Special Section: Meanings and Contexts: Anthropological Perspectives in Bioethics

Ambiguity and Hope: Disclosure Preferences of Less Acculturated Elderly Mexican Americans Concerning Terminal Cancer—A Case Story

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> *Disclosure [f. DISCLOSE v. + -URE, after CLOSURE]*
> *1. The action of disclosing or opening up to view; revelation, discovery, exposure*
> *Oxford English Dictionary*

A major shift has taken place since the 1960s concerning disclosure to patients that they have a diagnosis of cancer and that their disease is considered terminal.[1] Full disclosure is now considered the patient's right in the United States. However, there remain many countries in which nondisclosure is still the norm.[2] When patients from those countries are diagnosed with cancer in America, differences in attitudes and expectations can cause conflict and misunderstanding.

This paper presents an interview with Mr. Eliseo Ramirez, a 72-year-old working-class man who was born and raised in Mexico, has lived and worked in the United States for most of his adult life, and is being treated for cancer in Los Angeles. Our analysis focuses on Mr. Ramirez's indirect approach to disclosure. In our study of ethnicity and attitudes toward end-of-life decision-making, such an indirect approach was characteristic of those elderly Mexican Americans who were primarily monolingual in Spanish.[3]

The interview illustrates specific ways that this older Mexican-American patient, his family, and his care providers strategically manage information to anticipate death, yet maintain hope of survival. Our analysis of his narrative shows that Mr. Ramirez simultaneously presents two contradictory stories, one of survival and one of impending death. The story of survival dominates as Mr. Ramirez claims verbally that he has been cured of his previous cancer. Yet his actions and certain linguistic cues suggest that he is a man actively putting his affairs in order because he expects to die soon.[4]

Early in his interview, Mr. Ramirez was asked if it was true that he had cancer. Although he does not deny this, his response in Excerpt 1 downplays

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his condition by referring to it euphemistically as "a little problem with my right lung." He states explicitly that the tumor in his lung has been "dried"—that is, meaning to him that it was cured. However, it is likely that his treatment has in actuality only been palliative rather than curative. He has had a pleural effusion drained (therefore his tumor is "dry") and a laser procedure that is usually aimed at merely relieving an obstruction, as well as radiation. By his report, his treatment has not included surgery or intensive chemotherapy, which are the types of treatments done when the goal is curative, and from this we infer that his physicians felt that his cancer was too widespread to be cured.

Excerpt 1

> *Interviewer*: Very well . . . now [I would like to ask you something else], you told me over the telephone that you have had cancer, is that true?
>
> *Eliseo Ramirez*: Yes, I had a little problem with my right lung . . . but my doctors . . . although God willing, [saw to it] that they [detect] fast the . . . [the cancer] and it was treated on time, it was dried, and . . . I had other little illnesses, but they saw that my organism was well, my blood was good and . . . they operated on me, they took out all the illness [that I had], and . . . presently I am in perfect condition.

Strategic Ambiguity in Disclosure Practices

Mr. Ramirez is not alone in referencing his condition indirectly. His physician's manner of disclosure, illustrated in Excerpt 2, is in a style that the less acculturated members of the Mexican-American sample described as the one they prefer.[5] In this style, the patient's condition is never disclosed so directly or bluntly that the patient can have no hope. The disclosure leaves room for ambiguity both in what the doctor says and in what the patient hears. Thus, in Excerpt 2, Mr. Ramirez reveals that: (1) the doctor "didn't tell me; he told other people and then I found out"; (2) "They almost told me"; and finally, (3) "The doctor explained to me . . . your cancer. . . ." A process of clarification seems also to be implied (geared perhaps to the physician's assessment of Mr. Ramirez's desire to know his diagnosis and prognosis and his capacity as it changes over time to deal with such information).

Excerpt 2

> *Int*: Tell me, how did the doctor give you your diagnosis?
>
> *ER*: [No response.]
>
> *Int*: How did he tell you? "Look, you have 'this'?" Or did he say "cancer"?
>
> *ER*: Mmm, yes . . . no. No, he didn't tell me; he told other people and then I found out.

> *Int*: Whom did they tell?
>
> *ER*: Well . . . they almost told me . . . that everything had been on time, that they were going to send me to a doctor to get "shots" to spread the cancer [sic], eh? . . . that with medicine they would spread it, then they called the specialist, who was the one with the laser rays . . . then the doctor explained to me "with this medicine we are going to give you, your cancer will spread."

