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Publication Date

1998-04-01

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IN CASE OF FIRE, Stop, Drop, and Hold:
The Cultivation of the Ability to Maintain Multiple Perspectives during
Treatment Decision-Making Conflicts

by

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B.A. (Princeton University) 1994

A thesis submitted in partial satisfaction of the

requirements for the degree of

Master of Science
in

Health and Medical Sciences

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, BERKELEY

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Spring 1998

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University of California, Berkeley

Spring 1998

This thesis is dedicated in memory of my grandmother,

Wanda Hewitt Ramirez

1920-1997

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Preface

waiting

her cold hands lie swollen and freckled on
 sweaty sheets. the gown
 ties hang loose and run along the tubes
 that stick into her nose, her arm, her thigh, her genitals.
 wonder if she would have ever wanted me to see her like this.
 she never liked me to clean out her fridge, to see the shriveled nectarines or
 the puffy green molded over can of garden peas lodged behind the ketchup.
 so now I see her body and

watch her breathe;
 air is sucked between crusted brown moss teeth
 and her chest heaves up and down in small pants.
 fast fast in out fast fast but nothing else moves nearly so;
 her face flows languidly with a grimace
 the corners of her mouth pulled down on one side
 and her brow knit with perhaps the wrinkles of
 habitual wear or the erosion of long years.
 I imagine though that it is the tube going into her nose or the
 hushed harsh whispered word wars between my mother and grandfather,
 my mother and the doctor,
 or

but
 I
 as if Death
 would appear and introduce himself and tell me what
 should I be
 terrified or not.

this can't be a big deal
 I keep thinking it happens all the time
 people come into and out
 like bubbles

and why should that make me cry

The turning point for this thesis came when I walked into my grandmother's hospital room in the June of 1997. I found myself immersed in a bewildering array of doctors, nurses, and family members, each with a different opinion on what should

happen next in my grandmother's care. My grandmother was not able to communicate with us, and we had never talked to her about her wishes regarding medical care at the end of her life. One family member took on a very influential role as an advocate for "doing everything." Another family member, equally influential, felt strongly that my grandmother should be "allowed to die." The rest of us were thrown about in between. Doctors, nurses, administrators, and social workers occasionally played the much-needed role of mediator. More often, however, the members of the staff simply threw their own agendas into the fray. Disturbingly, many of the physicians involved in my grandmother's care used their medical knowledge as a manipulating tool rather than as a tool to be shared as equally as possible among all decision-makers. In many cases, the conflicts led to clearly compromised care for my grandmother. There was the time, for example, when the nursing home staff "forgot" to turn the feeding pump back on. Thus the feeding tube became clogged. When we finally succeeded in calling their attention to this twelve hours after the machine had been left off, the nurses removed the feeding tube and consulted the doctor, who then "forgot" to order IV fluids for my grandmother while we waited for a new feeding tube, which itself was delayed pending resolution of the conflict between family and staff over what size of feeding tube with which we were to replace the old one. In essence, my grandmother got some of the worst of both palliative and aggressive care worlds.

As I walked away from this mess, I began to formulate my own ideas about what had fueled this conflict. I had wanted my thesis to be about the role of spirituality in medical care. After witnessing this carnage, I realized that maybe spirituality was too much to ask at this point in the evolution of medical care in the United States. How about communication, for starters?

We could each name a significant number of barriers to physician-patient-family communication around end-of-life-care: social attitudes about death, physician time

pressure, cultural differences, language differences, the lack of physical space for private conversations in hospitals, lack of physician training in counseling, cost incentives to cut back on terminal care, the physician-family knowledge gap, widely differing expectations of physician and patient, the lack of a unified cultural view of death, and so on.

Conflict may, in fact, be an inevitable part of life and death. But since I know that I will probably become a physician and I will definitely die someday, I would like some tools to make end-of-life decision-making go a little smoother than it might otherwise. I decided, based on gut feelings in that hospital room and in medical school classrooms, that the skill I personally really need to develop for navigation of interpersonal (and intrapsychic) conflict is the ability to hold multiple perspectives without attempting to collapse them into each other (more on that later - don't worry!). This, for me, has been a big part of my spiritual path over at least the last year or so, but probably longer. That is why this thesis has the strong aura of personal quest to it. I wanted to write about spirituality in medicine and I came back around to the spirituality inherent to my own medical training. I guess that's why they call me introspective.

Acknowledgments

I would like to thank my thesis committee: Henrik Blum, Julian Boyd, and Guy Micco, for inspiration and support and wading through drafts; the unofficial members of the committee: Peter Freed, Nellie Hill, Tommie Kushner, and Ginny Mommsen, for the same thing; Bette Anton, for exceptional library support; the JMP staff: Susie Alpers, Nina Green, Jean Jacobson, Ronnie London, and Dyanna Sweeney, for warm and never-tiring general assistance; Jeff Burack for direction; Tom Boyce for his benchmark assignments; the members of my writing group not already mentioned above: Leila Alpers, Anna Davidson, Michele DiTomas, Lisa Kessler, Pamela Petersen-Crair, and Alex Smith, for bringing things to life; the members of the Humanities and Ethics thesis group not already mentioned above: Malkeet Gupta and Ori Tzvieli, for listening and feedback; the members of the Independent Thinkers thesis group not already mentioned above: Bimla Bachrach, Robert Ratner, Josh Reagan (you-know-what), Alan Steinbach, and Soma Stout, for the same thing; Ana Garcia for getting me to go to medical school in the first place and for being a great role model; Chuck Garcia for re-introducing me to the goblin universe; Gail Gordon for always being there; Amy Robbins for teaching me perspective-holding by example; my family: Lisa Bevier-Sakimura, Cathy Sakimura, Glenn Sakimura, Judy Sakimura, and my extended family, for all the love and for the many conflicts we've resolved together; my classmates not already mentioned above: Ingrid Binswanger, Cora Hoover, Dennis Kuo, Lesley Martin, Noah Novick, Michelle Stone, and Jenny Way, for friendship, laughter, and other very important things that one needs when writing a thesis.

Chapter One: Introduction

Please Call Me by My True Names

Do not say that I'll depart tomorrow
because even today I still arrive.

Look at me: I arrive in every second
to be a bud on a spring branch,
to be a tiny bird, whose wings are still fragile,
learning to sing in my new nest,
to be a caterpillar in the heart of a flower,
to be a jewel hiding itself in a stone.

I still arrive, in order to laugh and to cry,
in order to fear and to hope,
the rhythm is my heart is the birth and death
of all that are alive.

I am the mayfly metamorphosing on the surface
of the river.

I am also the bird, which, when spring comes,
arrives in time to eat the mayfly.

I am a frog swimming happily in the clear water
of a pond.

I am also the grass-snake who, approaching in
silence, feeds itself on the frog.

I am the child in Uganda, all skin and bones,
my legs as thin as bamboo sticks.

I am also the merchant of arms, selling deadly
weapons to Uganda.

I am the twelve-year-old girl, refugee on a small
boat, who throws herself into the ocean
after being raped by a sea pirate.

I am also the pirate, my heart not yet capable of
seeing and loving.

I am a member of the politburo, with plenty of
power in my hands.

I am also the man who has to pay his "debt of
blood" to my people, dying slowly in a
forced labor camp.

My joy is like the spring, so warm it makes
flowers bloom in my hands.

My pain is like a river of tears - so full it fills up
all the four oceans.

Please call me by my correct names so that I can
hear at the same time all my cries and
my laughs, so that I could see that my
joy and pain are but one.

Please call me by my correct names so that I
could become awake, so that the door
of my heart be left open, the door of
compassion.

Thich Nhat Hanh¹

This thesis explores the use of creative writing in treatment decision-making conflict resolution. It uses the conflict over Donald "Dax" Cowart's² care, as presented in the documentary Dax's Case³, as a case study.

The Problem

The advance of medical science has brought with it an increasing number of situations in which people must decide for themselves or for their loved ones at what point lifesaving or life-prolonging treatment has become inappropriate. Ninety percent of intensive care unit deaths in UCSF-affiliated hospitals in 1992 and 1993 were secondary to a decision to stop or withhold life-sustaining treatment.⁴ Such junctures are almost inevitably difficult for everyone involved, including the physician. Add to the dizzying pace of technical progress the complication that the microculture of American medicine has in the last ten years executed an about-face in its attitude toward the prolongation of life in terminal care situations. Physicians were once loath to agree to patients' or their surrogates' requests to stop futile treatment; now most physicians aim to avoid life-prolonging treatment as soon as possible after the discovery that the chances of a given patient's recovery is slim.⁵ While this development has been a welcome relief for many patients and their families, it has caught by surprise others who expected their physicians to be the last to want to stop treatment. The cultural image of the physician has not kept up with the real one. And add yet another twist - the United States grows ever more culturally diverse, with different attitudes toward death in each cultural group and subgroup. Thus, skill in approaching conflicts that arise during treatment decisions is becoming increasingly important for physicians and other health care providers.

Unfortunately, physician-patient-family communication in the area of end-of-life decisionmaking is poor. The SUPPORT study, a recent observational and intervention study of physician-patient communication in terminal care, found that physicians are no better at stating the end-of-life care wishes of their patients or the

patients' surrogates than is the flip of a coin (e.g. heads - do not resuscitate; tails - full code). Moreover, intensive interventions that included a specially trained nurse who encouraged patient-physician communication did not improve physicians' actual communication with patients.⁶ While it is clear from this that improved conflict resolution skills are not enough to address the problems with doctor-patient-family communication in terminal care, conflict resolution is nevertheless an important component of this communication.

Conflict Defined

By conflict I mean any state of disharmony among people. The people involved have not necessarily called lawyers or vandalized each other's cars. In fact, participants may not even consider themselves as being engaged in a "conflict." For the purposes of this thesis, conflict occurs whenever disharmony occurs, no matter how quickly the matter is resolved.

The reason I define conflict so liberally is that the clash of ideas or interests is often most easily and quickly concluded by some means of coercion. Coercion, which I also define liberally, takes many forms. For example, a physician can subtly exercise his or her sociocultural authority, manipulate the flow of information, obtain a court order, or use physical force. All of these activities involve a less-than-consensual exchange of power. Coercion is by my standards undesirable and to be avoided as much as possible. In order to minimize the use of coercion, it is best to identify conflicts before they are "resolved."

A Case Study of Conflict

In 1974, Donald “Dax” Cowart was in a propane explosion that left him with severe burns over two-thirds of his body. He was twenty-five years old. Although he demanded to be left at the scene of the accident, he was taken to the hospital and treated. For a period of over a year, Donald Cowart was treated over his objections at three different hospitals. He is alive today, half of his lifetime later, and insists that he should have been allowed to die.

Many people became involved in the conflict over Dax Cowart’s care. This thesis discusses the involvement of the seven principal participants: Dax Cowart; his mother, Ada Cowart; the Cowart family’s lawyer, Rex Houston; Dax’s three physicians, Charles Baxter, Robert Meier, and Duane Larson; and Dax’s psychiatrist, Robert White. Roughly speaking, Dax Cowart, Robert Meier, and Robert White could be put into the category of wanting/agreeing to stop treatment; whereas the remainder, Ada Cowart, Rex Houston, Charles Baxter, and Duane Larson, could be put into the category of wanting to continue treatment.

The conflict over Dax’s care remained unresolved as of the 1986 documentary Dax’s Case, with each person involved seemingly still certain that her or his own stance was the right one. Because each participant’s stance and involvement is well laid-out by the documentary, Dax’s case serves as an excellent case study of conflict over a treatment decision.

The rest of this chapter outlines a proposal for the approach to the resolution of treatment decision-making conflicts. We will return to Dax’s case in the following chapters.

General Approach to Conflict Resolution

Conflict resolution approaches have several common elements, outlined below.

- Create a physical environment suitable for comfortable conversation. Most hospitals are deplorable in this regard.
- Get a mediator who does not have any interests that conflict with those involved in the conflict. Some conflicts may be satisfactorily resolved without mediators, however.
- Identify the needs of each person or party.
- Collaborate to offer options which satisfy every participant.

A more specific approach to conflict resolution, the “integrative bargaining” approach, can be applied to treatment decision conflict. Major advantages of this technique are its clarity, comprehensiveness, and wide applicability.⁷

- Understand the potential causes of conflict. These include: financial conflicts of interest or limitations on the availability of hospital resources; incongruity of values among medical providers, patient, and family members; general lack of communication; unaddressed patient or family concerns about possible treatment outcomes; and ambiguity regarding appropriate roles or behavior for particular participants - for example, disagreement about which family member has final decision-making power in the care of an incompetent patient.

- Understand the potential causes of conflict escalation. These include poor communication; shifts to more coercive tactics; gratifying results of coercive tactics; changes in personnel or replacement of some family members by others; retaliation; provocation; escalation of demands; participants' distorted perceptions of each other (e.g. stereotyping); and entrapment of participants resulting from overcommitment of resources to the conflict.
- Identify the probable causes of conflict and its escalation specific to this situation.
- Acknowledge that a problem exists.
- Develop the appropriate conditions for effective communication. This includes the enlistment of a mediator; the establishment of a physical space amenable to open discussion; the negotiation of time constraints; and the agreement by participants to dedicate themselves to problem-solving rather than to competitive bargaining.
- Discuss participant perceptions of the problem and reach agreement on the definition of the problem. This includes open discussion of attitudes, perspectives, and values; depersonalization of the problem; and the creation of a checklist against which later proposed solutions can be checked.
- Generate alternative solutions. Brainstorm: defer judgment on proposals; list as many ideas as possible; encourage wild ideas; be exhaustive but take breaks.
- Evaluate and select viable alternatives. Refer to the problem checklist to assess whether the proposed solution addresses the problem satisfactorily.
- Implement solutions.

- Reassess solution with participants after implementation.

Internal and External Elements of Conflict Resolution

Conflict resolution can be roughly divided into internal and external elements. The external elements are issues such as those discussed above, e.g. appropriate room space for discussion, mediators, and protocol for conflict resolution. The internal elements, on the other hand, are qualities of mind⁸ that allow conflict participants and mediators to communicate better in the conflict situation. This thesis focuses on the internal elements.

Three qualities of mind in conflict resolution can be elucidated: empathic engagement, compassionate detachment, and perspective-holding. Empathic engagement is the attempt to feel the other person's feelings. Compassionate detachment is a slight stepping-back, an avoidance of entanglement, but not a turning-away, from the other person. Perspective-holding, which is the main focus of this thesis, is the practice of stepping into another person's shoes without walking away wearing them.⁹ Thus, perspective-holding is a combination of empathic engagement and compassionate detachment.

