

AMY ROSS: BODY STORY OR PERSON STORY?

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Physicians' failure to communicate effectively with patients can cause depression, anxiety, and poor adjustment to illness. In this narrative the author shares the story of one woman's communication with physicians while undergoing medical procedures that led to a diagnosis of cancer. Her experience reveals a cold and uncaring medical community, and the impact on her sense of self and quality of life is discussed.

My field of research and practice is gerontology. I conducted interviews for a research project on communication between elders and their physicians in 2001-2002. My interest in the topic came in part from experiences accompanying my mother to various physician appointments; her communication experience with doctors varied and I wondered if that was typical. I found that there were few research studies about physician-patient communication that focused on elders and even fewer that looked at the experience from the older person's perspective.

What we do know from the literature is that when we perceive the person with whom we are communicating to be old, we attribute them with more frailty and vulnerability than if we perceive them to be young (Hummert, Garstka, Shaner, & Strahm, 1995), and that we have a general belief that older adults have more communication difficulties than younger persons do (Giles, Coupland, Coupland, Williams, & Nussbaum, 1992; Hummert et al, 1995). These negative assumptions about the elderly cause us to over-accommodate and communicate in a patronizing manner. Although older patients tend to ask more questions than younger patients do, physicians tend to be less responsive when older patients raise issues. Physician responses to younger patients are considered significantly better than with older patients (65+) in that they are more engaged, respectful, and egalitarian (Greene, Adelman, Charon, & Hoffman, 1986). Additionally, research indicates that physicians

do not feel comfortable treating older patients or addressing the chronic problems they present (Béland & Maheux, 1990), and that among medical students, geriatrics ranks lowest compared to other subspecialties (Carmel, Cwikel, & Galinsky, 1992).

From my mother's experiences and the literature I read, I had some suppositions about what I would learn but was not prepared for what I heard from Amy (a self-chosen pseudonym). Amy's story is just that; it is her story, based on her perception and interpretation of events, but that does not mitigate the importance of telling it. As this study was a phenomenological inquiry, I did not have a large sample, interviewing eleven individuals age 70 and older. I was not concerned with being able to generalize the findings; rather, I wanted to understand each participant's experience and the meaning it had for them. Nonetheless, in interpreting the data several themes emerged: issues related to self-disclosure in the medial encounter; depersonalization or being treated as an object or "thing" called "thinging" in health care (Howard, 1975); wanting but not having a sense of control in the relationship with physicians; and wanting but not receiving empathy. Amy's story illustrates each of these themes and best exemplifies the participants' voices in the research I have done. It captures the essence of their experiences communicating with physicians—the need and the desire to have some control over their health, over treatment decisions, and over the care they receive; the

need to be heard; and the need to be treated as a person. While this does not reflect the experience of every patient with every physician, that was not the intent of my research.

I met with Amy over the course of nine months. She was very generous with her time, allowing me into her home on three occasions and answering follow-up questions by telephone. Amy wanted physicians to hear her story in the hopes that patient care would improve. I promised Amy that I would do my best to make her story known. Her story is compelling, and I want the reader to have a sense of who Amy was and what she experienced. I don't want to tell her story in a way that is maudlin; Amy was a very direct person, not given to feelings of self-pity. Having learned of her death, I have become convinced that I need to put it down on paper. Changes are needed in our health care system, both in accessibility to and delivery of services. I believe that Amy's story will add to the discourse.

Amy and I met in her living room, a rather large room that was dark despite a generously sized picture window; Amy's illness, along with poor lighting and loosely drawn curtains, contributed to the atmosphere. The artifacts of Amy's life since her diagnosis cluttered the room: an oxygen tank and one extra, so she wouldn't be without; a cot in one corner in case someone needed to stay over; a recliner, as she could no longer sleep lying down. Her diningroom table had been taken over by the numerous bills, statements, and "explanation of benefit" letters she had been receiving related to her medical care. Amy expressed frustration with the volume of mail and was looking for help in sorting it out. She had argued with the suppliers of oxygen about the bill and insurance, trying to explain that she no longer had the energy to figure it all out. If they wanted their bill paid, they would have to call Medicare themselves; after all, she was dying. Amy's back was to the little light that filtered in through the living room

window, and her face was in shadow. Although she spoke of having feelings of "rage" towards her physicians and the medical community, her affect was flat.