In Excerpt 3, Mr. Ramirez expresses his trust in his primary care physician, which made it unnecessary for him to ask direct questions for further information about his condition. When the oncologist admitted Mr. Ramirez to the hospital immediately, Mr. Ramirez interpreted this as a sign of the efficacy of his primary physician's referral rather than of his own urgent medical condition. Mr. Ramirez's response is similar to several other "less acculturated" Mexican-American interviewees who mentioned a preference for doctors who gain the patient's trust over time by being friendly, inviting a relationship of mutual joking, touching, and embracing the patient, and taking an interest in the patient's family. In this way, a doctor demonstrates that he cares about the patient and, in turn, the patient feels that he can put his faith in the doctor's judgment.

Note that although three specialists explained his condition to him, Mr. Ramirez ambiguously describes his disease as "a tumor in the lung with cancer" ("*tumor con cancer*"). Also note his confusing description of treatment to "spread" the tumor. In our view, the ambiguity in such representations of his condition should not be construed as psychological "denial" on the part of the patient, a defense that necessarily must be broken down and eliminated in order for properly informed treatment to take place.[6] More accurately, it may been seen as constituting a cultural style that enables Mr. Ramirez to sustain hope in the face of a life-threatening illness.

Excerpt 3

> *Int*: Who was the first person to tell you that you had cancer and that they were going to spread it?
>
> *ER*: A doctor who has a clinic here [in East Los Angeles], he is a friend of mine, he knows me already and treats me super good, that was the doctor that noticed that there was something wrong and he too . . . he sent me to get an X ray.
>
> *Int*: So he was the first one to tell you.
>
> *ER*: He was the one who said that I had something wrong with my lung, then he himself referred me to a specialist, and I went [to see] the specialist with the letter of referral. He saw it and said, "Go to the hospital immediately," because I had been recommended by Dr. Ortega [ER's primary care physician], that is why it went so fast. Then the doctor [the lung specialist] grabbed him [an oncologist] and got him to spread it [sic] [because] he was also a specialist. Then, between the lung specialist and the one that was going to spread [sic] the cancer,

> they looked for another specialist who was the one who used the laser ray. Then, the three of them explained it to me.
>
> *Int*: And how did they explain it to you?
>
> *ER*: That I had . . . that tumor . . . in the lung, with cancer. And that they were going to spread "that" with medicine.
>
> *Int*: And they assured you that you could be cured?
>
> *ER*: Yes. And then the doctors said that in order for it not to be dangerous, that the cancer would not spread [Note the conventional use here of the concept of cancer spreading] to my kidneys or my liver, they would burn it with a laser ray. That is why they put the probe up my nose, to burn me, they took me three times and they burned it.

* * *

> *Int*: And did you ask him anything else?
>
> *ER*: Regarding what they were telling me that they were going to do, I did not have to ask them any questions, because I saw that it was helping me.
>
> *Int*: Good. Did you like that the doctor here, Dr. Ortega, told you "Look you have cancer?" Or would you have preferred for him not to tell you directly?
>
> *ER*: Oh! Yes! Of course! That doctor knows me and I have . . . he is very fond of me. Imagine that even I am surprised that sometimes when I have a cold or a cough, and I go to him, and my greeting is a hug!

Excerpt 4 further illustrates the ambivalence about disclosure that is characteristic of those members of the Mexican-American sample, like Mr. Ramirez, who were relatively less acculturated. On the one hand, Mr. Ramirez insists that he would rather be told the truth about his diagnosis and that his doctors know he can handle it. However, he supports this preference with a description of how his doctors told him that he needed surgery for a hernia, a condition that is not life threatening and that can be repaired. When it comes to disclosing a diagnosis of terminal cancer, Mr. Ramirez feels that it is wrong to tell patients that they cannot be cured because they might give up hope and die. Further, his account of his specialist's disclosure that Mr. Ramirez had a hernia shows the physician's careful phrasing to avoid alarming Mr. Ramirez while directing him to get immediate treatment (" . . . tomorrow or the day after, when I am older, things could get complicated"). This phrase is repeated later in the interview, when Mr. Ramirez discusses provisions he is making for his youngest son in a way that will not alarm him.

Excerpt 4

> *Int*: Do you know why I asked you? Because some people don't want to be told directly, they are afraid or something like that and so they prefer not to.

