27. Patricia A.Marshall and J.Paul O'Keefe, Medical Students, First-Person Narratives of A Patient's Story of AIDS, Soc. Sci. Med. Vol. 40 No. 1, 67-76, 1995.

In this paper, we present the results of using a narrative technique in a seminar on AIDS for fourth year U.S.Medical students. The seminar was conducted in October of 1989. It was attended by 13 students in partial fulfillment of their medical humanities requirements. The seminar met for 2 hr on a weekly basis, for a period of four weeks.

The purpose of this course was to increase the students' knowledge about HIV-infection and to provide them with the opportunity to discuss issues such as fear of AIDS, the stigmatization of AIDS patients, and the physicians' duty to treat. At the second session, a patient with AIDS was invited to talk with the class about his infection and subsequent illness. Students were asked to write a short narrative, not more than five pages long, based on the patient's description of his experience and their group interview. They were requested to write the narrative in the first person, as if they were actually the patient talking. During the last session, students read and discussed their first person narratives of the patient interview.

The Narrative Approach in Medicine

Several important goals are achieved using the first-person narrative technique in medical training. First, a context is created for close identification with the personal character and concerns of the patient. The signifiers of 'him/her' change to 'I/me', and the emotional distance between the patient and the student is reduced. Second, as Charon notes, the 'writer' of the patient's story has a stronger investment in the patient's future and the outcome of medical care. Finally, the use of the first-person narrative technique challenges students to ask questions and raise issues that might not have been addressed.

The Patients' story

After being introduced to the students seated around the large table in the conference room where the course was held, Joe was invited to 'share his story.' Joe began his narrative at the biographical moment of learning he had tested positve for HIV:

> I was first diagnosed in September of 1987 with the HIV infection. I was living in Las Vegas at the time. The reason I got tested is because I was dating a young lady and she was really serious about marriage and every time we would walk by a chapel in Las Vegas, of which there is a lot of, she was tugging at my arm..... I knew that I was at risk... prior to .... 1982 because at that time I became a Born Again Christian and I left that homosexual life style.

After learning the test results, Joe was unable to discuss his concerns about HIV/AIDS with anyone, "....there was a period of about five months that I had no one to talk to about it." Wanting verification the students asked, "Wasn't there anybody you talked to?"

"Nobody, nobody," he said, "I talked to my cat and, you know, you don't get too much response." At the health department where he was tested, individuals received counselling that was limited to information on safe sex practices. "I was going bonkers....," Joe said. He felt as if he, "...had been given a death sentence which for me not knowing that much about AIDS, when they said I was HIV positive, you know, I thought I was going to die in a year or two. I really didn't know."

At the end of several months of emotional and social isolation, Joe became involved as a volunteer coordinator with a support group for persons with AIDS of Nevada. He said that the AIDS clinic then became his "primary focus." Eventually, Joe began having cramps in his legs and was told by his physician that he needed to cut back on his hours at work. When asked by his supervisor why it was necessary to work fewer hours, Joe told him he had cancer, "It is easier to say I got cancer, than it is to say I have AIDS." Later, Joe experienced guilt, "about telling him a lie," and he went back to his supervisor to explain that he had AIDS. Joe had not expected his employers to be responsive to him, but he said that they were supportive and allowed him to change his work schedule.

Joe experienced difficulties with his girlfriend after he tested positive for HIV and they ended their relationship without her knowing. He left Nevada in 1988 and moved to Oklahoma, to attend Bible School for approximately a year. When he began to have recurring headaches that prevented him from attending school and work, he moved to Chicago.

At this point in the narrative, Joe described his hospitalization and his subsequent need to share his diagnosis of AIDS with his church community:

> So, on December 26th I had one of those attacks, or whatever it was with my head.....I didn't want to deal with those headaches anymore, I was just fit to be tied...they diagnosed me as having toxoplasmosis...when I got out of the hospital I was on treatment....taking medications and everything and the Lord was dealing with me to be open with my Church, because I needed their prayers. At that time, I was very very sick and I needed their prayers. So in front of the church from the pulpit....I shared with them my diagnosis of AIDS...and asked for their prayers and that the elders lay hands on me and anoint me with oil and I believe God did heal me.