In addition to sharing her personal story, Amy spoke of other women she had come to know who also had a diagnosis of cancer and their experiences with physicians, and she relayed an experience an older relative had with her physician before she died. Amy spoke about the lack of concern expressed by these physicians; when her friends had chemotherapy treatments, they were called in turn by number, "number 5 is next," rather than by name. She talked about a play she watched on television, *Wit*, a story about a woman with ovarian cancer who had been a college professor. In the movie she is being treated by an intern who was once her student, who is so indifferent that he engages in a one-sided conversation with her, not realizing that she has died. Amy had been reading short stories (she told me that she did not have time to read a novel) about people who have had cancer. She needed to be able to identify with someone else's experience and didn't think that was morbid.

Amy was a retired registered nurse who, for most of her career, worked in a hospital, interacting with physicians on a regular basis. The physician she was seeing when I met her was someone she had worked with for many years and she knew him to be a kind and considerate man. When she began seeing him as a patient she had retired from nursing. Amy was 75 years old when I met her and lived alone, having never married. Her only relatives were a brother and a niece.

In the winter of 2000, Amy was diagnosed with pneumonia. "It was sort of [a] complicated pneumonia, and when I got over it they wanted to do some chest x-rays to see if the pneumonia had cleared." Amy went to the hospital and had the x-ray; shortly after she was asked if she would be willing to have a bronchoscopy. When she asked why, she

was told it was a “funny kind of pneumonia.” Later she was asked if she would be willing to have a biopsy and was told “we think you might have TB and we want to take some snips.” In the end it was clear that it was not an “odd pneumonia” or tuberculosis. Amy had lung cancer. But she didn’t know that yet. She saw a pulmonologist who did more tests and then asked to see her.

The very first day after he did the lung scan, he wanted me to come in so he could tell me the results. My friend came with me; we were both standing there. He calls us both over (to look at the chest x-ray) and he says, just like this, “This is what I’m concerned about, this cancer right here.” We both nearly fell to the floor. The word “cancer” is synonymous with death. Even the worst heart condition, it’s still not the same as telling you, “You have cancer.” When he said that, I just looked at him. I [said], “What?” “That’s what I’m concerned about, see, right here, right here it is. This cancer right here.”

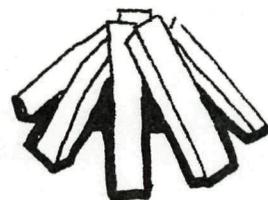
Through further testing Amy learned that the cancer had metastasized to the other lung. She was seen by an oncologist and a pulmonologist who both indicated that considering her overall poor health and her age she was not a good candidate for treatment. She was told that chemotherapy would prolong her life for only a few months and that during that time her quality of life would be “horrible.”

Amy decided not to seek treatment and was advised to return to her primary physician, but it was not a positive “reunion.”

Having known her physician for many years, Amy felt that their relationship had been on a more personal level. She believed that he cared about her as a person. Over the course of several weeks while Amy was having numerous tests, she had expected that her primary physician would call her, especially once he learned of her diagnosis. But he never did. Having been told that there was nothing

to be done, she needed to know if her physician was going to “stick with me through this.” She decided to confront him with her feelings about his not calling.