> *ER*: Oh no, no! Not me. I rather be told and be given whatever I need. . . .
>
> *Int*: Don't you think that if the doctor were to tell his patient, "Look, you have cancer," the patient would get worse?
>
> *ER*: I . . . I believe them [the doctors] whatever they tell me. If they tell me that I have something [an illness] and that needs . . . [treatment], I tell them, "Do it."
>
> *Int*: So you rather the patient be told.
>
> ER: Mmm, yes . . . [not too convinced]. I . . . when the hernia, that [the doctor] explained to me, that my blood was good, and all that . . . that it was time to have surgery . . . that . . . because it could be that tomorrow or the day after, when I am older, things could get complicated. Then I told him, "Do you think it's time?" He said, "Yes." [I answered,] "Go ahead, cut my stomach." [Laughs.]

When the interviewer tries to clarify whether he would indeed prefer direct disclosure of a cancer diagnosis, Mr. Ramirez returns in Excerpt 5 to the importance of mutual trust between patient and physician. In fact, he suggests that it is important not only for the patient to trust the doctor but also for the doctor to "trust" the patient's ability to be told. Given a hypothetical case in which it is his wife rather than himself who is diagnosed with terminal cancer, Mr. Ramirez euphemizes the diagnosis in his response, referring to the cancer as "this thing." He states plainly there is no point to telling his wife that she has cancer if it is incurable, nor would he tell anyone else, only pray to God.

Excerpt 5

> *Int*: And wouldn't it have been better . . . I ask myself . . . that Dr. Ortega, instead of telling you directly about the cancer would have told a relative? And if your relative in turn told you?
>
> *ER*: The thing is that Dr. Ortega trusts me and knows me, eh? For many years, for any little thing that I have, I go to see him. He knows me perfectly! . . . He clearly knows that I like him to tell me the truth, so that [the illness] can be corrected. I don't like to be wondering. If the doctor tells me, "You have this," [I say,] "Then let's go."
>
> *Int*: Imagine that you are not alone, that you were not divorced and that your wife had cancer. Would you like the doctor to tell her?
>
> *ER*: That I would leave to her conscience.
>
> *Int*: But let's imagine, put yourself in the place.
>
> *ER*: If she asked my opinion, in my opinion I would tell her, "Look, if you have 'this,' please let them remove it."

> *Int*: Now, let's put ourselves in the doctor's place. In your case he told you because he trusts you. But if the doctor doesn't trust other patients, in those cases, would he have to tell them?
>
> *ER*: The patients? . . . Well, then . . . In that case, if he didn't want to tell her, I would speak with the doctor and would tell him, "Do you think that surgery would do her any good or is it too late?"
>
> *Int*: But then, in that case, let's put ourselves in your wife's place. You would rather have the doctor tell you and, then, you tell her? Or . . . ?
>
> *ER*: I would find out first . . . with the doctor . . . if she would get better with surgery. I would tell her, "They are going to operate on you because of, this, 'this thing.' " But if the doctor tells me that it is too late, that she is gravely ill, I would shut my mouth and not say a thing.
>
> *Int*: Mmm?
>
> *ER*: Because there is no cure. Then, I would not tell her or anybody, only pray to God, and that is it.

In Excerpt 6, Mr. Ramirez is asked hypothetically about his own preference regarding disclosure if he were terminally ill. Note that the interviewer, an anthropologist who is not a physician, did not realize that this was probably Mr. Ramirez's actual condition at the time of the interview. Thus, in retrospect, Mr. Ramirez's response is extremely interesting: He euphemizes his cancer ("when I had 'this' ") and places it in the past. He reveals that he has instructed his family (i.e., his adult children) to make necessary treatment decisions for him. And he reveals with unusual clarity what has earlier been implied: that he expects his primary care physician *not* to tell him if his cancer were incurable.

Excerpt 6

> *Int*: Now, God forbid, but if your case would have been like that—serious, with no cure, would you rather have been told anyway?
>
> *ER*: I . . . well . . . Mmm, right away . . . when I had "this" [cancer], I told my children right away, always knowing that we all agreed. I told them, "It's up to you what you do. Whatever you do will be OK. If something happens to me, whatever your decision is, will be my decision, too."
>
> *Int*: Uh-huh! But let's suppose that. . . . In your case, you were lucky that it was curable, but let's imagine that it wasn't. You still would rather have been told?
>
> *ER*: [No response]
>
> *Int*: Or, would you rather have Dr. Ortega, in that case, not tell you?
>
> *ER*: He wouldn't have told me.

In Excerpt 7, the interviewer tries to engage Mr. Ramirez in a discussion of living wills. In response, Mr. Ramirez focuses on his will in the conventional sense of disposing of his property and his burial arrangements. Further, his comments show him actively preparing for his death, even though he has claimed to be cured of cancer.