More on Perspective-Holding

Perspective-holding is a creative synthesis of two opposing philosophical approaches: empiricism and relativism.

Physicians' communication with patients regarding treatment decision-making has two modalities. One modality, the empiricist approach, aims to change a patient's beliefs in order to change the patient's behavior. For example, a physician tries to learn

a smoker's beliefs about smoking, change those beliefs to fit the medical profession's beliefs about smoking, and then convince the person to quit smoking. The second modality, the relativist approach, aims to preserve patient autonomy. For example, a physician suggests an experimental treatment to a person with cancer, learns that the person wishes to forgo this treatment, and then accepts this person's decision.

By empiricism I mean a system of belief that holds science to be a "mirror of nature."¹⁰ Empiricists believe that not only is it possible to represent reality more or less accurately, but also that the most accurate representation of reality stems from the scientific method. This means that in the empiricist framework, doctors know better than patients because the former have better access to scientific knowledge about the body. By relativism I mean the philosophy that "human understanding is always a 'captive' of its historical situation."¹¹ Relativism proclaims that no one can wield a "mirror of nature," and thus no one can rightly claim to have a better depiction of reality than does anyone else. In other words, in the relativist framework, if the patient says that smoking is good for him and the doctor says it isn't, they may both be "right."

The debate between empiricism and relativism has raged on for decades in wide and ever-expanding circles of academia, and while there may be many ways of coaxing the two philosophies into an uneasy "fit,"¹² I remain convinced that empiricism and relativism are fundamentally irreconcilable. The happy result of this incompatibility is that empiricism and relativism are set into a perpetual creative tension with one another. By harnessing the repulsive force between the two belief systems, it may become possible to "hold" many perspectives at once.

How does this work? In the empiricist model the physician prioritizes her belief over that of the patient; in the relativist model the physician prioritizes the patient's belief over her own. In the synthesis, or perspective-holding, model, the beliefs are

both “held.” The perspective-holding model insists that it is possible for a single person to maintain multiple logically irreconcilable beliefs. A key aspect of perspective-holding is the fact that perspective holding does not dictate any one course of action. It is not necessary to act on all of the beliefs. It is not even necessary to abandon the original course of action dictated by one’s own belief - in the example above, this would be the physician’s decision to attempt to dissuade her patient from smoking. What is required is a willingness to suspend moral certainty for a moment, to acknowledge that it is possible to entertain multiple possibilities without abandoning one’s own beliefs.

The image that I have here is that of a competent parent “holding” a toddler. Before condemning my analogy as quaintly paternalistic, please note that the metaphor of the child signifies the idea or perspective, not the patient. The baby sometimes wants to cuddle and sometimes wants to investigate the toy on the ground and sometimes wants to run out into the street. The parent cuddles, puts down, or restrains the child as appropriate. No matter where the child is physically and emotionally in relation to the parent, the parent is always cradling the child in her or his heart and attention. Each perspective is another child to hold. As hard as it may be sometimes with small children, it is often even harder to do with strongly felt beliefs. Parents of young children may kick me in the shins at this point.

Perspective-holding is of great utility in conflict resolution because the suspension of moral certainty creates a space for communication. The person holding multiple perspectives can engage with others because he or she 1) does not have to be right and 2) does not have to be wrong. A person who thinks that she must be right does not listen but aims to convince the other person of her point. A person who thinks that the other person must be right does not listen but aims to implement the other

person's point of view. In either case, engagement and true dialogue are missing. Perspective-holding creates the conditions for dialogue. This will be discussed further in Chapter Three.

Although the skill of perspective holding is useful for everyone involved in treatment decision conflicts, this thesis mainly focuses on physicians and future physicians. Most medical schools currently do not provide formal training in the skill of perspective holding. I believe that any activity which calls attention to multiple perspectives may serve in the cultivation of this skill: for example, meditation, literature (reading and writing), visual art, history, drama, and anthropological analysis. Individuals may choose activities that work the best for them. I happen to be particularly interested in creative writing. Also, from my experience as a student in an ongoing creative writing class at the Joint Medical Program, I have found that writing can be an excellent avenue of education for medical students. In this class, we have begun to experiment with cultivating the multiple-perspective-holding skill by, for example, rewriting patient histories in the fictional "own voice" of the patient. It is the goal of this thesis to use Dax's case to experiment with creative writing as an approach to the cultivation of perspective-holding. By drawing out and giving voice to the multiple perspectives that arise within medical encounters, we may be better able to avoid collapsing perspectives into each other when the going gets rough. The goal throughout the thesis is to elaborate and hold the various perspectives of each key participant in the conflict over Dax's care.

Chapter Two provides an overview of what happened in Dax Cowart's medical care. Chapter Three reviews the medical ethics and other writing on his case. Chapter Four discusses the process of creative writing. Chapter Five consists of creative writing from the fictional perspectives of the conflict participants in Dax's case. Chapter

Six, the conclusion, discusses how the writing in Chapter Four contributed to my own goal of cultivating the perspective-holding skill and recommends some future directions.

Chapter Two: Overview of Dax's Case

What Happened to Dax¹³

Donald Herbert Cowart grew up in the Rio Grande Valley and then in East Texas. Popular in school and very athletic, he was captain of his high school football team and performed in rodeos. After high school, he attended the University of Texas at Austin. A year into college, he was notified of his draft selection for service in the Vietnam War. Cowart chose to join the U.S. Air Force. He served as a pilot in Vietnam and returned to Henderson, Texas in May 1973 to work with his father, Ray Cowart, in real estate. Dax tells the story of the accident:

In the July of 1973, I was 25 years old, unmarried, and just left active duty Air Force for a pilot slot in the Air Force Reserves. I'd returned here to East Texas to work with my father as a real estate broker and wait until the commercial airlines began hiring again. Hopefully I could get a position as a pilot with the airlines.

I'd learned that this tract of land was for sale, and late one hot July afternoon my father and I drove here to this bridge and since this was a shady cool spot, parked here and got out of the car and walked the land. He agreed that the land was a good buy.

But when we returned to the car and got in, we found that the car would not start. For about three or four minutes, we could not get the car to start. And about the time I felt that we were going to run down the battery, a flame shot up from the carburetor. And moments later there was a tremendous explosion. The blast from the explosion rocked me over into the car seat and I reached for the door and ran from the car about three steps from the car... toward the woods, which was the only area that was not engulfed in flames. I saw that the underbrush was so thick that I would probably become entangled and slowly burn to death, so I cut and then ran straight ahead down this road that we had driven in on.

I ran through about three walls of fire and after clearing the last wall instinctively threw myself to the ground, rolled three times, got back to my feet and continued running down the road hollering for help. While I was running, the whole or half of my vision was blurred, much as if I was trying to see underwater; my eyes had been so badly burned.

I can recall thinking while I was running or hollering for help that this really wasn't happening, this was really just a dream or a nightmare; but the pain and all that I was feeling I knew that it really was happening.

Finally I heard voices saying that they were coming, so I laid down in the grass in the side of the road and waited for them to come. At that point, I thought that my father and I had done something to the car that had caused the gas tank to explode. And it wasn't until two or three days later in the hospital that I was told what had actually occurred was there was a leak in a propane gas transmission line... It was this propane gas in the creek bed that exploded...

I heard a nearby farmer hollering we're coming we're coming. When he arrived, the first words he said was, "Oh my God." From this, I knew I was probably burned even worse than I had first thought. I had not seen my father since the explosion, and so I asked him, asked the farmer, to go and try to help him. I was afraid my father was still in the fire. When the farmer returned, I asked him to bring me a gun. And he wanted to know why. I told him, "Can't you see I'm a dead man?"

I'm going to die anyway. I've got to put myself out of this misery." He said in a very caring way, "I can't do that."

Later the first ambulance arrived, and I asked them to go down and pick up my father. And when the second ambulance came, I did not want to go with them. All I wanted to do was to die and to die as quickly as possible. I was placed in the ambulance anyway, and as they were preparing to put me on the stretcher, I could not imagine anyone touching me anywhere on my body, the pain from the burns were so excruciating. And so I asked them to pick me up by my belt to put me on the stretcher and they did.

Dax's mother, Ada Cowart, was at home with her daughter, Beth, at the time of the accident. Ada says:

My husband called me to say he and Donnie were going to go look at some property that Donnie was thinking about buying and that they would be home to supper in a few minutes. But after he didn't come home, my daughter and I went on and ate supper. And while we were eating, we heard on the radio that there'd been an explosion in the oil fields. And it did not occur to me that it could be them. And since quite often he was delayed in his work I didn't think anything about it. We went on and got ready and went to church, Wednesday night church services, and while we were in class they called me out to see the chief of police. My husband's secretary was also a close friend of ours and they told me that there had been an accident, they didn't know how badly Donnie and my husband were hurt.

Ada did not see her son until he arrived at a Dallas hospital, one hundred and forty miles away. Dax continues the story:

My father and I were taken in separate ambulances to a small town hospital about ten miles away. Since this hospital was not adequately equipped to treat us, we were both placed in one ambulance and taken to the burn ward at Parkland Hospital in Dallas, some one hundred and

forty miles away. As we were both being placed in the ambulance, I remember my father turning and looking at me and saying, "I'm sorry, Donnie boy." A day or two later, I learned that he had died on the way to the hospital.

Dr. Charles Baxter, a burn specialist, was the physician in charge of Donald Cowart's care at Parkland Hospital. Charles Baxter says:

I first began to treat Donnie Cowart actually by phone, from South Texas, and directed his fluid therapy prior to his arrival. I saw him a few hours after he had arrived; he was responding well to his initial therapy. On examination he had approximately a sixty-five percent very deep burn. Notably, his face was a deep third degree burn, and he had damage to both eyes, more severe on the left. His ears were severely burned very deeply, as were his hands.

When his mother arrived at the Parkland Hospital emergency room, Cowart gave her power of attorney over his care. Ada Cowart deferred to the physicians. She says:

The doctors made most of the decisions. They just asked for operative permits or whatever treatment had to have a signature to get permission. Since I had no knowledge of burn treatments, all I knew to do was to take the doctors' suggestions and recommendations. And sometimes I was frustrated; sometimes I wish I knew more. This happens to everybody.

Don Cowart, however, continued to demand the discontinuation of treatment that would extend his misery. His mother stood firm. "The treatment seemed to go rather well in spite of Donnie's protesting that he did not want to live."

Charles Baxter initially dismissed Don Cowart's refusal of care as a common early response of burn victims. Charles Baxter says:

I responded to Donnie's requests or demands to die at first rather flippantly. "Oh, you don't want to do that, Donnie," and go on with the treatment, and literally ignored his initial requests... I had felt that the initial expression of the desire to die, when he came in, could well be accounted, not accountable, because during the shock phase and with all the narcotics, burn patients are incompetent to make such decisions. And I would never, under any circumstances, meet the request at that point in time.

Later, Charles Baxter began to discuss Cowart's wish to die with Cowart, his mother, and the family's lawyer Rex Houston. Charles Baxter says:

At some point, it began exactly, when he called me in and said that he really did wish to die, wish to get legal consultation and file the proper brief or whatever to make me allow him to die, or to help him die, or to send him home, where he could commit suicide or whatever. And I felt at that point that he was serious about it... In the latter part of his treatment, when he complained almost daily and regularly to die, then Rex Houston [Cowart's attorney] became a very important decision-maker with us, because we discussed it with him from the legal standpoint, and from the moral standpoint, of obligation that we had to deliver medical care and Donnie to accept it.

Incidentally, Rex Houston was a close friend of the Cowart family and was representing Don and Ray Cowart in a suit against the propane company responsible for the explosion. Rex Houston says:

For several months after I filed the lawsuit we were busy engaged in the process of developing and getting it ready for trial. And I was conscious all the time, and moved by the fact, that this case needed to proceed to trial just as soon as it could be reached, the trial. My reason for that was that Dax was a single man, twenty-six years of age; he had no dependents... His lawsuit, were he dead, had no great value to it, because he had nobody surviving who was dependent on him. As a

living plaintiff, he had a lawsuit that had tremendous value to it. As you can imagine yourself without even being in the lawsuit business, because here you have a person who has lost both hands and both eyes. And it has any value to it as almost you can imagine. But we were faced with this, and it was of great concern to us and to me in taking care of the family and taking care of him, that I had to have a living plaintiff at the time the case had reached the trial.

Charles Baxter continued treatment after Ada Cowart and Rex Houston refused to consent to the withdrawal of Don's treatment. Rex Houston encouraged Don Cowart to endure treatment and see the end of the legal case. Don Cowart survived to see the case settled out of court in February 1974. His requests to die became even more insistent then. Cowart asked nurse Leslie Kerr, as he had also done earlier, to provide him with a lethal overdose injection. Leslie Kerr says:

I think that one of the first qualities of being a nurse on the burn unit was being able to feel honestly and to respect patients' feelings. And one of the reasons that I think that Don began to talk to me about wanting to die was the relationship that developed between he and I over the next few days. And that was built on being honest and his trust in me. And in that time in the days that followed, he began to feel that he was not going to be able to see, that his vision had been definitely damaged. I think that knowing also the extent of his burns, how badly he was burned, that he began to think about this and he began to ask questions and he began to want to die. I can remember the feeling that I had at thinking here was a young man who had once been probably very nice looking and very active in his life, and he was now at a point where he wanted not to live and he wanted to die. And he was asking me, as a nurse, to either give him something that would allow him to die, or to help him. And I was just out of nursing school, had just graduated although I had been working there a year. I can remember those feelings that I had, at wanting to, and feeling and wanting to help him but not being able to do that.

Cowart also asked his friend Art Rousseau to bring him a gun. Art Rousseau says:

I remember one night I was sitting there, and it's the only time I like to think that he ever really got to me, because he was talking and he said "Hey are you really listening to me?" I said, "Well, I'm here," and he said, "But are you hearing what I'm saying?" I said no. And so he starts talking again and he was talking about wanting to have a gun, and he was mad because everyone was keeping him from talking about anything like this. And he wanted to talk about possibly having someone come in. He wanted a gun. And he was sitting there and he just kept on talking and he says "Well, I guess I could get a gun; I've got means of doing it." And he said, "But I don't guess it would do any good anyway because I don't have any fingers to pull the trigger."

At the time, Don had a good point. He knew where he was coming from. He wasn't going to be Don Cowart anymore.

