

CONFRONTING DEATH: WHO CHOOSES, WHO CONTROLS?

A Dialogue between Dax Cowart and Robert Burt

On 21 November 1996, Dax Cowart and Robert Burt jointly delivered the Heather Koller Memorial Lecture at Pacific Lutheran University. This was the first time that they spoke together in a public forum.

Burt and Cowart have corresponded over the course of several years on the subject of Dax's case and related issues. They met for the first time during their trip to Tacoma, Washington for the Koller Memorial Lecture. The following is an edited transcript of their public remarks.

Robert Burt: Let me start at a place where I think we agree. Before 1974, the dominant attitude of physicians toward patients was by and large intensely disrespectful of patients' autonomy. The basic posture was paternalistic. Physicians knew what was best for patients, and the patient's job was just to go along. Dax himself has been a critically important actor and symbol in identifying the wrongdoing in that attitude, and raising into high social visibility the proposition that autonomy is a vitally important value; patients are the central actors here and physicians must attend to them in a respectful and careful way. On that point we agree.

The place at which I get troubled or confused is what exactly follows if we embrace this important norm of autonomy. Start with a simple version of two alternatives, perhaps extreme alternatives, to try and sharpen what the issues are. One version of autonomy says: well, it's the physician's job, like it's anybody's job who needs to respect autonomy, to say to a patient, "What do you want?"; the patient says "I want A, B, C," or "I don't want A, B, and C," and then it's just the physician's job to implement

that. That is a possible interpretation of the law and way of proceeding.

I find that interpretation of the law, however, to be quite unsatisfactory. It is not only permissible, but important—I would even say essential—that a somewhat different step be taken by a physician (or anyone dealing with a patient). "What do you want?" Dax says, "I don't want treatment." At that point I think it is not only permissible but imperative that whoever hears that respond not with "OK, great, let's go ahead," but instead with, "Well, why exactly do you want that? Why have you come to that conclusion? I want to explore that with you." Now imagine the next step. Dax says, "None of your business." I think it is then both permissible and essential for the doctor to say, "No, no, it is my business, and not because I'm a doctor but because I am another human being who is necessarily involved in your life. We define one another in important kinds of ways, and while, of course, I can't define you, we have to negotiate together what our shared meanings are about, what it is that you want me to do or not to do." It is correct not only for me to say, "Why do you want to do that?" but also permissible for me to argue with you if I disagree, and to argue strenuously with you on a variety of grounds.

Now come the end of the day, yes, it's your life, it's not my life. But the question is, When have we reached the end of the day? When may we terminate this conversation so that I believe that the choice that you're making is as considerate a choice as I think it is morally obligatory for you to make? I know that this can become a kind of trick, and it shouldn't be that; this is only the first step in a conversation.

Why do I think it's not just important but imperative that anybody hearing such a request on Dax's part explore it with him and even quarrel with him? I think we define one another for one another. We are not isolated creatures, popped

into this world, who chart ourselves only by what's in our head. We are intensely social creatures. Dax himself has become more than just an individual, he has become a symbol and independent force that shapes our way of thinking about ourselves when we imagine ourselves to be patients. We are mutually shaped by our expectation in lots of ways.

There is one way I want to particularize that in Dax's case. All of us, as members of a society, have attitudes toward people with disabilities. Those of us who are able-bodied or, as they say correctly among disability advocates, those of us who are temporarily able-bodied, often spend an enormous amount of energy denying the fact that our able-bodied status is, in fact, temporary. It is for many, many of us an unattractive, if not to say frightening, possibility to think of ourselves as significantly disabled. Many people in this society, for lots of different reasons, have stereotypical views of disabled people and what their possibilities are. You correct me if I misstep here, Dax, but just on the face of the matter, it seems to me that until your accident you were a member of the able-bodied community, and a very able-bodied member at that, for whom your physical prowess was a matter of great importance and pride to you. Suddenly and deeply beyond your control, in a way that can happen frighteningly to any of us, you found yourself pushed over this divide between the able-bodied and the not-able-bodied. But you inevitably brought with you attitudes that were shaped at a time when you were comfortably, happily, proudly a member of the able-bodied community.