Typical of the "less acculturated" portion of our Mexican-American sample, Mr. Ramirez expresses his reliance on family decisionmaking: He has given his older son the primary responsibility for decisions related to his dying. As in the account of his hernia operation earlier in the interview, Mr. Ramirez's use of language suggests an immediate and urgent condition ("If tomorrow or the day after . . . when I . . . pass away . . . when I die . . ."). Although the sense of the urgency is undercut by his conditional phrasing, so that his family can maintain a hopeful prospect, Mr. Ramirez reveals that he and his eldest son have recently visited the family cemetery plot and are planning a trip to the mortuary.

Excerpt 7

Int: And tell me, have you made a decision yet regarding this life-sustaining treatment? Have you written . . .

ER: A will . . .

Int: No, not a will. But anticipated decisions in reference to medical treatments, to prolong . . .

ER: No.

Int: But you just told me that you told your children . . .

ER: My children . . .

Int: For them to decide. In other words, that you leave all decision making up to them.

ER: I have four boys. But [of] all of them, I have one that I trust the most and that . . . yes. I have explained to him beforehand. . . . We went to the cemetery. We have a plot.

Int: Yes?

ER: Mmm. He'll be here later. We have agreed that we are going to a mortuary to arrange everything. He has understood everything. [He knows my wishes.] He is one of my sons. I don't do [it] with the one I have here, because he is still a minor.

Int: Of course. He is young.

ER: But with the other one, yes.

Int: So you have made all your decisions. You have explained them to that son.

> *ER*: Yes. He knows where the plot is. We have to go to a mortuary to pick a box so that everything will be ready. Because I tell him, "If tomorrow or the day after . . . when I . . . pass away . . . when I die, I don't want you to suffer looking for money for this. . . . And I want to leave everything paid for, ready, so that the only thing they have to do is take me, bury me, and that is it. . . . So they don't have any problems. [That is why] I have arranged everything.

Urgency about his impending death is also suggested by Mr. Ramirez's emphasis that his youngest son, Jaime, a minor, is *presently* not ready to take care of himself. Hence Mr. Ramirez's other, adult children have been made to understand that his assets will go entirely to Jaime, for whom arrangements have also been made so that he can continue living in the house that Mr. Ramirez has been renting for 34 years. Evidently a conversation about these arrangements took place with Jaime present because Mr. Ramirez reports, with laughter, that the eldest brother replied, "You see, your father wants you to stay here, everything is going to be left for you here. Everything will be arranged so that you can bring your girlfriend with you!" As in his relationship with his physician, Mr. Ramirez appears to display a preference for indirect disclosure with his family. The father's statement to his sons that he is going to die is made ambiguous and an effort is made by all to keep things hopeful by joking and looking at the bright side.

Mr. Ramirez's distaste for disclosure about a terminal prognosis was expressed, once and for all, at the end of the interview. Excerpt 8 gives his response to a hypothetical case.

Excerpt 8

> *Int*: The doctor realizes that you have cancer that has spread to certain areas of your body. Would you like the doctor to tell you?
>
> *ER*: No.
>
> *Int*: Mmm?
>
> *ER*: Because it would torment me.
>
> *Int*: Mmm?
>
> *ER*: Let them inform my relatives: "Your father has an incurable cancer. Take him home. Take care of him because he has X number of days left." But . . . I wouldn't want them to tell me! What for? There would be no reason to tell me.

Conclusion

Maintaining hope is the key bioethical principle articulated by Mr. Ramirez and those other elderly Mexican Americans in our study who adhered to a "family-centered model" versus an "autonomy model" of medical decisionmaking. This portion of the sample feels that it is the responsibility of the doctors and family to protect the patient from the worst news and to keep the patient's spirits up.

Patients in such cases, like Mr. Ramirez, may be aware of their condition. Yet, unambiguous verbal communication about a life-threatening diagnosis and especially a terminal prognosis appears to be culturally inappropriate. For these patients, what seems most important is to carefully balance disclosure with practices that maintain trust, caring, fellowship, and, above all, hope.