After over seven months at Parkland Hospital, Cowart was transferred to the Texas Institute for Research and Rehabilitation (TIRR) in Houston and the care of Dr. Robert Meier, who was nine months out of residency. Whereas at Parkland Hospital, Cowart had not been involved in his care as a participant, at TIRR he was offered choices in his care. Also, his mother was discouraged from staying with him. Ada says:

When I'm looking back at the last ten years, I think I made the right decision. I would have asked the doctors to give him more pain medicine in some instances, because I found out later they could have... And also I would have stayed in Houston than leave him there, because often, I hear people dying when the family goes home.

Three weeks into his stay at TIRR, Cowart began to refuse treatment for his open burn areas and stopped eating and drinking. Robert Meier, his physician at TIRR, says:

Don began to refuse medical treatment after he had a meeting with a plastic surgical resident who made an offhanded remark that his care plan and reconstructive surgery would probably take a period of years, which meant that the pain would be spread out over that period of time. I was caught in a rehabilitation dilemma because I had been trained to know how much functional ability people can achieve despite serious burns and yet also wanted people to make their own decisions. It was the first time I had ever had a patient for whom I was providing what I considered good treatment actually refuse the treatment that I felt that would help him achieve a level of functional independence. And I was uncomfortable with that, so I decided that I would give his attorney and his mother a call, ask them to come to Houston to talk to Don about what plans would be made for the future. We had the meeting with Don and the attorney and his mother. And at that point we decided that since the burns had gotten worse, since he had refused the whirlpool and the dressing changes, that he really needed to be back in an acute burn center, where they could pay attention to his burns, and we could go about his rehabilitation after they were completely healed.

They agreed to transfer Cowart to the burn unit of the John Sealy Hospital of the University of Texas at Galveston. Dr. Duane Larson advised active wound care and further skin grafts to treat Cowart, whose hands and arms were locked up in burned skin and whose eyes were severely infected. Cowart protested the daily tankings, which only added to his excruciating pain, and refused to consent to surgery. Dax says:

The tankings at John Sealy were by far the most painful because a Chlorox solution was placed in the water. Even though they gave me very heavy doses of morphine before the tankings, it was still as if

alcohol was being poured over raw flesh. Then when I was raised out of the tank, the room was kept so cold that I felt as if I were freezing to death. They'd then take me back to the room and even there the pain was so intense that I could do nothing but scream at the top of my lungs until I thoroughly passed out from exhaustion. Even knowing that this would do absolutely no good. This pain of the tankings continued seven days a week, week after week after week.

Cowart tried to jump out of his hospital window at least once but was prevented from doing so by the staff. Larson consulted the psychiatrist Dr. Robert White.

Robert White says:

I was asked to see [Mr. Cowart] in consultation psychiatrically by the surgeons in charge of his care because they were concerned that his very depressed state of mind and his disinclination to allow treatment to proceed was perhaps a result of some mental illness or something that needed psychiatric care. Finally it became very clear that he was not in the least mentally ill, nor was in the least mentally incompetent to make whatever decision he might wish to make regarding his care. I was greatly puzzled. On the one hand, it was clear his yearning to die, his protests of wishing to die was not the product of a mental illness. On the other hand, here was a case in which a man would surely survive, could probably could achieve some degree of normalcy in his life and some ability to again find ways to enjoy life and make something of his own existence. And yet he wanted to die.

White and a colleague independently deemed Cowart competent to refuse treatment. Further, White was so impressed with the articulation of his wish to die that he asked Cowart's permission to film an interview with him to create an educational video. The two of them thus produced a video, titled Please Let Me Die.¹⁴

Meanwhile, Duane Larson continued in his attempts to treat Don Cowart. Larson says:

I said, "Hey fella. If you're half the man I think you are, if you're what I've been led to believe the kind of person you were before you were burned, then don't ask us to let you die because in a sense what that means is that we're killing you. If you want to die, then let me fix your hands. Let me go and operate on those hands and at least open them up so you can do something with them. And then if you commit suicide, that's, you're able to do it. But don't ask us to stand here, and ask us to, to, to literally kill you. If you want to die, you do it yourself." And with this kind of verbal attack, it was obvious that he was shocked. And so he agreed to allow us to have him returned to the operating room in hopes of obtaining enough function that he could begin to feel a little independent.

Whether it was indeed Larson's challenge to Cowart, or if it was White's affirmation of his right to decide for himself, or if there were other factors that influenced his decision, Don Cowart consented to the surgery on his hands and was released from the hospital shortly thereafter.¹⁵ Dax says:

After being in the hospital and being away from home for almost a year, a little over a year, there's no way to describe how great it felt to be back to my own house again. It's been almost nine years now and I can still remember just how great it felt to be at home, what my bed felt like for the first time, our German Shepherd Sheba coming up and licking me in the face and being glad to see me again and the feel of the cool air conditioner on a hot summer day, the feel of being out in the country. It was really a good feeling. It was only a few weeks until this really good feeling of being out of the hospital at home gave way to a deep depression. I felt confined, I could not go anywhere without having someone take me, I was really not well enough to go too many places. I had to depend on someone for practically everything I did. I felt more or less like a caged animal and just did not have the independence I'd always had before.

Ada Cowart found this time trying as well. She says:

After we got home it was still the same question: What was going to happen. He was so bored. He was so afraid he would never be able to do anything in life. He tried to spend all his time sleeping so he wouldn't have to lie there and worry about it. I'd have to continue praying. And sometimes he got real bad when we'd get into battles about frustrations of how he wanted to dress and how I thought he should dress. There were things that he wanted to do that I did not think were appropriate to do.

Rex Houston intervened sometimes. He says:

...When he had his first major problem with his mother was that her religious beliefs prohibited anybody having beer in her home. And I remember when Dax had his first six pack of beer in the house. And I hid it under his bed for him because she didn't want it in the refrigerator. And I chided her about it and I said, "Now quit worrying about it. That sixpack of beer is not going to make or break the world," and that he'd be far better off having the beer here at home than he would going out to get a beer or telling him he can't have a beer. I told her that the way to look at that is that most twenty-six-year-olds, if they want a beer, they have a beer. And that if this is going to be his home then she should do it.

Don Cowart remained extremely depressed, and Ada remained deeply worried.

She says:

Donnie was so concerned about what he was going to do with the rest of his life. He maintained that all he could do was sit on the corner and sell pencils. When he came home he tried desperately to find things that would help him spend his time, and we also did everything we could for him. He enjoyed listening to his tapes; he enjoyed CB radio which was new at that time. All the rest of us did everything we could imagine might occupy his time. He said did you ever know how awful it was

just to hate to wake up in the morning and wonder what you were going to do with all the rest of that day. One night he was particularly depressed. He said he was leaving on a date, and then he slipped out the back door. And when I could not find him when I started looking for him... I called the highway patrol because we lived in the country. And when they came out, they found him down on the highway listening to how long it took a dump truck hauling clay to a brick plant to go by and thinking he might throw himself in front of the truck. Of course this alarmed me, and after that I had a hard time getting any rest. And finally I put a TV tray out in the hallway with a metal trash can near it, and a cowbell inside of that, thinking surely he would tip it over and wake me if he was trying to get out. And after that I was able to rest and feel like a decent person the next day.

After two years at home with his mother, Cowart enrolled as a part-time student at Baylor University's School of Law. He says:

When I started at Baylor, I of course had to live with someone else at that time. I had not learned to do nearly as much as I can now. I lived with a married couple. The man was going to law school also.

Law school went well up through about the end of the third quarter. The entire time I was still having severe sleep problems, being awake till early in the morning and then having to get up for eight o'clock classes and trying to stay awake to attend the classes. I was making my grades, and as I said doing well, but it was a struggle.

I had developed a personal relationship that along about then the third quarter deteriorated. This, with the sleep problems, and with the strain of having to live with other individuals and not having the freedom of movement on my own, everything really all came together at that point to where I felt like I had given it everything I had to give, and I really tried my hardest, but I felt like I was just not going to be able to make my life work.

One night while I was alone - I had listened before when the sleeping pills were taken out of the chest of drawers - I figured out fairly

easily where the medication was being kept, and while I was alone took an overdose of sleeping pills and tranquilizers. I was found out - it was apparently obvious that I had taken an overdose. An ambulance was called and I was taken to a hospital and my stomach pumped.

When I had been at Galveston with the burns many different individuals, even the professionals there, told me, "Go ahead, get well, give life a try, then if you don't think it's worth it, take your own life." I was finding out that this was very difficult.

After three years of dropping out and re-enrolling, and after moving back into his mother's house, and after slashing at his wrists with a razor blade, Cowart contacted White, with whom he had been in contact by letter. White says:

...He called me one Sunday morning from a motel in Galveston and asked me to come and have breakfast with him. I did, and he explained many of the problems that were troubling him at that time. He was again very depressed, there had been another suicide attempt, and he was desperate because of his severe insomnia. I advised at that time that he reenter the hospital so that we could evaluate fully exactly what was causing these difficulties, and he accepted that and entered the hospital then in April [1980].

During his month in the hospital, Cowart met Keith Burton, a free-lance journalist, who collaborated with him in the five-year endeavor of producing the documentary Dax's Case, which appeared in 1985. Over those five years, Cowart also married and started a business. Yet after that, his business failed and his marriage ended. In the summer of 1986, Cowart passed the bar examination. Twenty-five years later, Dax Cowart practices law in Texas. He continues to insist that he should have been allowed to die.¹⁶

Summary of Personae

The main players in the conflict are: Dax Cowart, Ada Cowart, Rex Houston (lawyer), Charles Baxter (first doctor), Robert Meier (second doctor), Duane Larson (third doctor), and Robert White (psychiatrist). A quick summary of their positions, in the form of "I" statements, follows.

Dax Cowart

- The pain was too great to handle.
- I am blind, disfigured, and no longer able to do the things I loved to do before the accident.
- Individuals should be allowed to decide their own fate.

Ada Cowart

- I would never give up my son.
- It was God's will for him to live.
- What if, after stopping treatment, Donnie were to change his mind and it would be too late?

Rex Houston

- It was in my client's best interest to remain a living plaintiff.
- As a friend of the family, I encouraged Donnie to stick it out.

Charles Baxter

- In the initial phases, Donnie was too much in shock to make a rational decision to stop treatment.
- In the later phases, Donnie's demands to die were nothing more than an attempt to control the people around him.
- A physician has a duty to treat, and a patient has a duty to receive that treatment.

Robert Meier

- It is best for patients to play an active role in treatment. I won't force them to be treated.
- I want to rehabilitate the world, but not everyone wants my help.

Duane Larson

- In demanding that I stop treatment, Donnie Cowart was asking me to murder him.

Robert White

- Although I found it difficult to understand why he should wish to die, I am convinced that Donald Cowart's wish to die was not the result of a mental illness, that he was capable of making an informed decision to stop treatment, and that he should have been allowed to discontinue treatment.

Participants in this conflict participated in a wider dialogue about choice, autonomy, and paternalism. To better understand this context, we now turn to an overview of the ethical writings regarding Dax's case.

Chapter Three: Ethical Frameworks

Although the purpose of this thesis is not to provide an analysis of whether Donald “Dax” Cowart’s physicians made ethically correct treatment decisions, it is useful to summarize here what ethicists have written about Cowart’s case. Those who have written on the documentary Dax’s Case have utilized this story to elucidate many important themes in medical ethics. Many of these themes also arise in the documentary interviewees’ discussion of Dax Cowart’s case.

It is useful to look at these themes here not only because the interviewees in the documentary allude to many of these themes but also because everyone who writes about Dax Cowart’s story provides another perspective on the matter of his treatment. In some way, however indirect, these writers are also participants in the discussion of the treatment decisions in Dax Cowart’s case.

Similarly, we the readers and the author of this thesis are also part of the discussion. We must be attentive to, and hold, our own perspectives as they arise in the process of taking in the myriad of perspectives that come our way throughout our analysis of Dax’s case. In this way, we can develop the ability to hold the perspectives that will arise within us when we participate in or discuss treatment decisions in the future.

Autonomy

In medical ethics, autonomy is a major staple. This makes sense from a sociological standpoint. The ethics field flows from the academia of the affluent, industrialized countries, whose societies are characterized by a profound secular pluralism. The society of the United States, one of the most powerful of these producers of ethical thought, is particularly pluralistic. Its status as a nation of immigrants minus a small number of beleaguered indigenes and its history of astounding border-pushing makes it a nation of heterogeneous pioneers. Self-reliance is our legacy, and secular pluralism comes in very handy as we struggle to cope with our diversity. With this social context in mind, we now turn to H. Tristram Engelhardt, Jr.'s apology for the primacy of autonomy in ethical decision-making.

Engelhardt argues that the performance of an action on an individual without her or his consent requires, for its justification, the fulfillment of three criteria: "(1) The actions or omissions they endorse achieve what is correct or good to do, (2) they have the moral authority to realize what is correct or good to do without the consent of those involved, and (3) the use of coercive force will not do more harm than good. The common denominator needed for the fulfillment of all these criteria is the ability to place values; such as life, liberty, and the pursuit of happiness; in order relative to each other."¹⁷ This, argues Engelhardt, is impossible to do in a society which has "given up the Enlightenment assumption that one can discover the morally authoritative ranking of goods and harms so as to judge how one ought to act in particular kinds of situations."¹⁸ Therefore, Engelhardt concludes, "one must derive the moral authority for coercive force from the consent of those involved."¹⁹

James Childress and Courtney Campbell, in an article on Dax's Case, distinguish two basic elements of autonomy: "effective deliberation" and "freedom of action."²⁰

The capacity for effective deliberation is also known as competence. Competence is the ability of an individual to understand the ramifications of an action that is being considered. Donald Cowart, who was an adult in perfect health before the accident, nevertheless was considered by his first doctor, Charles Baxter, to be incompetent immediately following his accident due to shock of the accident and the narcotics he was being given. William J. Winslade, in reference to this assessment, cautions that "it is common for physicians to question the competence of patients when the patient rejects a proposed treatment but to assume that they are competent when they consent."²¹ Whatever the accuracy of the initial judgment, White and another psychiatrist independently found Cowart to be competent ten months after the explosion.²² Despite this seemingly definitive pronouncement, the conflict over Cowart's care raged on for many months afterward. In order to partially explain why this was so, Childress and Campbell invoke the second aspect of autonomy.