Now it seems to me that having been pushed over that divide in physical terms, there still was a question, at least, about your attitudinal concerns, your attitudinal shift.

Let me read one passage from this initial conversation that Dax had with Dr. White.¹ Dr. White said to Dax, "From the very beginning, according to what you've told me, and what's been written in your hospital record, you had very strong feelings that you didn't want the doctors to go on with your treatment, that you wanted them to leave you alone and not attempt to sustain your life. How do you feel about that at this point?" Dax said in response, "At this point I feel much the same way. If I felt that I could be rehabilitated

to where I could walk and do other things normally, I might have a different feeling about it. I don't know. But being blind itself is one big factor that influences my thinking on the matter. I know that there's no way that I want to go on as a blind and a cripple."

How realistic was your perception at that point, just a few months after your accident? How realistic was it of the full range of capacities that could be held out to you, even if you were permanently blind, and even if you were permanently unable to walk (which it turns out, of course, you were not)? How much contact had you had with people with significant disabilities of these sorts? How much were you devaluing your own capacity, thinking that in fact you would be able to do nothing more than your mother's observation in the subsequent videotape interview. She said that you said at one point, "You know, all I'm going to be able to do is to sit on a street corner and sell pencils." Well, of course we see today that you are very active and don't sell pencils. But this is a very common fear of able-bodied people who have had no substantial contact with people with disabilities.

So I would ask myself first of all, how realistic is someone like Dax's sense of the real possibilities open for him? But then second of all, how can I as a helper, someone who wants to be useful and helpful to him, communicate in a way that is fully understandable and believable what the real range of options are to him, disabled, that he, formerly able-bodied and now still able-bodied in his image of himself, is not able to see. What do you do? There are many possibilities. You bring people to talk, you discuss, you challenge. All this takes time. It's not something that you can just say to Dax, "Well, how realistic are you? Let's have a brief discussion." In the kind of immensely difficult, immensely traumatic situation in which he found himself, in the midst of his treatment and with the physical pain that he was feeling, and with the psychological pain of his losses including the loss of his father in the same accident, this is not a conversation that can take place in ten minutes or one day. Over how much time and with what kind of constraints?

Dax Cowart: Now I know how it feels to be killed with kindness. It makes it more difficult to take the

opposing position, but being the good lawyer that I am I will do my best (audience laughter).

The right to control your own body is a right you're born with, not something that you have to ask anyone else for, not the government, not your treating physician, not your next-of-kin. No one has the right to amputate your arms or your legs without your consent. No one has the right to remove your internal organs without your consent. No one has the right to force other kinds of medical treatment upon you without your consent. There is no legitimate law, there is no legitimate authority, there is no legitimate power anywhere on the face of this earth that can take the right away from a mentally competent human being and give it to a state, to a federal government, or to any other person.

In the first part of this century, Justice Louis Brandeis wrote in one of his Supreme Court opinions: "The makers of our Constitution sought to protect Americans, and their beliefs, their thoughts, their emotions, and their sensations. They conferred as against the government the right to be left alone, the most comprehensive of rights and the right most valued by civilized man."

Warren Burger, who later became chief justice, referred to Justice Brandeis: "Nothing suggests that Justice Brandeis thought an individual possessed these rights only as to sensible beliefs, valid thoughts, reasonable emotions or well-founded sensations. I suggest that he intended to include a great many foolish, unreasonable and even absurd ideas that do not conform, such as refusing medical treatment even at great risk."

Justice Burger did not want to encourage foolish, unreasonable, or absurd conduct, but he did recognize the importance that the individual has in making his or her own decision. He understood that what some of us might think of as foolish, unreasonable, or absurd can also be something that is very precious and dear to someone else.

