of life support depended on whether or not the person could afford it.

*Advance Directives.* Early in our fieldwork, we interviewed the leader of the women's empowerment group. She told us that advance

directives were "countercultural" to the Latino way of thinking. She explained:

Latinos certainly have an element of fatalismo. When your time is up, it's up. This ties in with the fact that we are very present-oriented. Advance directives are countercultural because people don't want to and are not accustomed to thinking about things in advance. For example, Latinos are not all that concerned with buying insurance. Their kids are their insurance. They work hard to invest in their children who will provide for them when they're old.

A few respondents had living wills, but most were unfamiliar with the terms "advance directives for health care" and "living wills"; and many were also unfamiliar with the concept behind these terms. In addition, we found that there is no direct translation of these terms into Spanish, which makes them difficult to discuss.

*Caring Conversations.* "Caring Conversations" is a Midwest Bioethics term for the discussions that occur between loved ones regarding their wishes for the end of life. We found that several of the focus group participants had engaged in caring conversations. Many of these discussions occurred around the topic of life support. Those who are not in favor of life-sustaining treatment often felt the need to discuss this with their loved ones ahead of time. Others held caring conversations because they did not want to suffer needlessly at the end of life. A woman in the Spanish-speaking women's support group explained:

I have talked to my husband and kids about it. If there were an accident that was bad, I told them not to let me live because I would be suffering. I also told them, "don't battle with me on this one." If I'm going to basically die in all modes, what's the point of keeping me alive?

*Nursing Homes.* Without any specific prompting, we heard much concern about nursing homes. None of our respondents wanted to die in a nursing home. A woman in the cancer support group summed up the feelings of her group when she

said, "We don't believe in nursing homes." She went on to explain:

If my mother or father or any member of my family is ill; [even] if it meant leaving my job, we [would] do anything if we had to, like mop or scrape toilets to get by, until that family member is taken care of. That's just the way we were raised. . . . Our mothers and fathers will come first when it comes to caring.

*Hospice.* Most respondents were unfamiliar with hospice. When we had the opportunity to explain the concept, participants were either favorable (in six instances), or said they knew of hospice but did not comment on whether they were in favor of it or not (four instances). One informant, the leader of the women's empowerment group, told us that Latinos do not use hospice very frequently because of the cost and also because families tend to take care of their sick more so than wanting hospitals, nursing homes, or hospice personnel to do it for them. We got the impression that hospice sounded nice once it was explained though none of our informants really considered it a central issue to their health care needs and concerns.

*Faith and Fatalism.* Of utmost importance to many participants is a strong faith in, and reliance on, God. This faith was often expressed in comments that have a fatalistic tone, particularly when we discussed the subject of death or serious illness. These sentiments on *La Fe y el Fatalismo* were expressed by adolescents and groups of adults alike, across a wide variety of backgrounds and experiences.

We heard comments such as, "I know that when I go, I go" or "I'm gonna fight [this disease] but it's in Your hands" or "If it's time to go, it's time to go" or "If God says I'm dead, then I'm dead." One of the most articulate comments regarding faith and fatalism came from the leader of a group who has worked in health care for many years. When recounting her experience working in a cancer ward whose patients were primarily Anglos, she said:

All the patients say, "Why me?" and I say to that, "Why *not* you?" Who are *you*? Why not you? We have another attitude. [People say] if something happens to me, it's O.K. It's something God gave me. . . . Latinos accept everything. Decimos aceptamos con filosofia (we accept with conviction).

## Conclusion

### *Fieldwork Summary*

We designed this project as an exploratory, descriptive project. Our aim was to explore, through personal accounts, the health care experiences of some Latinos in our community. We did not expect our sample to represent all Latinos in Kansas City, let alone all Latinos encountering the U.S. health care system. We believe that this project gives us a solid foundation on which to improve our engagement with the local Latino population.

We are hopeful that through our descriptive reporting, we have provided a glimpse into the lived experiences of some Latinos in our community. Further, we also hope that this project helped to illuminate some of the issues surrounding appropriate patient care, and that these illustrations will help guide Midwest Bioethics Center as it embarks on a new working domain — vulnerable populations.

Many factors contributed to the successful execution of this project. First, several members of the staff had already established relationships with the Latino community. These relationships gave us starting points in the community on which to build. Second, the Center has a commitment to "community-based bioethics," by which we try to ground our programs and activities in the community's needs. Third, we had a medical student on our project team, John Murphy, who is colloquially fluent in Spanish. Fluency was needed to flesh out the nuances in the dialogue.