Freedom of action is the ability of an individual to carry out her or his wishes. Cowart, who after the accident was abjectly dependent on others for the fulfillment of all of his bodily needs, did not have freedom of action. That means that he could not simply fill out an "Against Medical Advice" form and walk out of the hospital. In addition, Childress and Campbell point out, although Cowart wished to discontinue his daily and horribly painful immersion in the Hubbard tank, he did "not intend to die from the infection" that this stopping of treatment would inevitably bring.²³ Cowart wished to have additional, palliative treatment which would have enabled him to die more comfortably. White and Larson both felt that Cowart was in effect asking his physicians to participate in his suicide. Larson told Cowart, "If you're the kind of

person I've been led to believe you were before you were burned, don't ask us to let you die, because that means we're killing you."²⁴ Freedom of action enables an individual to carry out her or his wishes without imposing on the autonomy of others.

Attention to autonomy alone would be a barren excuse for ethical medical treatment. Let us imagine for a moment that Dax Cowart did have the physical ability to leave the hospital by himself and then take his life. The outcome that would maximize the exercise of the autonomy of all concerned would be for Dax Cowart to leave the hospital "against medical advice" and kill himself by what means he chose. While this might be a viable option, it would be unthinkable for this to occur without resistance by Dax Cowart's family, friends, and medical providers.

This resistance is what ethicists call "beneficence." Although, as Childress and Campbell point out, the first dictum of medical practice is *primum non nocere*; "first, do no harm;" the point of medical practice is patient benefit - cure, comfort, prolongation of life, and so on. Beneficence is this desire for patient benefit. Childress and Campbell liken beneficence to a train engine that motivates medical care, while patient autonomy provides the tracks that determine where the train goes. In other words, autonomy an important guide for the exercise of beneficence. This may be the ideal, but the medical vehicle often derails. One way by which this can happen is through paternalism.

Paternalism

Childress and Campbell define paternalism as "nonacquiescence to a person's wishes, choices, or actions for that person's own benefit."²⁵ Paternalism, the authors assert, gives primacy to beneficence over autonomy.

Childress and Campbell classify paternalism according to three axes: pure vs. impure, active vs. passive, and hard vs. soft. The more impure, passive, and soft the paternalism, Childress and Campbell argue, the more defensible it is. The first axis concerns the effect of a nonconsensual action on people other than the patient. Whereas purely paternalistic actions aim solely at the benefit of the patient, those who engage in impure paternalism point also to the benefit that others will receive from their actions. White, for example, claimed that to stop Cowart's treatment would be to impose an "unfair burden" on his mother.²⁶ Impure paternalism, where it involves real, rather than simply rationalized, benefits to others, is more defensible than impure paternalism because impure paternalism invokes the limits of autonomy. Self-government may be a good, but it is not morally justifiable for that autonomy to seriously harm others. The second axis of paternalism, active vs. passive, refers to whether the paternalism involves an act of commission or omission. In active paternalism, a person intervenes where the patient has not granted permission to do so. In passive paternalism, on the other hand, a person refuses to perform an action requested by the patient. The treatment of Cowart over his objections was an instance of active paternalism. Nurse Leslie Kerr's refusal to provide Cowart with a lethal injection was an instance of passive paternalism. Passive paternalism, argue Childress and Campbell, is easier to justify than active paternalism because it involves the exercise of the practitioner's autonomy and because it leaves the patient with other options. Active paternalism, on the other hand, involves the use of coercive force. The final axis of paternalism, hard versus soft, reflects the extent to which the justification for an action appeals to values foreign to the patient. There were many instances of hard paternalism in the conflict over Cowart's treatment. Ada Cowart engaged in hard paternalism when she defended her decision to accede to the doctors' wishes rather than to her son's. She spoke of the wish that her son might remain alive long enough to reconcile himself to God. Because

Don Cowart had earlier left the church, this religious consideration was alien to his value system. Childress and Campbell offer as an example of soft paternalism Larson's appeal to Cowart's love of independence: "If you want to die, at least let me fix those hands, at least you can do something with them. Then if you want to commit suicide, that's for you to decide."²⁷ This is not an ideal example of soft paternalism. Because Cowart agreed to undergo the surgery, it is not clear that Larson intended to perform the surgery if Cowart had not consented. If Larson had gone ahead with the surgery over Cowart's objections, then this would have been an instance of soft paternalism. Childress and Campbell argue that soft paternalism is more excusable than hard paternalism because soft paternalism appeals to the patient's own values.

In order to think about such a situation where an appeal to the patient's own values in justifying paternalism might indeed be more than mere rationalization, it is necessary to consider the dimension of time, the subject of the next section.

Time

Childress and Campbell argue that medical ethics too often considers a patient only as she or he appears in the immediate situation to be analyzed. A patient, however, brings to the hospital a personality that has continuity over time. The choices that a patient makes can be interpreted as being more or less "in character." The more a patient's choices correspond with what is known about his or her value system, the more confident one can be that the patient is acting autonomously. Authenticity, however, is not a criterion for autonomy; "at most, considerations of authenticity should alert us to ask further questions."²⁸

In Dax's case, the question of appeals to the future self was a central issue. Dax's mother, Dax's physicians, and others who opposed Dax's wish to die worked

feverishly to “protect” Dax’s future self. Ada Cowart in Dax’s Case uses the eventual outcome of Dax’s treatment to ratify her choice: “Looking back over the last ten years, I think I made the right decision... Now that he’s married, enjoying life and his business, I know it’s right now.”²⁹ Dax, on the other hand, continues to insist that “The ends do not justify the means.” That is, despite the fact that Dax in Dax’s Case allows that he enjoys life now, he emphasizes that the suffering that he went through to get to that point was not worth it. In fact, he says, if he were to sustain similar injuries tomorrow, and he had some way of knowing that in ten years he would reach his current state of well-being, he would still want to die.

Agreeing with Dax, Engelhardt and also Childress and Campbell conclude that appeals to the future self cannot be used to justify paternalism.³⁰ In Childress and Campbell’s words: “An appeal to future ratification is insufficient to justify paternalistic interventions; ...such appeals at the time of decision making simply reflect the agent’s hope [that the patient will be glad in the end].”³¹ Engelhardt argues that in order for us to appeal to the claim that “the future self will live a long and fulfilling life, albeit with major physical handicaps [if lifesaving treatment is performed],” one would need to weigh the costs of violating the present self’s demands against the benefits of saving that person’s life.³² “One needs an ideal observer with a univocal measuring rod, neither of which appears to be available to resolve the issue.”³³

On the other hand, Robert Burt argues that the present self, in cases such as Dax’s early post-accident condition, may not be the best judge of the situation.³⁴ A patient dealing for the first time with the reality of a future filled with extreme disfigurement and disability will have a different perspective than one who has lived with disfigurement and disability for a while. The question for Burt is, how long do you try to help the patient gain this potential perspective, and at what point do you step aside and let the present self decide?

In thinking about appeals to the future self in Dax's case, it is difficult to ignore the fact that Dax's mother (for example) and Dax' each had a different future self in mind. On first inspection, Dax's mother seems to have tended to gloss over Dax's concerns about his disability and disfigurement. To be fair, however, Ada Cowart was perhaps doing that which, out of everyone, mothers seem to do the best: she saw her child in a way that transcended his physical self. Dax's view of his present and future self, on the other hand, was one of utter despair. He did not want to go through life blind, his face burned off, unable to do things for himself.

Disability and Disfigurement

Because it is an inescapable part of Dax's experience and of those who come in contact with him, a consideration of disability and disfigurement must figure strongly into any practitioner's encounter with someone so suffering. "For in leaving them disfigured, medicine leaves them with a chronic sorrow, a limitless grief, which the aversive swoons of others salute but cannot heal."³⁵ What is this chronic sorrow? What is this limitless grief? What are these aversive swoons? What is it for Dax? Even with the foreknowledge that we cannot satisfactorily answer them, we must ask these questions.

Let us turn first to the problem of aversion. This, as May writes, the disfigured person cannot escape. "The visual impact on others flies out ahead, beyond control... Thus the scar not only encases and distorts the victim; in a sense, it also encases and distorts the responses of others."³⁶ Dax says that he is lucky that at least he is blind and cannot see the reactions of others to his looks. Undeniable, however, is the impact of his disfigurement on his relationship to others. "Profound disfigurement aborts many

of the common and reassuring signals by means of which ordinary life is conducted between people.”³⁷

The impact of aversion on ethicists and others mulling over the fate of a disfigured/disabled person who asks to die merits consideration. Stanley Johannesen sounds the haunting warning: “If we are persuaded by a film that a badly injured young man ought to have been allowed to die when he wanted to, we are either influenced by his political ideology and do not need the visual evidence of his tragedy, or we need the visual evidence and are therefore calling our repressed revulsion into play to assent to a death that would otherwise seem unnecessary as a premature and wasteful death.”³⁸ Further: “Has Dax received all that we can give him out of our spiritual resources if we agree that being damaged as he was he ought to have been allowed to die?”³⁹ Even if revulsion plays only a tiny role in our assessment of Dax’s case, we must recognize it before we go on. In our effort to bear empathic witness to another’s suffering, we must attempt to hold our aversion as we would any perspective. By avoiding the repressive or suppressive response to aversion, it may become possible to be more fully present with the other person.

And what of grief? In the film, Dax shares a little of the desolate fear that gripped him after he left the hospital that he would never “have a real relationship, a meaningful relationship with any member of the opposite sex.” He also talks of staying at home for as long as he could:

I could not see myself to know what I looked like, but I knew that I was scarred and disfigured and after coming home considered not going out in public at all. ...I had a case of cabin fever so bad that I finally said just to hell with it, and went ahead and did go to restaurants and stores and other places in public.

Dax went from golden child (he really did have wavy golden hair before the accident), captain of his high school football team, Air Force pilot to being the object of imagined stares and being unable to look at himself in a mirror to even get used to the sight of himself.

What is this “sight of himself”? May adds another element to aversion: aversion to self. Patients with catastrophic conditions become extraordinarily sensitive to others. “The foolish inspire contempt; the nervous, impatience; the transient philanthropists and tourists, anger; and friends and professionals, the temptation to manipulate. No sensitive patients can fail to note their own unsavory responses and more. Thus they experience a profound aversion not only to the event but also to themselves.”⁴⁰

The sight of oneself is also about one’s deepest sense of identity. “The patient’s “look” is not an abstract object of aesthetic judgment. It is always someone’s look and therefore cuts to the core of self-presentation.”⁴¹ Don Cowart’s face is gone, melted in the fire that took from him nearly everything that he once thought he was. “Don Cowart knows that he has not simply suffered a modification in his quality of life, some changes at the margins of life; the explosion has annihilated him. Don Cowart, as defined by everything that he was, has died.”⁴² The rodeo rider, the pilot, the football player, is gone. What was left in the debris of the explosion was a rugged individualist who could no longer be at all independent: “These various losses [of physical function]... will blast that identity which each of us assumes with our bodies as the instrument of mastery.”⁴³ For Dax, born and raised in Texas, this loss might have been the worst.

What does Dax think of when he counts his losses? Lonnie D. Kliever writes that whereas many who suffer try to locate themselves “within a larger universe of meaning and purpose,” that is, to redeem their suffering, Dax does not. “He nowhere sees his accident as an occasion for deepening his spiritual relationship to God. He

nowhere confronts his pain as the supreme test of his faith in the face of adversity. He nowhere resolves to conquer his handicaps to help others facing similar circumstances.”⁴⁴ Kliever compares Dax’s response to the Biblical Job’s response to Eliphaz, Bildad, and Zophar, who come to Job as he sits on the dung heap. “Eliphaz insists that human standards of justice cannot be applied to the divine purpose. Bildad insists that God’s justice forecloses all debate about whether human beings suffer necessarily for cause. Zophar drives the argument home by insisting that human wickedness deserves even worse punishments than God allows to befall the sinner. But Job... stoutly maintains his integrity against their charges.”⁴⁵ Whereas Kliever characterizes Job’s comportment as being full of integrity, however, he criticizes Dax’s response. “Dax has not reached a clearly positive alternative to the scheme of redemptive suffering he rejects... Caught between bemoaning his survival and begrudging his existence, Dax remains torn between life and death.”⁴⁶

I disagree with Kliever; I believe that Dax has not altogether rejected redemptive suffering. What about the making of the documentaries? What about Dax’s decision to become a personal injury lawyer? Certainly Dax has refused to say that he is glad he went through what he did, or even that he is glad that he survived his treatment; he nevertheless seems to have tried to make the best of his situation. Instead of redeeming his suffering, Dax has simply used it as, for example, someone might use a white elephant gift as a paperweight. This, I argue, is a positive alternative to a more traditional framework of redemptive suffering.

Dax the individualist, Dax the football team captain, Dax the disfigured man with cabin fever who fears and seeks out the company of others, Dax was never alone. And yet, he is alone. Let us now seek to understand the relationships he had and the separations.

Relation and Separation

We have come a small full circle now, to consider again Childress and Campbell's ethical analysis. They write of the importance of "community" in medical care and medical ethics. It is ethically important for all involved in a patient's care express concern, to express community.⁴⁷ "Respect for persons unleavened by care can appear as indifference to the life and death of others."⁴⁸ Burt warns against implementing a patient's wishes without actually engaging with the patient. "It is not only permissible but imperative that whoever hears [a patient's request] 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?'"⁴⁹ Blind adherence to "respect for persons" may be seen as a failure to hold perspectives. It is a short-cutting of the process; it is like saying, "OK, you win," before the wrestling match starts. True engagement requires that the patient's desire to stop treatment and the physician's desire to continue it be held as separate perspectives.

Relation

Let us look at some of those who make up a big part of Dax's "community:" his mother, his physicians, and his lawyer.

- For Ada Cowart, Dax was her son, critically ill in the immediate aftermath of losing her husband. "As a mother it was hard for me to say that I could give up a child. I don't think I could ever reach this decision."⁵⁰ "Donnie" was, to her, also a lost sheep who had left the church. "I had prayed that he would never be killed instantly because he liked activities which were very dangerous, such as rodeo and flying and so forth. And I was hoping that he would have time to realize his responsibility to God." Patently obvious was their raging power struggle, over his

treatment, over whether he could drink beer in her house (he could be nowhere else at that time), and of course, over what he wore. "There were things he wanted to do that I did not think were appropriate to do." I can only imagine. According to Winslade, Ada was clearly a mother trying to protect her child. And Dax?

Winslade says: "The power struggle with his mother was of course in part a reaction to his dependence on her, an unavoidable emotional regression in the face of his injury, and in part a reaction to his being a captive held for treatment by his physicians."⁵¹ White argues, similarly, "When a small child is hurt and helpless he or she predictably will turn hurt into anger toward the parents and others who provide care and on whom he or she depends. The child feels that if the parent (or other caretakers) really cared they would not inflict such pain."⁵² In other words, Dax and his mother often related to each other as mother and young son.