The English poet John Keats, almost 200 years ago, wrote simply, "Until we are sick, we understand not." That is so true—until we are the ones who are feeling the pain, until we are the ones who are on the sick bed, we cannot fully appreciate what the other person is going through. And even having been there myself, today I cannot fully appreciate what someone who has been badly burned is going

through on the burn ward. Our mind mercifully blocks out much of that pain.

John Stuart Mill, the English philosopher, in his essay *On Liberty*, came down on the side of the right to self-determination by dividing acts into those that are self-regarding and those that are other-regarding in nature. Mill concluded that when the act is self-regarding in nature, the individual should be left to make his or her own decisions. That is precisely my view. In a medical context, I am saying that before a physician is allowed to pick up a saw and saw off a patient's fingers or pick up a scalpel and cut out a patient's eyes, we must make sure that the physician has first obtained that patient's informed consent. I always like to stick the word "voluntary" in there—informed and *voluntary* consent—because consent that is obtained through coercion or by telling half-truths or withholding the full measure of risk and benefit is not truly consent. Medical providers need to understand that patients do not lose their constitutional rights simply because they find themselves behind a hospital wall. They have the same constitutional rights that the rest of us have, that we expect and enjoy outside hospital walls.

Fortunately today we have many protections that we did not have when I was in the hospital in 1973 and 1974. We have legally enforceable advance directives such as durable power of attorney and other health care proxies. Studies, though, have shown that even when these advance directives are part of the patient's hospital records, over half the time they are ignored by the patient's physician.

When I was in the hospital there were many reasons I wanted to refuse treatment, but one was overriding—the pain. The pain was so excruciating, it was so far beyond any pain that I ever knew was possible, that I simply could not endure it. I was very naive. I had always thought in that day and age, 1973, that a doctor would not let his or her patient undergo that kind of pain; they would be given whatever was needed to control it. Then I found out that was not true. I found out later that much more could have been done for my pain.

There were other important issues, too. One, though it was a distant second, was what Dr. Burt mentioned, my quality of life. I just did not feel that living my life blind, disfigured, with my fingers

amputated and at that time not even able to walk, would be worthwhile. With that quality of life it did not seem that I would ever want to live. I have freely admitted for many years now that I was wrong about that.

I want to clarify this, though. Freedom, true freedom, not only gives us the right to make the correct choices; it also has to give us the right sometimes to make the wrong choices. In my case, however, it was a moot point whether I was wrong as far as my quality of life went, because that was a secondary issue. The immediate issue, the urgent issue, was that my pain was not being taken care of. That was why I wanted to die.

Today I'm happy; in fact I even feel that I'm happier than most people. I'm more active physically than I thought I ever would be. I've taken karate for a couple of years, I've climbed a 50-foot utility pole with the assistance of a belay line on the ropes course. I do other mental things, like write poetry and practice law. That is not to say, though, that the doctors were right. To say that would reflect a mentality that says, all's well that ends well, or the ends justify the means—whatever means necessary to achieve the results are okay to use. That totally ignores the pain that I had to go through. I check myself on this very often, several times a year, since I do speak so much. I ask if the same thing were to happen today under identical circumstances, would I still want the freedom? Knowing what I know now, would I still want the freedom to refuse treatment and die? And the answer is always yes, a resounding yes. If I think about having to go through that kind of pain again, I know that it's not something I would want. Another individual may well make a different decision. That's the beauty of freedom; that's his or her choice to do so.

Burt: You said at the end of your remarks that if you had to, if it happened all over again to you, you would nonetheless come to the same conclusion. If instead of this happening to you, imagine for a minute that there would be somebody in exactly the same situation that you were in, but that today you were called in to talk with this person. This person had also said to his or her physicians, "I don't want to be treated. Stop now." What would you say to that person?