Notes

1. Compare Oken D. What to tell cancer patients: a study of medical attitudes. *JAMA* 1961;175:1120–8 and Novak DR, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physician attitudes toward telling the cancer patient. *JAMA* 1979;241:897–900. See discussion in Good MD, Hunt L, Munakata T, Kobayashi Y. A comparative analysis of the culture of biomedicine: disclosure and consequences for treatment in the practice of oncology. In: Conrad P, Gallagher E, eds. *Health and Health Care in Developing Countries*. Philadelphia: Temple University Press, 1993:180–210.
2. The rapidly growing cross-cultural literature on this topic is too extensive to note here. For an excellent discussion of the relationship of concealment to hope in a contemporary European context, see Gordon DR, Paci E. Disclosure practices and cultural narratives: understanding concealment and silence around cancer in Tuscany, Italy. *Social Science and Medicine* 1997;44(10):1433–52. In the United States, see Good MD, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Culture, Medicine, and Psychiatry* 1990;14:59–79.
3. The case we present comes from a two-year, multidisciplinary study of attitudes toward end-of-life care among 800 elderly individuals in four ethnic groups: European American (EA), African American (AA), Korean American (KA), Mexican American (MA). In Year One, a face-to-face survey in their language of choice focused on issues such as truth-telling, advance directives, and withholding and withdrawing life support. See Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *JAMA* 1995;274(10):820–5; Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. *Social Science and Medicine* 1999; 48:1779–89; Murphy ST, Palmer JM, Azen S, Frank G, Michel V, Blackhall LJ. Ethnicity and advance care directives. *Journal of Law, Medicine, and Ethics* 1996;24:108–17.

   In Year Two, open-ended interviews were conducted with 10% of each sample by anthropologists with expertise in each of the four ethnic groups in the research participant's language of choice. See Frank G, Blackhall LJ, Michel V, Murphy ST, Azen SP, Park K. A discourse of relationships in bioethics: patient autonomy and end-of-life decision making among elderly Korean Americans. *Medical Anthropology Quarterly* 1998;12(4):403–23; Blackhall et al., forthcoming.

   AAs and EAs in our study tended to favor disclosing the truth to patients about their diagnosis and prognosis of terminal cancer. KAs and MAs were less likely to agree with full disclosure. They also preferred family members to make decisions for the patient. These differences were attributable to ethnicity, or culture, after controlling for education, income, functional status, and other demographic factors. We broadly characterized the data using two models of disclosure and decisionmaking: an autonomy model (AA and EA) and a family-centered model (KA and MA).

   Results for MAs were more complex, however, than for the other samples: Although 65% of MAs favored disclosing a diagnosis of metastatic cancer to the patient, only 48% said they would tell patients they are dying (versus EAs 87% and 69%, respectively). MAs tended to prefer the decision to use life support to be made by the family (45%), rather than the patient (41%) or the doctor (14%). (EA preferences were: patient 65%, family 0%, doctor 35%.) [Note: MAs statistically different from EAs at the 0.001 level.]
4. It could be said that Mr. Ramirez is "emplotting" two narratives simultaneously. See Mattingly C. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. New York: Cambridge University Press, 1998.
5. Mexican Americans (MAs) in our study were almost evenly split between an autonomy model and a family-decisionmaking model. Further, the following pattern was found: The family decisionmaking model, including nondisclosure, was more common among those MAs who were monolingual or relied mainly on the use of Spanish (i.e., were less fully integrated in mainstream American culture) as measured by the Marin Acculturation Scale (see Marin G,

Sabogal F, Marin BV, Otero-Sabogal R, Perez-Stable E. Development of a short acculturation scale for Hispanics. *Hispanic Journal of Behavioral Science* 1987;9:183–205). The autonomy model, including disclosure, was more common among those MAs who used the English language and media more frequently. Mr. Ramirez's case is typical only of the "less acculturated" MAs.

6. Although insightful regarding mainstream Western Europeans and Americans, the classic approaches to denial as a psychological defense almost never question their own cultural presuppositions. An exception is psychologist Robert White's comments written 25 years ago:

> In the psychological and psychiatric literature there lies a concealed assumption . . . that any delay, avoidance, retreat or cognitive distortion of reality is in the end a reprehensible piece of cowardice. We must march forward, ever forward, facing our problems, overcoming all obstacles, masters of our fate. . . . In actuality, of course, there are many situations that can be met only by compromise or even resignation . . . adaptation often calls for delay, strategic retreat, regrouping of forces, abandoning of tenable positions. . . . Recovery from a personal loss or disaster requires a long period of internal readjustment that may not be well served at the start by forceful action or total clarity of perception.

Quoted on p. 613 in Cohen F, Lazarus, RS. Coping and adaptation in health and illness. In: Mechanic D, ed. *Handbook of Health, Health Care, and the Health Professions*. New York: The Free Press, 1983:608–35.