- Rex Houston first knew Dax as the son of his friend, Ray Cowart. "Dax Cowart himself I had known since he was a high school boy. I followed his career through the Air Force... where he... had a very good service record. He was an outstanding young man, had a good mental outlook and a bright future." Houston describes himself as friend and attorney to the Cowart family "of long standing." Houston, after the accident, became not Dax's personal lawyer but his family's lawyer and, as discussed above, was filing a personal injury suit on behalf of Dax and his father. But at least sometime over the course of Dax's recovery from the accident, Houston became Dax's personal friend and advocate. As described in the last chapter, Houston even helped Dax to smuggle beer into his mother's house.
- For Charles Baxter, Dax is a difficult patient. At first, Baxter interpreted Dax's disturbing demands to be allowed to die as the result of "shock." Later, however, Baxter came to see Dax as manipulative. "...I felt that most of his expressions to

nurses and other people were just means that this individual used in order to get what he wanted.” Dax, on the other hand, “...perceived his relationship with Dr. Baxter to be that of a prisoner as well as a patient.”⁵³ Dax himself says: “The truth of the matter is that I was the one who was being manipulated. I had absolutely no desire to control anyone around me. All I wanted to do was to leave the hospital. The only thing I’ve ever been guilty of was doing whatever it took to gain my release.”

- Robert Meier saw Dax as a new ethical challenge, a profound confrontation to his belief system, that he encountered in his first year after residency. Meier was trained to believe strongly in patient participation in treatment, and here was Dax Cowart calling his bluff. Ten years after his first encounter with Dax, Meier feels “more comfortable with people choosing to not necessarily achieve the level of function that [he thinks] is possible for them.” I would imagine that Dax played a major role in this process for Meier.
- Duane Larson, who as discussed above, received Dax after massive infection had erupted as a result of Meier’s cessation of treatment, probably saw Dax as a tragic mess to clean up. He acknowledges that “Don was a very difficult patient to treat.” Although Larson claims that his decision to treat Dax against his will was not a difficult one, he speaks of having been haunted by the memory of treating him. “He is the one I remember most.”
- Dax entered Robert White’s life and has never left. Dax was for Robert White a patient, someone to advocate for, a teaching model, and quite probably, a friend. I was tempted to say that Dax was White’s poster boy for the right-to-die issue, but I cannot; White simply accorded Dax too much respect in order for that to be the

case. Notably, White was the only person with real decision-making power to perceive Dax as an adult competent to make the decision to stop lifesaving treatment. The respect accorded to Dax by White had a profound impact on their relationship and on Dax's decisions to receive treatment. White's pronouncement of Dax's competence roughly coincided with Dax's acceptance of the skin graft surgery on his hands that he had earlier refused. Dax's and White's breakfast in Galveston in 1980 led to Dax's decision to enter a mental hospital for acute treatment of his depression. With what I know of Dax, I doubt that he would have ever made such a decision to accept psychiatric hospitalization if it were not for White.

In all of these relationships arose the specter of nonverbal communication, of that which lies between the lines. Childress and Campbell warn: "Although claims about the patient's real wishes or messages are not always mistaken, they need to be taken with caution when they are at odds with the patient's expressed wish to die."⁵⁴ White, trained as a psychoanalyst, writes of this level of communication with his characteristic thoughtfulness: "...There was the complex issue of ambivalence in human behavior, that is, people are often quite divided in their intent. They may very much want a certain goal and simultaneously not want it."⁵⁵

Dax's demands to die have been the object of much speculation regarding the nonverbal components of this demand. Robert Burt writes that Dax's plea to be allowed to die was "more of a question to others about their wishes toward him."⁵⁶ Speaking also to this relational nexus, Winslade "...suspect[s] that Dax knew he could rely on his mother not to abandon him no matter what he said to her. He may have been less comfortable about and confident in expressing his outrage at his disability,

anger at being treated, and grief over the loss of his capacities to his physicians and other medical staff.”⁵⁷

Regardless of whether communication was explicit or implicit, it formed a precious commodity that Richard M. Zaner calls “dialogue.” Dialogue, argues Zaner, is essential in ethics. “Morality is... not a matter merely of autonomy; it is, rather, that of mutual enablement, an act of communing with one another about issues that matter, make a difference in one’s life.”⁵⁸ Zaner defines dialogue as the “need for ‘talk’ or ‘speech’ about what ‘things truly are.’”⁵⁹ A good example of dialogue is what Robert Burt proposes for the physician’s response, discussed above, to a patient’s request to terminate treatment. Burt elaborates:

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... We are mutually shaped by our expectation in lots of ways.⁶⁰

Dialogue has the quality of emergency. “The participant in dialogue at some point feels overcome or set upon, unable to continue to do (whatever it may be) or be (whatever he or she has been up to then), without stopping and thoughtfully dwelling within the happening of what, through dialogical speaking, has overcome him or her and obliged questioning.”⁶¹ Dialogue is an inextricably relational process that depends on everyone involved to give it form and substance. Ideas, assertions in dialogue are being continually shaped as they travel among the participants.⁶² This relational quality of dialogue paradoxically means that a participant or potential participant can destroy dialogue at any time. Nothing can guarantee that the person being questioned will respond with dialogue or even respond at all. “The issue of dialogue is that the

questioner cannot be assured in advance and in the same ways about the genuineness of the response, or even whether he or she will be listened to.”⁶³ In a sense, then, dialogue includes both relation and separation.

Separation

Relation does not seem to exist without separation or the possibility of separation, and separation in turn does not exist without people who could potentially be relating to each other. Two major elements surface as one looks at the sources of separation among participants in Dax’s case: embodiment/disembodiment and moral certainty.

Sally Gadow argues that there is a profound separation between Dax and his caregivers caused by the fact that he is “embodied” and others are “disembodied.” “The distance between Dax and his therapists can be summarized as the difference between, in his case, having the body as one’s entire - and entirely negative - sphere of existence and, in [his therapists’] case, freely functioning without regard for the possible torments of embodiment.”⁶⁴ Dax is “...physically powerless to resist, to flee, or even to shield his body... Familiar avenues - the eyes and the hands - that lead out of the body and away from its pain are permanently closed.”⁶⁵ “Dax’s therapists,” on the other hand, “cannot be seen with or without their clothing, since in his case they cannot be seen at all, while he cannot be unseen. Nor can he feel their bodies, clasp their hands in his. They touch him at their discretion, usually gloved and with instruments, reminding him palpably of his own body more than theirs.”⁶⁶ In a similar vein, May argues that ethics is essentially “unheroic” for the doctor but the very opposite for the patient. “A doctor solves problems, but those problems, except at the technical level, make no further personal demands. Solving a problem provides the physician with a release from tension... Agonizing is a temporary phase of decision making from which,

in a given case, one expects release.” The patient gets nothing of the kind. “When the staff has long since done its work and snatched the patient from the jaws of biological death, the agony, the suffering, of the patient has just begun. Thrown out into a no-man’s-land, without much resource from his or her former life, cut off from former goals, old skills suddenly irrelevant, aspirations utterly unattainable, old identities and enthusiasms on the ash heap, the old persona unwearable, and the familiar rhythms and tempo of life faltering, such an individual faces vastly more than a quandary to be solved.”⁶⁷

With such an existential divide between physician and patient, it is a wonder that any communication occurs at all. Gadow argues, however, that “...though inevitable, the chasm is not yet unbridgeable; only moral certainty can make it so.”⁶⁸ By moral certainty, Gadow means the refusal to let in alternate perspectives; moral certainty in this context is a failure to hold the other person’s perspective. It is like saying, “I win,” before the wrestling match starts.

What happened in Dax’s case was in part the creation of moral certainty via the language of rights. In Zaner’s words: “By framing the moral issues in the language of rights, Dax’s demand inevitably elicited the response of an opposing right.”⁶⁹ Like Gadow, Zaner asserts that the drawing of this moral line in the sand leads to an uncrossable separation.

In such a situation, inevitable and unresolvable rivalry and conflict ensue, there being... no culturally or logically compelling way by which to weigh and resolve the multiple claims inherent to the rivaling viewpoints... It thus becomes almost fateful that the continuation of treatment gets construed as paternalistic in the worst sense; ... to construe the moral situation in this way is to make it at best adversarial, a situation in which someone has to be right and someone else wrong.⁷⁰

Robert White seems to have crossed this divide. Although it is fully possible that he did not start with a strong orientation toward treating patients at any cost, it is also clear that he engaged in perspective-holding. His ability to make room for the possibility that someone can simultaneously want something and not want it is evidence for his skill in perspective-holding. Also, his acknowledgment of his own puzzlement over Dax's demands to die shows a willingness to engage with multiple perspectives and with Dax.

We now turn to the use of creative writing as a tool to develop the ability to hold multiple perspectives.

Chapter Four: The Process of Writing

Since the purpose of this thesis is to illustrate how physicians might cultivate the quality of holding multiple perspectives through creative writing, it is worthwhile at this point to discuss the process of writing the fiction portion of this thesis.

The Raw Material

There are a number of problems with using the documentary, Dax's Case, for any form of analysis of the conflict surrounding Dax Cowart's care. First, Dax's Case was made twelve years after Dax's accident. Twelve years is a long time for people to digest their memories. Second, there is no portrayal of conversations between any of the interviewees. It is difficult to extrapolate how the participants interacted between 1974 and 1980. Finally, the documentary squeezes interviews with nine people into an hour of film. This process of editing severely limits the quantity of material available for analysis and biases the content of the material toward the agenda of the film's producers.

On the other hand, any analysis a physician would make of a conflict in her or his own practice would suffer from limitations of quantity and bias of content with which to work. The physician, of course, has the advantage of having fresh material. Nevertheless, the purpose of the thesis is to provide an example of how analysis and free writing might be done in the case of a conflict encountered in real time. Dax's Case will serve as the substrate for such a demonstration.

The Basic Approach to Writing

I have modeled my approach to creative writing after my experience in Dr. Guy Micco and Nellie Hill's creative writing class, which I have taken each semester for the last two years. It is my hope that groups like these will become more prevalent among medical students and physicians and that these will serve as the basis for the kind of creative writing I am proposing in this thesis. Dr. Guy Micco and Nellie Hill co-teach an elective class on creative writing for medical students each semester. The group, composed of Guy, Nellie, and a handful of students from the Joint Medical Program, meet for two hours every two weeks. The class session consists of two or three short cycles of writing on topics that one of the instructors or occasionally one of the students proposes. The subject matter can be non-medical or medical. For example, a popular recurring topic is to write, with the non-dominant hand, a childhood memory. Sometimes we are asked to re-write a patient write-up from the perspective of the patient. Once, Nellie proposed that we write a description of ourselves from the point of view of a patient we just interviewed.

One of the traditions of the class is that each person is free to modify the topic or choose not to write on the topic at all. After we agree on a topic, we write for about ten minutes. Usually someone begs for more time, and we negotiate. Another tradition is that we encourage each other to write with as little editing as possible. Then, we take turns reading our writing to the group. A fun, and perhaps also important, tradition is that we poke fun at ourselves for the critical comments we make before reading; someone writes down everything we say before we start reading. The comment usually runs something like, "This is the worst thing I have ever written." After each person finishes, we have space for brief commentary on the writing, usually more

related to content than form, and then we continue on to the next person. There are many benefits to writing this way, including a sense of camaraderie; an inducement to take time to write; the cultivation of a non-judgmental environment to drown out the internal critic(s), probably the main barriers to writing for most people; and a lot of fun.

Another great benefit to writing in this particular group is Nellie's practice of giving out customized homework assignments. When I told her about my thesis, she suggested that I sit down for five minutes a night and write from the perspective of each person in the documentary. While I did this somewhat erratically, I nevertheless found it an extremely effective way to get this writing going.

Writing from Various Perspectives

Each night I wrote from the perspective of a different "character." Here is an example from January 17, 1998.

Dax: God, if there is a God, why are you doing this to me? I don't see how my mother can believe in you the way she does. How can there be an omnipotent being who is all good, when something like this can happen? I understand death; that is fine. But why should we be forced to suffer and not be allowed to die? I know that the free will thing is plausible; I mean, there could be a God that decided to allow men to do bad things to others. That would be fair, I guess. But I am innocent. I don't deserve to go through this. Why can't you just kill me? What do you want from me?

This writing, like every other fiction piece written for the thesis, mixes my own experiences with what I "know" about each character. This particular passage, for example, is quite faithful to my own idea of how extreme pain, helplessness, and debilitation might impact, and has in fact impacted, my own relationship with God. The piece also takes into account the fact that Dax's mother spoke of wanting Dax to

reconcile himself with God before he died. From this, I speculate that perhaps Dax does not believe in God. Of course, there is a myriad of other possibilities for what Dax's belief system might look like, but this passage just takes one possibility and runs with it.

This melding of my own experience with Dax's is an act of empathy and is vital to the overall goal of perspective-holding in conflict resolution. While connection-making may seem to run counter to the idea of maintaining multiple irreconcilable perspectives, it is actually not an attempt to force any logical resolution of perspectives. The writer must keep in mind that the connection is grounded in fiction and not necessarily in fact. Lines of empathy are tentative tendrils sent out to the other and extended or withdrawn as the case need be.

Thematic Analysis

As an adjunct to the creative writing, I undertook an ambitious attempt to perform an analysis in the style of the semiotic network analyses of Byron Good, a medical anthropologist. My goal here was to use an analytical technique to elucidate themes around which to focus my creative writing. I gravitated toward Good's analytical technique because it potentially offered a simple way to look at the relationships among different people's perspectives.

Good's Semiotic Networks

The term "semiotics," as used by Good, refers to the study of how concepts are linked to one another. Semiotic networks are representations of that linkage. Perhaps the best way to elucidate this definition is to give an example from Good's own work.

Introducing his analysis of a medical resident's interview with a Jehovah's Witness woman presenting with rectal bleeding, Good cautions about the problem of translating a patient interview into medical knowledge.

Physicians and their patients categorize signs and symptoms differently; in [Benjamin Lee] Whorf's terms, they "cut nature up, organize it into concepts, and ascribe significances" in a fashion appropriate to their own speech community and their own existential concerns.⁷¹ Because categories and lifeworlds differ between patients and physicians, medical conversations are filled with interruptions, misinterpretations, and failures of understanding - a finding reported commonly in the medical social sciences and experienced by nearly anyone who has visited a physician.⁷²

Good goes on to present a portion of the transcript from the interview:⁷³

Jehovah's Witnesses don't take blood, because the blood is, the Bible refers to the blood as the life, and we're not to take anybody's life into our own bodies, and it's no different if a doctor tells you not to drink alcohol, if you don't, if it doesn't pass over your lips, and they take it and put it into an I.V., it's no different, you're still disobeying the doctor's orders, and the same goes with drinkin' blood. You wouldn't slice somebody's throat and drink it, so you don't stick it into your veins, and Biblically it's in Leviticus in...