Cowart: I would say to that person, just as you suggested earlier, "What are your concerns?" I do not urge, when a physician goes to a patient's bedside and the patient says, "Doc, I don't want to be treated, leave me alone," that the physician say, "It's your decision" and walk away. The physician has a duty to inform the patient, as well as he or she can, what in all honesty can be done and then solicit the patient's concerns. I'm not talking about painting some rosy scenario that is really not accurate. So to answer your specific question, were I called to that patient's bedside, I would want to ask why he or she wanted to refuse treatment. I would expect that one of the answers might be the pain. I would then say, "If that were addressed, would that change things for you?" They may say yes, and they may say no. I would try to give that person the benefit of my own experiences—not just the positive points, but the negative ones, because it took me seven years following the explosion before I even began to get on my feet again and life became really worth living. But I would try to reaffirm the person, let him or her know what I thought was possible, what I thought could help, but I would not skirt the problems. One of the problems we have today, for example, is that once patients are out of the multi-million-dollar hospital facilities and away from all the nurses and doctors there, they don't often have good support. They have understaffed and underfunded government agencies to rely on in most cases, and often they fall far short of what they should be.

Burt: That's interesting. I continue to be puzzled about whether we significantly disagree. I completely buy your proposition that there is a right here, a right of autonomous choice. The only point that I keep pushing is your old question of how that is implemented.

Cowart: A physician has to establish rapport with his or her patient, treat that patient as a human being, let the patient know that he or she really cares. I don't know whether it's taught or whether it's just picked up or by watching other physicians, but I think there is a professional distance, a real displacement, by physicians that is counterproductive for good medical treatment. I'll give you an example. When I was in the hospital, the director of

the burn ward wanted to do surgery on my fingers. He felt I could probably get some use out of my hand, but I wouldn't do it, because the surgery I had had before on my hands was so painful.

There was a medical student, though, who was assigned to work with me. He'd come by every day. We'd have friendly, heart-to-heart talks, and I liked the guy a lot. He wanted me to have my hands operated on and asked me why I would not allow the doctor to do it. I explained to him about the pain. He said, "Well if I guaranteed you that you would be kept out of pain, would you?" I told him I'd consider it, but I just didn't see how he could guarantee that, especially since he was a medical student. But he continued to talk with me until finally I agreed to talk to the director of the burn ward about it, who then came in and assured me that he would do everything he could to keep me out of pain. He would give me as much pain medication as he possibly could and not jeopardize my life. It wasn't until then that I agreed to the surgery, and he did keep his word on the pain control. That is more the model of what should take place. But the physician should not have the power to force upon the patient a long, ongoing discussion like that over an extended period of time, whether it be days or weeks.

Audience Question: Mr. Cowart, it seems to me that you are a perfect example of what now seems to be success in spite of any physical disability. Do you now feel at all grateful, thinking back? Are you glad that the doctors fought your request to die?

Cowart: I do not feel grateful to anyone for fighting my request to die. What I do feel grateful to them for is that I believe they honestly felt they were acting in my best interest. But no, I'm not glad they forcibly treated me because the pain that I went through was pure hell. We lose sight of how painful pain can be. Einstein apparently once talked about comparing sitting five minutes on a park bench beside a beautiful girl with sitting five minutes on a hot plate and said, "that's relativity!"

Audience Question: Mr. Cowart, when you were first injured, if your intractable pain had been effectively managed, do you think that your attitude

would have been different? Do you think you might have had a very different outlook as to prolonging your life? Do you think that the pain was really the main issue that wasn't being addressed by your physicians and the medical community, and that that interfered with your ability to really look at the future?