My primary physician is somebody I’ve known for many years, I knew him when I worked at the hospital, and I felt that I knew him, I mean that we had more of a relationship than just, I mean we weren’t buddies, but more of a relationship than just doctor and patient. I mean we really knew each other well when I worked with him at the hospital. But in that six or seven weeks that I was having all those tests I really did expect him to call me to say, “Gee, Amy, I’m really sorry to hear your diagnosis.” Or, “What’s going on?” So, when they told me to go back to my primary physician, I knew I’d go back to him. But before I did I was thinking very seriously about confronting him about just how I felt. Because he was going to be my doctor, I had to find out if he was going to stick with me through this. And so, I decided to confront him with it. And when I did see him, I [said], “I’m really surprised that you didn’t call and inquire, that you weren’t even interested when you knew I had this diagnosis or was going to have it. And I thought I would hear from you before they ran out of options and had to come back to you.” And he said, “Well, what was I going to call you about?” I [said], “Well, just as more than as a doctor, friend, we have had that relationship.” He really didn’t get it; he kept making excuses. I said, “Well, now I have to find out if you’re the only one left.” The pulmonary doctor said there’s no point in coming back, unless I really needed him for a pulmonary problem. The oncologist said there’s no point in coming back. When I was there, he comes right out and says, “I’ll give you October of 2000.” He says, “You have six months to a year.” Just like that. Then I nearly fainted, fell on the floor.



I happened to be alone that day. I have a friend who usually comes with me to these things but she couldn't come. And I didn't think anything like that was going to happen. I said, "Six months to a year?" Well, I don't have to tell you I was in total shock. I mean, the other guys had told me it was no good, and it was aggressive cancer. But they didn't come right out and give me a time.

The response of Amy's physician was one of indifference: "Well, what was I going to call about?" Amy had issued a "call that asks 'Where art thou?'" which "needs to be addressed in a positive manner: 'Here I am!'" Amy's physician had failed the "call of conscience" (Hyde, 2001).

When I asked Amy if, once she had gone back to her physician, she had ever talked to him about her illness and her concerns, or if her physician ever asked how she was doing, she indicated that she did not talk to him. I wondered if she had anyone else she could talk to, someone who might be able to offer some kind of assistance, some support. She told me that she talked to the social worker employed by the housing program where she lived.

Now, I'll tell you the truth. If it weren't for her, I'd be crazy. Because she is a very kind, understanding person. And she is very helpful and I called her when I first found out about it. And she came up and she was very helpful and she gave me all kinds of places I could call, and she said she'd be willing to come up and talk to me. I don't have any family here, no one really to turn to. I cannot tell you how kind and understanding she's been. So when I had that interview, when he told me all that stuff, when I came home, I just knocked on her door and went in and saw her. And all I can say is what a social worker she is. And she has been since. And I truly appreciate that. So when you say,

"Did he talk to you?" I talked to her. I don't talk to him about how I really feel.

Amy indicated that she had resigned herself to the cancer diagnosis; she knew she was dying. She wanted to have some control over what time was left but she felt that since her diagnosis her life was not her own. It was taken over by the medical community, one that, for her, often lacked warmth and care. She had been treated not as a person but as a "patient with cancer" and was identified by her test results, not by the person she was. Her physician demonstrated little caring about Amy as an individual, not taking the time to ask how she was feeling, how she was doing emotionally. He treated her disease but not her self.

I just felt abandoned. Especially with this diagnosis. If he were going to abandon me, where am I going to be? I need a doctor. He's never reached out. I feel like I'm not getting full support. I often wish it were different. I often wish I could talk to him. He never once asks, "How are you getting along?" or "How are you taking it?" or "How are you dealing with it?" He never once asked. Now, I don't know if another doctor would take me on. I feel I have to keep him. How many internists take on a cancer patient?

During my last visit with Amy it was clear that her illness had progressed. She was taking more and more pain medication, but there were unpleasant side effects and she occasionally had pain in her hands and feet. She was tired but was unable to get any rest; when she would recline she couldn't breathe so she slept for only brief periods of time.

I made one final phone call to Amy, and she shared with me that she had been feeling more pain recently and more anxiety. A trip to the emergency room resulted in an inpatient stay in the psychiatric unit of a local hospital. She had responded to the emergency room physician's question about depression. Asked if she had feelings of depression and

had ever considered suicide, she confirmed that she had, in fact, felt more depressed as the pain worsened, but that although she had considered suicide, she would never act on those feelings. Without being told where she was going she was transported to a locked psychiatric unit and put on "72-hour guard" in a room with a mattress on the floor, no other furniture, and bars on the windows. Amy told me that she was "trying to hold on as tight as I can," but it is a "helpless feeling to feel that you've been trapped in their indifference." When talking about the kind and manner of treatment she was receiving, she indicated that her "expectations [were getting] lower."