This event marked a turning point in Joe's experience of himself as being someone with AIDS-simultaneously 'sick' and 'healed'. Members of Joe's church invited him to come to a prayer group:

> I went to their home and as I walked into their basement I felt the presence of the Lord there... He touched me at that time because up to that point I had absolutely no appetite whatsoever. I was losing weight, I would eat three or four bites of food... and I just couldn't take

> any more food. So when they prayed for me, instantly, within that hour I went upstairs and I've been eating like crazy ever since and to me that was a sign from the Lord that He had touched me.

Joe's belief that he had been healed prompted him to request another test for HIV. When the Western blot came back positive, Joe said he was unconcerned, "...I believe that God's healing hand is upon me and that He is using Dr O'Keefe and the people here.... to heal me, to touch me and if nothing else. His sustaining hand is upon me because I feel great and the symptoms are gone..." When a student asked, "What will happen if you get sick again?," Joe said, ' I'll start all over again...you know, I don't live by sights. I dont't live by the fact that test says I'm positive. I live by the fact that God says that He is a healer... that I could be healed and that's what I believe and that's where my faith lies...I pray that a cure comes quickly."

Joe's story is about transformation and transcendence. The future is an imagined world of potential change and the temporal horizon extends into infinity, as Joe reminds his audience, "I believae that I'm going to spend eternity in heaven... when I am totally set free from this disease." Joe died in 1990.

The Student Narratives

In our analysis of the student's first-person narratives, we use a conceptual framework that builds on the interactive model of narrative critique. We are interested in exploring what we call relational convergence/relational dissonance and affective convergence/affective dissonance. In relational convergence, the interactional world portrayed by the patient is literally or symbolically replicated in the students' reconfiguration of the narrative. The term relational dissonance is used to refer to divergent constructions of the social world described by the patient and the students. Affective convergence to denote the likeness between patient and studeants' constructions of emotions and feelings in the narratives on AIDS. Affective dissonance is analogous to relational dissonance in that it suggests a fundamental reconfiguration of the sentiments-and beliefs about their source and intentionality-expressed by the patient in the student narratives.

Relational convergence and dissonance

Isolation. Relational convergence is illustrated by the students in their narrative constructions of personal and social alienation. When Joe learned that he tested positive for HIV, he said, "I really didn't feel I could talk to anyone about it because it was not like cancer, you can talk about cancer, but AIDS is a venereal disease....and it's difficult to talk to people when you first find out and everything." Mimicking Joe's account, the students represent his social world as diminished and confined. They describe his interactional life in terms of what is missing-his lack of communication with others, the absence of social connectedness. One student suggests that, "Ties were served." Another student said, "I really need to talk to someone...I need to share my despair."

Joe did not mention the individuals in his family who might be unsupportive. In fact, in his narrative, Joe commented on the overall acceptance he experienced from others, "I haven't had anybody reject me because of this disease and I give God the glory for that because I have seen people with this disease, their family departs from them, they can lose their jobs. It can be really devastating, and I haven't had anything like that. Nobody has rejected me." The indeterminate and somewhat ambiguous nature of Joe's representation of acceptance and rejection allows for several multiple interpretations. One student, projecting the imagined response of a homophobic father, constructs a scenario in which the potent force of rejection is underscored by a recognition of love-but not acceptance, "My father rose, his face red. What the hell are you saying? Are you saying you're a faggot?" His fists crashed down on the table. Damn it! He sank into his chair as if defeated, his head in his hands. He looked up at me slowly; I know then how much he loved me."