Cowart: Your concern is what I hear time after time from many people in the health care professions. Dr. White, the psychiatrist who was called in, expressed that same type of concern. Another concern Dr. White had was whether I had a major issue with control, whether once I showed that I was in control, then I would want to be treated. That just was not the case. It was not the future that I was concerned with; it was the present moment, the pain that I was undergoing. I knew that the physical pain would be gone eventually, but I was not willing to tolerate it for long enough to get beyond it. Even if my pain had been competently managed, I still don't think that I would want to have been treated, because of my physical condition and what I did see as the future. Possibly without the pain, and possibly with much better professional support, maybe I could have been persuaded to go ahead and accept treatment. But you know, a psychiatrist was not called in to try to help me with these concerns until almost a year into my hospitalization. And then they called the psychiatrist in, not for the purpose of helping me, but to have me declared incompetent. He refused to do it and in fact found me competent, and so did the second psychiatrist, as you know.

Audience Question: Mr. Burt, I get the impression that both the medical profession and the society assume a temporary incompetence in anybody who is in severe pain or in severe emotional grief. Do you take the word of somebody in severe pain as at that moment truly their decision? Is a presumption of temporary incompetence justifiable?

Burt: I don't like the language, "presumption of temporary incompetence." It has a disrespectful and excessive quality to it. I don't think we should operate on such a premise. What I do think is that people in grief or extraordinary pain deserve a response by a whole range of caretakers, personal

and professional: "I'm with you and I'll stick with you, and I'll be as helpful as I possibly can in working this through with you. I won't abandon you." Sometimes, in fact maybe even frequently, I think people who are in severe grief or severe pain have trouble, because they feel so hopeless, believing that people are responding to them in this way. So it takes an awful lot of assurance—not just words but being there when it counts, and it's not something that you can just say once and have it sink in to someone in great physical or psychological pain. Now I don't call that incompetence; I call that humanity—our human condition. It's naturally how people respond in times of enormous stress, woe, and trouble. In organizing caretaking we should be thinking of ourselves as responding to that—not just in cheap words, and that takes time.

Audience Question: It seems to me that you, Mr. Cowart, actually made a very articulate defense of Mr. Burt's position when you so ably identified the essentials of informed consent, making the very clear point, well respected and recognized in medical-legal law, that informed volitional consent demands a full appraisal and understanding of the risks and benefits of the therapy. The difficulty that I see Mr. Burt focusing on here is that these decisions don't take place instantaneously in time. Even a patient who is not in pain, to make a fully informed decision about the risks versus benefits of treatment, has to be able to appropriate a different set of attitudes and expectations, and the process for that is one of knowledge and dialogue and information. Setting aside the pain issue, which ought to be aggressively manageable, how does your own experience help us understand how to balance respecting the patient's request with confidence that enough time has been given to the patient to allow a truly informed personal assessment of what the risks and benefits are?

Cowart: Assuming that pain is not an issue and that there's not some other issue present analogous to pain as far as the immediacy of the situation goes, I would not be nearly as inclined to favor a very short time period. I probably would favor a longer period of time, maybe weeks, maybe even months, but I don't think that I would be in favor of years. As far as physicians being able to work with a patient during that time, I think it would probably be good in instances where you don't have the immediacy that something like severe physical pain requires. The trouble I have is how you go about assessing what is sufficient time from the patient's viewpoint, since we're all different. I just know that for myself I would like to have the right to make my own decisions at zero point in time. At the same time I'm willing to forgo some of my own autonomy in the interest of better decisions being made. What I don't know is how to determine always, as Dr. Burt calls it, when the end of the day has come. If the patient gives away some of that autonomy, I just don't know how you go about protecting the patient so he or she can still say, "Okay, I've heard you out, I've tried what you said, and it's not for me."

ACKNOWLEDGMENTS

Quotation from "Dax's Case" used with permission of Choice in Dying, 1035 30th Street, N.W., Washington, D.C. 20007.

REFERENCES

1. From the transcript made of the initial videotape and published as an appendix to Robert Burt, *Taking Care of Strangers: The Rule of Law in Doctor-Patient Relations* (New York: The Free Press, 1979), pp. 174–80.