I've got a card that I show my doctors, you know, I had that put on my medical records in case of an emergency where a doctor might feel in his opinion that I'd lose my life if I didn't have a blood transfusion. It's on my records here at the medical center, and then there's also a booklet that I can give my doctor if I'm going to go in for surgery and he doesn't understand it, then there's a whole bunch of information on blood, how it's, really it's a filthy product, because it's takin' somebody else's, you know, stuff into your body. It does a lot of things. You can even die from takin' blood transfusion. [So you mentioned that blood is a filthy product?]

Uh huh. It's unclear. People don't even handle it when they're, when they go through the purification process, whatever it is, I'm not exactly sure what it is, but I know that they don't handle it because it even makes their skin break out just to touch it. And for people to die from taking it into their body, it's something foreign. The only thing the way we're set up, we won't live with anything foreign in our bodies, except for a woman when she's giving birth to a child, that's the only foreign thing that really lives in the body. Outside of that, after you leave your mother's body, you're a different person, the blood's not the same; it's an individual.⁷⁴

Blood, argues Good, is for this patient the center of a number of symbolic oppositions:

"blood as the life"	"you can even die"
"it's an individual"	"it's something foreign"
	"filthy product"
	"unclean"
	requires "purification" ⁷⁵

The resident does not share this semiotic network. His primary, and appropriate, concern as a physician is the possible relationship of the patient's bleeding to a disease process, such as cancer or anal fissures. Good does not map out a semiotic network for the resident's concept of blood, but my guess is that such a network would look somewhat like a differential diagnosis decision tree. Of course, things are not as simple as that. The patient is in all likelihood concerned with the physiologic implications of her symptoms, although we do not get a peek here at what her differential diagnosis decision tree would look like. The resident, in turn, probably shares a similarly dualistic view of blood, acknowledging its life-sustaining and its

disease-transmitting properties. Nevertheless, these two individuals' "formulations of reality"⁷⁶ differ markedly from each other. It is important for the physician to hold both of these symbolic sets as he proceeds with her care. Not only does this holding help him to show the patient empathy for its own sake; holding both perspectives also facilitates the negotiation of future treatment, making it less likely that any conflicts that arise will be resolved coercively.

Clearly, this analysis does not do justice to the woman's narrative. For example, it does not satisfactorily address the woman's apparent anxiety about the possibility that physicians will not understand her religious objection to blood transfusions. Despite its limitations, semiotic network analysis has its utility in clarifying the connections and discontinuities among individuals' "formulations of reality."

Thematic Analysis in Dax's Case

When I set out to apply this analysis to Dax's case, however, I found instead of symbolic oppositions a perhaps simpler configuration of values among conflict participants. Two closely related themes of value conflict emerged during the process of creative writing: 1) the contextualization of individual will; and 2) that upon whom or what one relies in times of hardship. The first theme outlines the relationship of an individual's wishes with someone or something else that has some kind of power in reference to that choice.

For Dax, the individual's will opposes itself to an oppressive, imposed will of another individual or of an institution. He says:

What astonished me the most was that all of this was happening at the very same time that our country was undergoing a revolutionary change in favor of civil liberties and while there was a very heightened awareness of freedom of choice by the individual. I have absolutely no interest for anyone to refuse

treatment or die. The only interest I do have is that the individual be able to refuse treatment if that is what she or he wishes. I have felt, even far before the accident, that we as individuals have the right to act on our own perils and that in the end we're going to have the best overall result if individuals are allowed to make their own decisions when they wish and be accountable for those decisions.

For Ada, the individual's will must answer to the will of God. She says, for example, "Had I believed it was God's will, for him to go on and die, I think I could've accepted that." The individual must also yield to the will of physicians. "The doctors made most of the decisions."

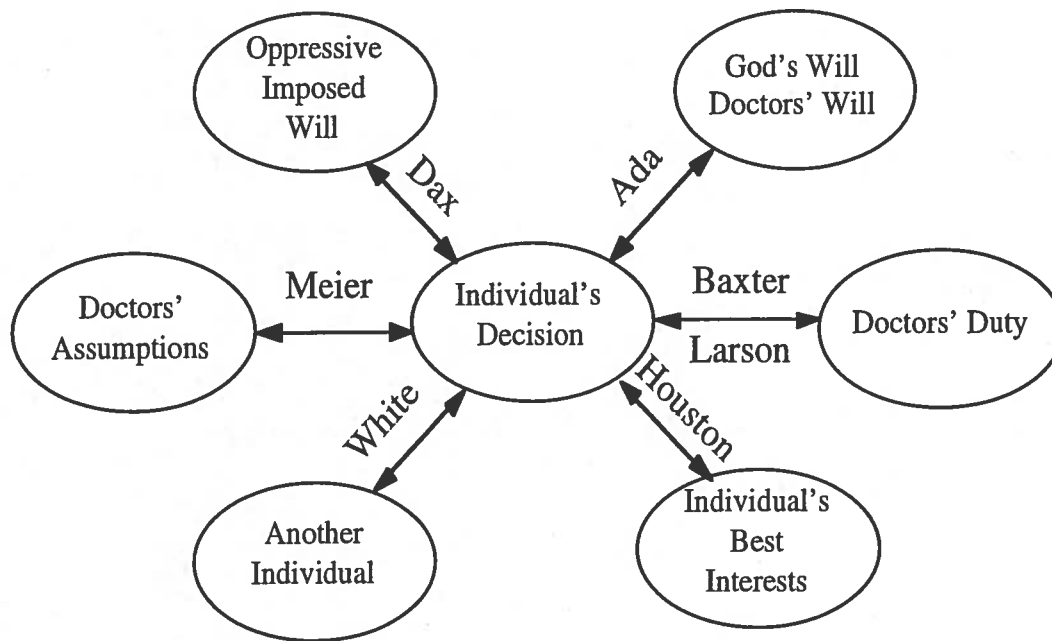
For Drs. Baxter and Larson, the individual will is opposed to the duty of the physician. Baxter says: "...From the moral standpoint, [we had an] obligation... to deliver medical care and Donnie to accept it." Larson says: ... "Don't ask us to let you die because in a sense what that means is that we're killing you... Don't ask us to stand here, and ask us to, to, to literally kill you."

For Dr. Meier, individual will asserts itself against what doctors assume that they should do for their patients. "I was caught in a rehabilitation dilemma because I had been trained to know how much functional ability people can achieve despite serious burns and yet also wanted people to make their own decisions."

For Rex Houston, it is individual will versus best interest. "As a living plaintiff, he had a lawsuit that had tremendous value to it."

Finally, for Dr. White, individual will opposes itself to another individual's will or to a conflicting desire within the same person. "...There was the complex issue of ambivalence in human behavior, that is, people are often quite divided in their intent. They may very much want a certain goal and simultaneously not want it. So the surface message, 'I want to die,' might not be the whole story."⁷⁷

This can be summarized as a diagram:



The boxes on the left side of the diagram represent value systems that fit roughly into a framework that values autonomy and the ultimate right of the individual to decide his fate. The values on the right side of the diagram are consistent with a more paternalistic framework that asserts that the ultimate decider of an individual's fate could rightfully be someone or something else. It is easy to stop there, to put Dax, White, and Meier in one camp, facing off against Ada, Baxter, Larson, and Houston. But there exists, even within these autonomistic and paternalistic frameworks, an undeniable diversity of values. It may seem straightforward for the people on either side of the diagram to agree amongst themselves on a course of action for Dax's treatment, but they each arrive at their conclusions somewhat differently. Such distinctions are important in conflict resolution, where it is vital to counteract the

tendency to polarize the situation. One who is interested in conflict resolution must strive to hold each perspective individually, rather than to lump them together.

The other main theme emerging from the writing process is that of reliance. As mentioned above, the perspectives here are quite closely related to those in the decision-making theme.

Dax relies on freedom: "As far back as I can recall, I have always felt a strong sense of independence and freedom." Speaking of one of his later suicide attempts, Dax says, "This, with the sleep problems, and with the strain of having to live with other individuals and not having the freedom of movement on my own, everything really all came together at that point to where I felt like I had given it everything I had to give, and I really tried my hardest, but I felt like I was just not going to be able to make my life work."

Ada relies on God: "...If you don't have God to go to, who can you depend on?" She emphasizes the importance of prayer:

He was so afraid he would never be able to do anything in life. He tried to spend all his time sleeping so he wouldn't have to lie there and worry about it. I'd have to continue praying.

Charles Baxter and Duane Larson rely on duty. Baxter says:

I have felt... that it is my obligation to deliver those techniques and services and things that we have been endowed with and know how to do to the best of my ability. It's not my decision whether they work or don't work in an individual case.

Larson says:

But in order for me to practice medicine, I've got to do the best I can. Don has certainly had an impression on my life, but I can't change my way of taking care of patients."

Rex Houston's reliance upon common sense comes through in his approach to Ada and Dax's fights:

...Her religious beliefs prohibited anybody having beer in her home. And I remember when Dax had his first six pack of beer in the house. And I hid it under his bed for him because she didn't want it in the refrigerator. And I chided her about it and I said, "Now quit worrying about it. That sixpack of beer is not going to make or break the world..." I told her that the way to look at that is that most twenty-six-year-olds, if they want a beer, they have a beer.

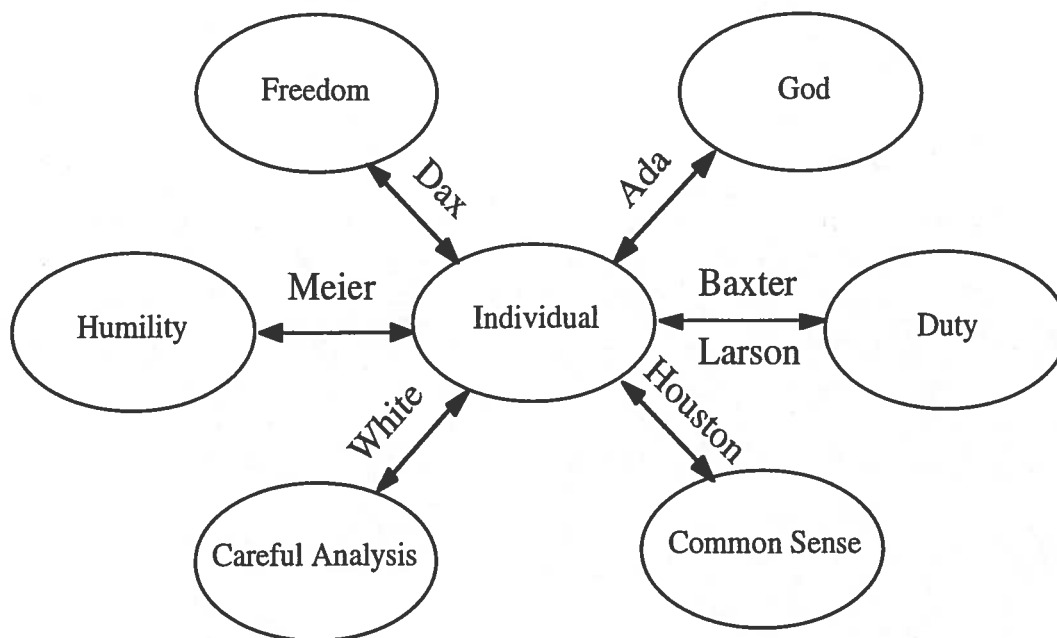
Robert Meier relies on humility:

I wanted to rehabilitate the world. And especially Don Cowart. That wasn't necessarily his priority. The difference now is that I'm more comfortable with people choosing to not necessarily achieve the level of function that I think is possible for them.

Lastly, Robert White relies on careful analysis of the situation:

We must find a judicious and reasoned response to this view that Dax stoutly maintains to this day. Our response must be one that safeguards patients when such requests are a symptom of mental illness. It must protect patients who act impulsively as a result of temporary exhaustion and stress... Patients must also be safeguarded against unscrupulous physicians or family members who, out of hope for personal gain, request that a patient be allowed to die. Perhaps most of all, patients must be protected against those physicians who out of personal bias blindly adhere to the view that human life must be sustained as long as possible and regardless of the wishes of the patient.⁷⁸

A diagram, very similar to the last one, sums up these views:



Taken together, the themes of decision and reliance in Dax's case suggest that each participant comes from a very different place. The decisions to stop or continue treatment mean something different to each person. For Dax, the continuation of treatment meant that one of his premier values, freedom, was thrown to the wind. For Ada, the continuation of treatment meant submitting to God's will; to stop treatment would be to fly in the face of that upon which she ultimately depended. For Rex Houston, common sense must prevail, and to refuse treatment would be to defy common sense (if only for the reasons mentioned above, of needing to be a living plaintiff for the sake of the predicted large settlement). For Robert Meier, discontinuing treatment meant approaching a patient with the humble acknowledgment that doctor does not know best. Charles Baxter and Duane Larson continued treatment secure in the knowledge they were being true to their duty. To forsake this duty would be to turn away from the one thing that they knew for sure - that they were here to give of their knowledge and skills in the service of saving lives. And finally, for Robert White, the

ultimate object of reliance was a careful analysis of the situation. He concluded that Dax's decision to forgo treatment was not clouded by insanity or even by an infantile regression in the face of extreme pain and helplessness. Once he reached that conclusion, he seems to have felt reasonably secure about the situation, though he also says, "For the entirety of the twelve years since that meeting, Dax Cowart has disturbed my peace of mind..." Perhaps the key to my impression of Robert White's ultimate sense of serenity in relation to Dax's case is his addendum: "But it is fitting that my peace of mind be disturbed by the issues Dax raised, and I hope he has disturbed the peace of mind of all who have given thought to these matters."⁷⁹ Thus, I am convinced that Robert White remains comfortably discomforted by the case of Dax Cowart.

Thus, it is clear that although it initially seems possible to divide the conflict participants into two opposing camps, there lies immediately beneath the surface a rich multitude of approaches to the situation. The decision to treat or not treat means something different to each person,⁸⁰ and each of these meanings needs to be held with equanimity. In this way, we can depolarize the situation and suspend moral certainty enough to take in new information. How do we cultivate this place of holding? As we say in writing class to almost any difficult question or situation, "Write about it."