In addition, John's medical profession made our work easier to explain to potential participants. The presence of a "doctor," even a student doctor, made the explanation of our work more concrete. Bioethics and anthropology, on the other hand,

were harder to explain to focus group participants and community gatekeepers. Finally, because our project team contained a medical anthropologist trained in ethnographic field methods, we were able to tackle successfully all the problems that beset effective and respectful inquiry.

### *Lessons from the Field*

*The Importance of Listening.* We learned a great deal by combining anthropological field methods with bioethical inquiry. First, we learned the value of “getting out of our own backyard” and listening — as free of agenda as possible. We learned that it is not enough to ask others to come into our domain — we also need to move beyond our normal surroundings. Rather than assume our usual roles as teachers or educators, we needed to listen actively and let the agenda emerge from those who were speaking.

*Establishing Trust.* In addition, we learned about the important of establishing trust with those from whom we wish to listen and learn. On one occasion, we were met with some fear and resistance. A group of recent immigrant men, who likely have not had many positive experiences with white men, initially feared that John was a police officer. Once the leader of the group convinced them that he was “O.K.,” we were able to have a lively and informative discussion with this group. These situations emphasized for us the importance of establishing trust with both community gatekeepers and focus group participants.

*Reciprocity.* We also struggled with how to reciprocate with our informants. We did not want to be seen as using people as “guinea pigs for our experiments,” as one interviewee suggested we might be. We thought we could do for these audiences what we often do at the Center; namely, lead educational sessions on the use of advance directives for health care as one way of “giving back” to participants. Based on what early informants said, however, we were uncertain whether people would be receptive to advance directives and whether by advocating their use, we would be imposing our values on another culture.

Other community leaders insisted that educational sessions on advance directives would be welcome in the community. Therefore, we invited all groups to receive an educational session on advance directives, but only four of the groups accepted. This response is not sufficient, and we are now looking for more meaningful ways to disseminate the findings of this project and the importance of conducting similar projects, to create a greater impact on the community.

*Stereotyping.* We also learned that stereotyping is *not* what this project was all about. We did not want to generalize from what we heard from our respondents to all Latinos. Certainly, experiences, access, and treatment will vary depending on many factors, including one’s social and economic status. We intend for this project to guide our further engagement with Latinos, and believe that by sharing our findings and experiences, we may impart to other bioethicists the importance of engaging in this type of activity in other communities.

*The Relevancy to Bioethics.* The challenges in this project confronted us from the outset. The determination of where we should go, who should serve as our entrée and guides, and how we broach the topic without arrogantly imposing our agenda and distorting the data left us perplexed. Certainly the approach that we generally used was inadequate at best and might be invalid if it meant imposing on other cultures whole categories of concerns and questions that have their roots in Anglo and Euro-American cultures and heritage.

We learned firsthand that bioethicists need preliminary exercises before embarking on this kind of fieldwork. Anthropology and some of the other social sciences have learned to approach data collection in the field respectfully. In bioethics, we need to construct a model of inquiry that is devoid of assumptions and presuppositions, that facilitates active (even humble) listening, that draws on the collaborative thinking that we have long claimed to espouse but have only demonstrated in groups of like cultural background.

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## Appendix

### Focus Group Questions

#### Introduction

- Introduce Project Personnel
- Introduce MBC — working on a project to improve the health care people receive when they are seriously ill or dying
- We want to better understand your experiences in the health care system, what needs and concerns you or a loved one have when you are or have been seriously ill or dying. We are looking for insights into how the situation can be improved from the way it is today.
- We're going to ask you some questions. There are no right and wrong answers. We want to hear what your experiences have been and are here to learn from you. If there's something we do not ask about that you think is important to tell us, please do so.

#### Questions

Let's talk about your experiences when you've been seriously ill or when you've taken care of someone who's seriously ill (in hospital, clinic, at home; as a patient, caregiver, or family member).

- Were there things that happened that you didn't like? Or didn't think was the right thing to do? What did you do in those circumstances?

- Were there things that happened that you did like?
- When you've been seriously ill or find yourself in a situation of need, please tell us about who you go to for help (pastor, health care provider, family, friends, etc.)
- Who do you take care of and who takes care of you?
- Who do you want to be near you when you're ill or dying?
- Who makes decisions about your medical treatment? (self, family, doctors)

When you've been seriously ill or loved ones have been seriously ill or dying, where do you prefer to go? (clinic, hospital, home)

- Where would you want to die?
- When does this vary?

Of all the possible treatments, please tell us about what types of treatment you would like to receive when you are seriously ill or dying?

- Have you heard of advance directives?
- What types of treatment would you want or not want to receive?
- How do you feel about life support?
- Do you know about hospice? Is this an option you would like?