Amy's story is about the effect of physician-patient communication and of dying and death on the physician-patient relationship. Communication with elders can have an effect on the individual's sense of her/his own life satisfaction (Allman, Ragan, Newsome, Scoufos, & Nussbaum, 1999) and patient-physician interactions can have important consequences for the quality of life of older patients (Beisecker & Thompson, 1995). As Amy experienced when she was admitted to the psychiatric unit, poor physician communication skills can also lead to costly and inappropriate medical interventions.

How communication between physicians and patients occur and the quality of the interaction can be traced to several factors, including the physicians' medical training. As students progress through medical school, the demands placed on them often cause initial humanistic ideals to be rejected. In observing medical interviews, Kramer, Ber, and Moore found that medical students demonstrated "rejecting behaviors" such as ignoring their patients' emotions, being poor communicators evidenced by not listening to patients' concerns, and avoiding eye contact (as cited in Allman, et al., 1999). Additionally, the attitudes that physicians hold towards older pa-

tients can have a negative effect on healthy aging (Grant, 1996).

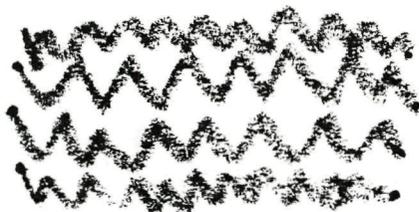
Researchers have looked at the outcomes of teaching communication skills to medical students (Winefield & Chur-Hansen, 2000; Wolf, Woolliscroft, Calhoun & Boxer, 1987) and the efficacy of physician communication skills with people who have cancer (Ellis & Tattersall, 1999; Maguire, 1999). Medical students have been found to improve their ability to demonstrate empathy through responses to patients after being taught basic communication skills (Winefield & Chur-Hansen, 2000), and those who received both small-group instruction and large-group lectures improved their ability to respond to patients' emotional concerns (Wolf, et al, 1987).

Physicians, trained to treat illness and disease, may have difficulty when their patients are diagnosed with a terminal illness and have revealed that they feel uncomfortable disclosing a diagnosis of cancer (Ellis & Tattersall, 1999). The inability to effectively communicate with patients may cause physicians to feel as though they have "failed the dying patient" (Baile, et al., 1999). As a consequence of poor physician communication skills, patients may feel anxiety and depression, causing them to have a poorer psychological adjustment to their diagnosis (Ellis & Tattersall, 1999), which can influence their quality of life (Maguire, 1999). It seems clear that improved physician communication can have a positive impact on patients' adjustment to illness and to their overall sense of well-being. Some attempts are being made by medical schools to assist medical students in their communication (Tufts e-news, 2003) while a number of medical organizations are calling for "improved training and competence in communication skills" (Lurie, 2003). This emphasis in further education for medical students may help to avoid more stories like Amy's.

Over the months that I met with Amy, I came to know and like her. She seemed to appreciate my interest in hearing her story and

my promise to share what I had learned about and from her with others. Most of the individuals I met with for this research project reported negative communication experiences with their physicians. Participants indicated that their physicians objectified them, took complete control of the medical encounter, and demonstrated little or no caring about them as "human beings." I was saddened, depressed, and angry by the stories I heard. At the time I was conducting the research, one of my neighbors was a physician. We talked about what I was hearing, and he shared his frustration that he was "allowed" fifteen minutes for each patient visit, which was supposed to include time for him to dictate his notes. I believe that many, perhaps most, medical students begin their education with lots of energy and visions of providing care and treatment for their patients and end their education feeling tired and rushed and discouraged. The emphasis of medical schools and organizations on physician communication training is a good step in the direction of improving relationships between patients and physicians, and it is something that will benefit all of us. The next step is to return the practice of medicine to physicians and other health care providers.

Amy did not need to read a research report to understand the effects of poor physician communication skills or the lack of empathy on her well-being. She experienced being objectified, and she continued to be a victim, until the end of her life, of a cold and uncaring medical system. Amy died on December 6, 2002.



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