Contamination

At the heart of contamination is the fear of touching someone or something that is perceived as unclean. This, of course, has significant implications for social relationships in every sphere of life. In his narrative, Joe described his apprehensions about being someone with a stigmatized infectious disease, someone capable of 'contaminating' others, "I read in an article about an individual trying to get dental work done but because he was HIV-positive, dentist after dentist after dentist refused to treat him and you know, that scared me....reading those articles you put yourself in that position. You think about, like going swimming in a public pool, like what would they do, scour the pool if they found out? Thoughts like that go through your head."

Perhaps the most powerful allusion to the social consequences of being some one 'infected' is a student's representation of Joe's fear that others will reject him because of his power to defile their world, 'Though they have accepted my past I do not know if they will now reject me. Will I be allowed in their homes or are they going to be afraid to be near me? Afraid I will contaminate their world?"

In telling his story, Joe expressed concern about transmitting HIV-infection to others. Regarding physical contact with his niece and nephew, Joe said, "When my niece would come to greet me she'd always kiss me. So I would turn my cheek so she would have to kiss me on the cheek.

Joe's presentation of his cautious behaviour regarding personal contact was matter-of-fact and unemotional. In the subjective mode of the 'reader', however, a student recreates the scene, attributing Joe with a longing for physical closeness, and an awareness of the social consequences, "I couldn't bear it anymore. Today I (phoned by sister- in-law). I spoke to the children...I can't wait to hold them, to kiss them. No, No, I cannot kiss them. What if I transmit the virus to them!...once again a chill went through my spine. What if she stops me from seeing her kids. What if she never lets me play with them or hold them?"

Affective Convergence and disonance

Shame Shame is forcefully represented in the students' portrayal of Joe's affective response to AIDS. Illustrating the way in which shame is embedded in the framework of social relationships, one student describes Joe's desire to talk with his girlfriend about testing positive for HIV, "The shame of my previous life was too great, and although I felt I would eventually lose her...I also knew that to tell her now risked instant detachment." The power of shame is imagined to be so great that to say anything at all would bring an immediate, an 'instant' end to his relationship. Other students' narrative constructions suggest that the force of Joe's shame is so compelling that Joe knows in his heart people can see by looking at him that he has AIDS.

In his narrative, Joe does not use the word 'shame', nor does he mention ever experiencing shame. Moreover, he does not describe specific incidents in which shame is insinuated. In this regard, the students' narrative constructions of shame indicate affective dissonance-a fundamental reworking of the affective content in the original story.

The students imagine that Joe has internalized a social morality that rejects homosexuality and defines it as a sin. Joe has told us this himself. However, in direct opposition to what Joe said, the students credit him with a belief that AIDS is a punishment.

The essence of fear is an awareness of a threat combined with uncertainty about its occurrence and one's ability to cope with it.

After hearing the results of his HIV test, two students imagine Joe's fear, as 'numbing,' 'paralyzing' and 'suffocating.' Joe is depicted as simultaneously backed into a corner and 'slumped' to the floor.

How did Joe actually describe his experience of learning the results of his HIV test? His narrative suggests a very different version of the story. When asked, "What was it like to hear it (the test results) over the phone?," Joe replied, "I think that a personal one-on-one is probably better....I don't think it affected me, how I took the news, because you know, at that point...I had been building up to this especially after I was tested...so in that two weeks I was in a personal (state) of like building myself up in case it was positive.

Over and over again, the students envision Joe's fear of death, and more specifically, his fear of being left alone to die a painful death, a death without love.

Joe's actual references to death were quite limited.

Using the first-person narrative approach in the seminar on AIDS proved to be an effective method of sensitizing students to the personal experience of living with HIV infection. Course evaluations were extremely positive, particularly in relation to this assignment. The challenge for medical educators lies in creating and reinforcing opportunities for students to develop increased awareness of and empathy toward individuals with AIDS. Learning experiences that transform fear into compassion will be crucial in alleviating student anxiety about working with patients infected with the AIDS virus. It is only through the amelioration of fear surrounding HIV infection that students in training will be amenable to pursuing medical careers that bring them into contact with AIDS patients.