Chapter Five: Creative Writing⁸¹

Dax Cowart

I remember only the orange
That grabbed at my eyes
In the heat so hot it froze
My arms and legs into slow motion
I ran knowing nothing but having to
Get away get away get away get away -
But tangles caught my feet caught me I slowed
I slowed
I had to
Turn
Back
Through that fire again that fire again
My feet hit the road I ran flew float
Through blur through
Then
Out
And down finished I knew
I
Broken
Worse
Than dead.

There are times, events in your life, that change everything. I should have died out there in that explosion. In fact, I did die. The trouble was, no one besides myself could respect that fact. What do you do then? And what do you do when, on top of all that, there is the pain that demands the attention of every cell in your body that remains? My mother prayed. I could not. All I wanted to do was to die and to die as quickly as possible. I felt, and still feel, that a quick death was what was owed to me. If I had to go through such an unspeakably excruciating experience, why should I be denied the death that was coming to me? Only medical science, with its cruelly innocent intentions, could deprive me of my last right.

I remember it as a dream and as the most undeniably real thing that has ever happened to me. I was running, blurry, as if underwater. Voices, pain in the distance. They were coming, they said. I laid down in the grass.

"Oh my God," said the farmer when he saw me. From this I knew that I was probably burned even worse than I first thought.

"Go help my father..." I managed to say, and then everything faded again for a while.

"I've called the ambulance, son." The farmer had returned.

"No, no. Please. Bring me a gun. I'm going to die anyway. I've got to put myself out of this misery."

"I can't do that."

He said it in a very caring way. Yet, I would have kicked him if I could have. No, I would have shaken him. "Can't you see I'm a dead man? Can't you help me to get out of pain while I'm dying right here on this spot?" But, I understand. He couldn't kill me. I know now that I was not even physically capable of pulling the trigger. My hands had been so badly burned.

Then the ambulance came. I asked them to leave me there. They picked me up anyway. I could not imagine anyone touching me anywhere on my body, so I asked them to pick me up by my belt. I cannot describe what that felt like. Like a belt made of a red hot strap of metal, searing and slicing into your skin. I should have just died from the pain. I wish I had.

I saw my father then. He was in the ambulance with me on the way to the first hospital. He just turned to me and said, "I'm so sorry, Donnie Boy." I didn't know then that those were his last words to me. My best friend in the world. Now I was alone.

There were doctors and nurses and lots of people over me, sticking things into me, and everything swam around me, a dark sea of acid pain. My mother's anxious presence soon assailed me. I love my mother very much, but without the cushioning of my father, she was just too much for me to take. I heard the doctors talking to her. I would shout, "Just leave me alone! Just let me die!" And of course they turned to her for ratification. I was twenty-five years old, but they deferred to my mother because they did not want to hear what I had to say. They used her.

Ada Cowart

When they first brought Donnie into the hospital, they would not let me come near him. There were doctors and nurses and all manner of people dressed in white swarming around him, but they did not shout at each other like they do in the movies nowadays. They spoke almost in whispers. He was hurt so badly, they did not think that he would survive. I prayed. I asked that if he were to die, that he would at last be reconciled to God, that he realize his responsibility to Him. But it was God's will that he should live, and so he survived. Only, he insisted that he did not want to live. The doctors told me that this was a natural response to severe trauma, the shock of the accident. I knew it was. Donnie always loved life. He would fly airplanes, ride in rodeos; I could not stop him from doing those things, which I felt were dangerous. But he loved them; and there would be nothing I could say to stop him anyhow.

Charles Baxter

Every so often, there comes a patient who does nothing but wear you down. Donnie Cowart was one of those patients. As a doctor, you realize that these individuals are in terrible pain, terrible agony, but you can't help but wonder why they simply cannot accept the care you are there to offer. The shock of the accidents that bring these patients to the hospital does something, causes these distortions to take

place, and sometimes the patients even become delusional. Donnie Cowart was hallucinating as well as delusional. He was convinced that the intern and the nurse were performing experiments on him late at night. But I was later to realize that Donnie Cowart was not typical of this class of patients. There was something even more disturbing than most. There was something I simply couldn't shake. I'm not sure what it was about the whole thing, but I couldn't get him out of my mind, when I lay down to sleep at night.

It was not that I questioned my decision to treat him despite his protests; not at all. I had and have absolutely no doubts in my mind that we did the right thing for Donnie. I'd never accede to such requests to stop treatment so that a patient could die an unnecessary death. But the thorn in my side never left me, while Donnie was under my care.

Dax Cowart

After what happened with the farmer and the paramedics, I guess I never expected any of the medical people to stop treating me just because I asked them to. But it was a shock to me just how they treated me. Every day they took me into the tub room, and they hoisted me onto a tray, like some piece of meat. The radio in the room blared all the time. It wasn't for the patients; it was for them. It was like being a car in a mechanic's shop or something. We patients were just a job for them. I don't think they even listened to the radio. The radio didn't care. It just went on playing music, having talk shows, letting obnoxious disc jockeys terrorize the airways, and always airing those awful commercials. With the radio and the smell of the chemicals and the anticipation of what was about to happen, it really was hell. Nothing in my life, not even Vietnam, prepared me for this. The only thing worse, of course, was being put into the tub itself. Then you didn't hear the radio anymore. I eventually got to the

point where I didn't scream anymore. Still, the pain was the same. You don't get used to it. First you feel the cold. Then slowly, quickly, smoothly, the thousand needles grab your skin and rip it off. I had no skin to rip off anymore, but somehow it managed to feel as if I were losing my skin each time. They'd say nothing, except, "I'm going to turn you over now, OK?" NO!!! They'd do it anyway.

I always found it bitter that they were wasting their time, and getting paid for it, treating someone who didn't want to be treated. Inflicting great pain, moreover. What a horrible waste. What a travesty.

When I was in the Air Force, in Vietnam, I would wonder what it would be like if my plane were gunned down and I was captured and tortured. But I now know that I could never have imagined what torture was like. I have had plenty of pain in my life, in football, or being thrown from horses, or even being stepped on by a large bull. But torture is different. It just never stops. No one acknowledges what they're inflicting on you. They just play that damn radio. It's like in the German concentration camps, where the Nazis would play classical music for their prisoners while they starved and tortured them.

Well no American army will come and save me. I fought for my country only to be tortured upon returning to my own soil. Surrounded by my own family, even. My mother didn't help me; she perpetuated the whole thing by going along with the doctors. I know that she loves me, and that this was the only thing she knew how to do, but, I don't know. We used to fight about this constantly.

"How can you go and talk about God when you keep me in this hell!"

"What are you talking about, Donnie?"

"You know very well what I'm talking about. You just go on and sign those nice forms for the doctors. You don't think I don't notice just because I'm blind!"

“Honey, I know this is hard for you, but we need to listen to the doctors and...”

“You know? What could you know about this? Have you ever been tortured? If you knew what agony I’m in every living second, you wouldn’t come near those forms with a ten foot pole.”

“Oh, Donnie. I’m your mother. You don’t think I don’t suffer to watch you in pain? I would do anything just to take your place. If only it could be me instead of you.”

“If it were you, you would want to die, too.”

“Donnie, you must not talk like that.”

“Why, Mom? Why not? Does it make you uncomfortable or something?”

“You think that this is easy for me? I come to the hospital in the morning, look at you, see how you suffer, listen to you insisting that you want to die, worry about you, go back to my motel room, toss and turn all night, only to start it all again the next day. You don’t know what it is like to be a mother. Your child comes out of your body. You are a part of me, Donnie. You cannot ask me to give up my child. Here I am just losing your father. I’m not supposed to lose my son. Children are supposed to outlive you. That is how it works. Why don’t you just let the doctors help you? You will get well, and you will be happy again. I know that it is hard for you to see how life will be when you get better and get out of the hospital, but it will happen.”

“What are you talking about? This isn’t the flu. I’m not going to ‘get better.’”
I’m a cripple. I’m disfigured. I’m blind.”

Ada Cowart

Oh, I worried about Donnie so much back then. I convinced myself that he really did not want to die, but now I think that maybe he really did want to die. I remember all the fights we used to have.

“Mom, I’m sorry. But can’t you see that there is nothing for me now? You know who I was before. You know that I can’t just change what I like to do. I can’t just learn to enjoy sitting on a streetcorner and selling pencils.”

“Donnie, I know that’s how you feel. The pain is making you crazy. Anyone would be crazy with all that pain you’re in.”

“No, I’m not! I know I’m in pain, I sure know I’m in pain, but I’m not out of my mind. I’m sorry that it’s so hard for you, but I have a right to make my own choices. Look at what’s been going on around us. Women’s Lib and Martin Luther King and Free Speech and all that. Why shouldn’t I be accorded the same rights?”

“Well, dear, I don’t know about all of those things. Things were fine the way they used to be. People had respect for each other. These days people don’t realize their responsibility and they take what they want and do what they want. They have to realize their responsibility to society and to God.”

“You would put me through all of this because I have a responsibility to society to stay alive?”

“And to God. And to your family. If God meant for you to die, you would not have survived the first few days after the accident. How can you ignore that miracle? The doctors did not expect you to live. But you did. And here you go talking about taking your own life. You have no right.”

Rex Houston

They used to fight all the time. About everything. Without the father, they just went at each other all the time. When Ray was alive, he mediated between the two of them. He kept things reasonable. But when he died in the accident, God. I can't believe the things they used to fight about. The thing about the beer in the house after Donnie got out of the hospital. And fighting every day over what he was to wear. And back when he was in the hospital, it was ten times worse. The doctors and nurses would pass me in the hall and just shake their heads. I was expected to deal with it. This was a natural thing for me, anyway, since I am an old friend of the family. It was just that Ray used to do it, so I wasn't exactly used to seeing the full brunt of it. Actually I don't think they ever really fought like that when he was alive. Donnie and Ray spent most of their time in the business, anyhow, so there just wasn't even the opportunity.

But even though I tried to get both of them to be reasonable, at least don't inflame the situation for chrissake, I basically agreed with Ada that Donnie should not be allowed to leave the hospital. He planned to take his life. Even if we were not going to allow him to leave the hospital, he tried to get people to smuggle in guns for him, push him out windows, poison him; you name it. He asked me several times.

"Well I know you want to die. But you just have to think about your family."

"My family will be alright without me. People have to take care of themselves. My mother raised me to be independent. Now that's what I am. I know she can take care of herself, too."

"Listen to yourself. Don't you see how selfish you are being?"

"Look, I am an adult. I don't have to take care of my own mother. Besides, what would I do for her in a state like this? I'll only be a burden to her this way."

"That is maybe wishful thinking on your part. Try to imagine what it would be like for your mother, having lost your father, my good friend and a truly great man, and you, her son, a fine young man in the prime of his life. Try to imagine it."

"Try to imagine losing your sight, part of your hearing, you hands, your skin." Losing things you never even thought of losing. Knowing that you can never again do the things you love. Knowing that you will always have to have someone following after you to help you take care of everything, even your private functions."

"Yes, Donnie, I have given it quite a bit of thought. But it may not be as bleak as it seems. With the money you will make from this settlement, you can have practically anything you want. You can go back to school. You could go back into real estate - hire someone to be your eyes - your father would be so proud."

"Listen to yourself. And my father didn't want me to go through this."

"Of course he didn't. What father wants this for his child? But do you then think that he would want you to go home and put a gun to your head? Do you think he would forgive me if I gave in to your request to put an end to your life?"

We had more than one conversation like that. He was always a talker. I wasn't really surprised when he decided to go to law school later on. I'm sure his father would be exceedingly proud of that boy. He did it. He stuck it through.

Charles Baxter

Sometimes I wonder if I really did want Donnie Cowart to die. Or at least some of the time. I didn't want to be the one responsible for his death, but sometimes I would think, maybe it would be better if he were to die. The burn unit is like a war hospital. All these young people, scarred up into little wretched balls. They all want out, but it's my job to pull them through. What kind of doctor would I be if I didn't? Sometimes I see their faces at night.

Dax Cowart

I could understand my mother not wanting me to die. But the doctors shouldn't have put her in a position of having to make my life-and-death decision. The doctors made up their minds that I should be treated, and they had absolutely no regard for my rights as an individual. Dr. Baxter was especially condescending.

"No, no, you don't want to die, Donnie. It's too painful."

"If I could, I'd kill you with my bare hands."

"What about your mother? What about your family? What about the suit against the pipeline company?"

"That's none of your business."

"It is my business. You are my patient. I care about your well-being."

"Hah! Say that one more time."

"Donnie. Be reasonable. You don't really expect me to discharge you from the hospital so you can go kill yourself, now, do you? Is that what I went to medical school for? To be a murderer? To allow my patients to commit suicide?"

"You went to medical school to inflict pain on unwilling victims."

"Donnie. You don't understand what it is like to be a doctor."

"You don't know what you are doing."

"I know what I'm doing. Believe me."

"Yeah. You just go on believing that."

You know, you say every day that you want to die. I'm not even convinced that you do truly want to die, Donnie. Some patients hold threats over the staff just to get what they want."

"You are calling me manipulative? Who's getting my mother to sign the consent forms I won't sign? What do you call that?"

“You couldn’t sign the forms. Your hands are so badly injured.”

“You know damn well that I wouldn’t sign the forms. You just go on making yourself feel good. You’re going to hold out for the day I come back and thank you for saving my life. Well, I can tell you this: As long as I draw breath, I will never ratify your little justifications.”

“Well, I’ll check on you tomorrow.”

Everything was so strange then. They told me that I was not in my right mind. In a way, I was not. I had strange notions about what was happening to me; dreams and reality were mercilessly intertwined. There were Nazi doctors experimenting on me, there were Viet Minh soldiers poking me with bamboo spears, and day and night had no meaning whatsoever. Sometimes I’d have conversations with my father. To this day I’m not sure if it was just a hallucination or if it really was him.

“Donnie, son; I’m alright. I’m sorry, Donnie boy. I’m sorry. I can’t help you. I’m so sorry. I shouldn’t have been fooling around with the car like that. I thought I knew what I was doing, but I guess I didn’t.”

“No, Dad. It wasn’t your fault. It wasn’t our fault. It was a propane gas leak. It wasn’t our fault. God, I just wish you were alive. This wouldn’t be happening to me if you were around. You’d make them let me go home.”

“No, Donnie. Your mother needs you right now. You have got to be strong. That’s my good boy. You’re tough.”

“What good is it to be tough, when you’re going to be a cripple for life? People will even have to help me to use the toilet. No more rodeo or flying. No more nothing. I’m just a blind, twisted up man who wants to die.”

I have often wondered what my father would have said if he had been alive and participating in the whole debate that happened about my treatment. Would he urge me

to go on with treatment? Or would he bring me a gun? I think that once he realized how serious I was about it, he'd help me. He'd help my mother to accept my wishes.

Charles Baxter

After almost eight months on my burn unit, Donnie was well enough to be a candidate for rehabilitative therapy. We were all very happy. Well who knows about Donnie. He was determined to fail his treatment no matter what.

Dax Cowart

When they transferred me to the Texas Institute of Research and Rehabilitation in Houston, I was immediately struck by the difference in tone. The doctor in charge of my care, Dr. Robert Meier, was young, not much older than me. He asked me what I wanted to do. No one had ever asked me that before. Yet, it turned out not to be so great. I wanted to be discharged home, but they wouldn't do that because I could never survive at home. So instead, they gave me "choices" about my care. Which meant that I got some say in which treatments I got, and not in others.

Robert Meier

Don Cowart. Why'd they have to send him to me? He doesn't want to be rehabilitated. I can understand why he'd feel that way. But if only he could see what I've seen. Patients get a lot of their function back and start enjoying life again. They adapt. These are extraordinary experiences. I don't know what I'd do in their situations. But you just can't deny the evidence. Major improvement is possible. It's a long road, sure, but it's a road.

And then there's his family. His mother and his younger sister. If he dies now, it will essentially be suicide. That's got to take its toll on a family. But who am I

to say anything? I want to rehabilitate the world. But everybody doesn't want my help.

I just wish I didn't have to deal with this right now.

Ada Cowart

They did not let me spend so much time with Donnie in Houston. Since then, I found out that patients sometimes die just because they do not have family around. I wish that I had been more insistent about spending time with him. And I do not want to criticize anyone, but it seems to me that his doctors neglected him there. His condition was always worse and worse each time I went to see him. I tried to speak to his doctor about this.

"Doctor, why are my son's injuries getting worse, when he is supposed to be rehabilitated here?"

"Mrs. Cowart, here at TIRR we don't force patients to be rehabilitated. We ask patients to take an active role in their treatment. Your son has refused the tankings and the range of motion therapy and we cannot force him to do these things."

"But he is dying because of this. What if at some point, Donnie decides that he wants to live, and it is too late to do anything about it?"

"Fortunately, we're not near that point, Mrs. Cowart. We have antibiotics to treat his infections. If his condition gets any worse, though, we'll have to transfer him to another hospital better equipped to deal with his skin infections."

Rex Houston

Donnie Cowart's condition deteriorated rapidly during his time in Houston. Within a matter of weeks, his hands became gangrenous and his body became infected all over. Dr. Meier called us into a meeting to discuss the next course of action. Donnie, not surprisingly, just wanted to go home. Ada would not hear of it. Since it

was her home in question, and since Donnie surely wouldn't survive if he were not to receive intensive medical care, we all agreed to transfer Donnie to the burn unit at John Sealy Hospital in Galveston.

Dax Cowart

Once again, they pretended to make decisions with me but did whatever they wanted. I know that they felt they were doing the right thing, and that they cared about me, but you can never really put yourself in someone else's shoes enough to be able to make decisions for them. Especially when that person is in constant, agonizing pain. You can't imagine what it's like if you haven't gone through it. If you've gone through it, even you tend to forget just how bad it was. A person in pain is a person in a country that no one else can set foot in. And even if you aren't blind and completely immobile, there is simply nowhere you can go. You're exiled to this place and no one can see you. They talk to a surrogate who stands in your place but doesn't truly represent you. You try to translate through this stand-in person, but it doesn't really work. Other people can never know what this country is like, and you can't remember what it is like to be free of pain. You can't remember what it is like to take a walk outside or ride a horse or pet your dog. It doesn't even occur to you to try. Nothing helps you. No one helps you. There is no way to be more alone, than to be in severe pain.

I call out across the abyss
Blackness in blackness
Shadows among shadows
Swirl slowly around
And I call out
And I call out
And no one is there to hear.

Hours and minutes have no meaning, because you have nothing to look forward to. Days pass like decades, and months are centuries. There is only the rhythm of the treatments and the bandaging and unbandaging and then of course the numerous other indignities to which a burn patient is subjected. Then they sit there and tell you it will get better but you simply cannot imagine what a year or two years of this pain means.

Duane Larson

Don Cowart was brought to me after an unsuccessful stint at Texas Institute for Research and Rehabilitation. To this day I can't begin to understand just how Don was allowed to get into the condition he was in when he arrived here. His doctor over there, Robert Meier, apparently allowed Cowart to intimidate him out of doing his job. Now I had to clean it up. It was not just unpleasant; it was an absolute tragedy. His body was overrun by infection and gangrene; there is no telling how this set back his recovery in the long run. He was lucky to even survive. How much of his future functioning level did he lose by having this kind of farce of a treatment? I called Meier one day, shortly after Don Cowart arrived on my unit.

"Why did you let him get like this?"

"At TIRR we don't force patients to undergo treatment they don't want."

"So why are you giving him to us? What are we supposed to do with him? Are we supposed to 'not treat' him too?"

"There was nothing left for us to do for him. He's not rehabilitable in his current condition."

"So you just dumped him on us."

"What am I supposed to say? We couldn't just discharge him home to die of sepsis."

"Yet it's your fault that he is infected in the first place."

"It's really an impossible dilemma. There wasn't any way to really make him better."

"Yes there was. You could have pulled it together and done what was your duty to him as a physician."

"Is that really my duty? To rehabilitate a patient who doesn't want to be rehabilitated? There is only so much you can force a patient to do, even if you are into that sort of thing."

"Christ, you didn't have to get him walking or anything; you could have just kept his wounds clean."

"Perhaps he should never have been transferred to us in the first place."

"Perhaps."

Robert White

Mr. Cowart was introduced to me by Dr. Larson, who was concerned that Mr. Cowart might not be competent to refuse the surgical procedures they proposed for him. After I interviewed Mr. Cowart, I found him fully capable of making an informed decision to refuse treatment. The medical staff were done with me at that point. Their purpose for me was to declare Mr. Cowart incompetent so they could do their surgery with impunity. Really Mr. Cowart's doctors should have been worrying about competence and incompetence many months ago. I believe that Don Cowart was grossly mistreated by his physicians.

I suppose that it is human nature. Doctors don't want their patients to die. When life slips through their fingers, pulled by a non-person, a cancer or massive hemorrhage or overwhelming sepsis, they rage but they cannot direct it at a person.

But when it seems that the patient is the one doing the pulling, their rage is of course directed at that individual. So it was with Don Cowart and Duane Larson.

After deciding all of that, I was not sure what my further role in this matter should be, if any. It was Mr. Cowart's desperate aloneness that compelled me to stay involved. Here was a patient with no advocate. Not even his lawyer was able to fill that responsibility. I tried to convince Dr. Larson to stop treatment, as Mr. Cowart had urged him to do.

"You have no business in this matter. Leave it to us to make the medical decisions."

"At some point the medical decision is up to the patient."

"What are you, a Communist or something? Where did you go to medical school, anyway? What happened to preserving life?"

"I understand that it is difficult to let a patient go."

"Hey. Who's the patient here? Don't you psychoanalyze me, you pink pansy. No one is going to die an unnecessary death on my unit."

I quickly realized that there was nothing I could do directly to change Mr. Cowart's immediate situation. I was out of my jurisdiction.

Ada Cowart

When Dr. White proposed to make a documentary about Donnie that would teach young doctors to let their patients die, I thought that that was immoral. Condoning suicide is wrong. Why did he have to pick Donnie? Dr. White, I felt, was using my son for his own purposes.

He keeps talking about patient autonomy. People just want to do what they want, what they think is best for them. How do they know? We are frail beings; we

do not know what is right for us. Only God can know that. We let our arrogance guide us, and we are led to certain ruin.

Robert White

Mr. Cowart and I decided to make a documentary that would be shown to residents to educate them about the issues of patient autonomy. I worried about my motivations for this. Was I simply using Mr. Cowart to promote my own agenda? On the other hand, this was the first time that Mr. Cowart had the opportunity to work collaboratively with a physician and the first opportunity for him to really be heard. If his own doctors could not hear him, the next generation might.

Dax Cowart

Dr. White and I decided to make a documentary together. At first I felt reluctant to have my disfigured face and my body on display more than it would absolutely have to be. But I realized that if there was to be hope for situations like mine, it was to be had in the future. There is really no way to redeem what I have gone through, but there must be something done to keep other people safe from my experience.

Duane Larson

The psychiatrist, Dr. White, found Donnie Cowart to be competent to make an informed decision to refuse treatment. That didn't mean to me that I couldn't go about trying to convince Donnie to undergo surgery on his hands that would restore a significant amount of function. I went into his room one day to try one more time.

"How are you doing today?"

"I want to die."

"Same as yesterday and all the days before."

"Oh, you get it."

"But I don't get it. Why do you want to force your mother to cope with the death of a child? Why do you ask us to commit murder? You have such a fighting chance at your life, but you don't even want to try.

"What are you talking about, murder? All I'm asking you to do is cease and desist from the ongoing crime you are committing against me, which is holding me and treating me against my will."

"Physicians have a duty to treat their patients. It's not always hunky dory with ribbons and roses. You just have to take it like a man. Hey fella. If you want to die, then let me fix your hands. Let me go and operate on those hands and at least open them up so you can do something with them. And then if you commit suicide, that's your choice and you don't have to drag us into it. If you want to die, do it yourself."

That shocked him. He agreed to the surgery after that.

Dax Cowart

Dr. Larson believes that he talked me into the surgery on my hands. Actually it was a medical student that came and talked to me every day. He obviously wanted me to agree to the surgery.

"I know that you are in pain. But don't throw away this chance. You could get out of this place and become more independent."

"But you don't understand. Before I came into the hospital, I was like you. I had more faith in surgeons. Now, though, I know that they operate on you and they don't tell you that they might not succeed, and they don't tell you what it's like to have your arm in traction and be in even more pain that you started out with."

"Is it pain, the main issue? What if I guaranteed you that you would receive adequate pain control after the surgery?"

“You? You’re just a medical student. They listen to you only slightly more than they do me.”

“What if we were to have a meeting, you, me, and Dr. Larson? See what he says about pain control.”

Well I agreed to talk to Dr. Larson, and he promised me that my pain would be controlled, and then I agreed to the surgery.

Robert White

I continue to be disturbed by Mr. Cowart’s case. A young man with so much going for him despite his injuries, clearly mentally competent, not clinically depressed, wanting to die. Even competent individuals sometimes don’t really mean what they say, although they may think they do. It is possible to be truly conflicted. In Mr. Cowart’s situation, I had to find out whether his expressed wish to die might represent some need, perhaps a need for control over a desperately uncontrollable situation. It is no service to a patient to stop at the surface level of the conversation.

“So you’re saying that I claim to want to die, simply out of a desire for control? You’re not the first to accuse me of being manipulative. It’s not I who is manipulative. It is all of you.”

“No, no, that’s not what I’m saying. I’m talking about something that happens more on an unconscious level. A way to cope with the overwhelming loss of control that these injuries have brought about.”

“Well, it seems to me more logical that I would want to die because every second is an age, with this kind of constant pain that doesn’t let go of you for a moment.”

“If you had adequate pain control, what would things look like then?”

“How can you ask me to imagine such a thing? Pain knows no boundaries. It doesn’t let you feel what it’s like to not be in it.”

“Well in that case, what if we get your pain under control and talk about these decisions then?”

“Okay. That would be alright.”

Dax Cowart

I almost wish I could say that things got better after the surgery and getting discharged from the hospital. After a brief honeymoon period, I was miserable again. Over the next few years, through depressions and several suicide attempts, one psychiatric hospitalization, two tries at law school, a failed marriage, and eventually getting into legal practice, things gradually got better. But I will never cede to a happy ending. None of this suffering was worth the happy life I have now.

Chapter Six: Conclusion

Now I woke up in the middle of a dream
Scared the world was too much for me
Sejarez said
Don't let go -
Just plant the seeds and watch them grow.

Amy Ray⁸²

Did it Work?

The process of writing has led me to conclude that there are major benefits and caveats for creative writing for the purpose of conflict resolution. I will first summarize these briefly and then go on to discuss them in greater detail.

Benefits:

- Creates empathic connections as the writer tries to feel the other person's feelings in order to make the writing ring true.
- Challenges the writer to acknowledge how much or how little she knows of the people about whom she writes.
- Creates space for compassionate detachment.
- Creates space for perspective-holding.

Caveats:

- Extended writing can lead to a confusion of fiction and reality.
- There is a danger that the writer will come to feel that she “owns” the people about whom she writes, that she knows them better than they know themselves.

Separation and Identification

When I first started, the act of writing encouraged me to be honest about the assumptions I was making regarding the person about whom I was writing. I had already discovered this in the process of re-writing patient writeups from the perspective of the patient. While rewriting writeups, I realized how many gaps there were in my knowledge of the person about whom I was writing. It seemed to me that I was thus able to cultivate through this writing a healthy detachment in relation to the person about whom I was writing. It also seemed to me that if I were in an ongoing relationship with the patient, the writing process would encourage me to get more information, to engage with the patient further in order to fill out my picture of him or her.

After a few months of writing about Dax and the other documentary interviewees, however, something shifted. These people have truly become “characters” for me, alive beyond their existence in “real life,” which supposedly is what the documentary represents. Creative writing goes beyond representation to re-creation. This is dangerous. I can only hope that in the actual situation of a physician writing about a patient, the constant checking-in with the real person at hand will help to ameliorate this tendency to take ownership of the person whom the writing supposedly concerns.

On the other hand, this deep identification has allowed me an empathy that I would not have had otherwise. Though I risk sounding extremely crass, I shall name a few of my impressions upon watching Dax's Case for the first time. There was a smoldering thought in me that went something like this: "What a rampantly individualist, white, powerful, Texan man he is. He probably votes against welfare and taxes every chance he gets. They should have let him die just so he could taste the fruits of his philosophy, which is every man for himself." There were many other thoughts kicking around in there, but this was one of the most disturbing. I also thought that Charles Baxter was a complete idiot, self-justifying and abjectly a pitiful excuse for a physician. Ada seemed to me like a paper cut-out Down-South Christian who looked and talked like Edith Bunker from "All in the Family."

These people did not truly exist for me until I started writing. With Dax I became aware of my own fervent desires for independence and self-sufficiency. With Ada I tapped into my relationship with my own mother. As I acknowledged my revulsion toward her seemingly militant Christianity, I realized that I have my own fears of spiritual emptiness and spiritual abandonment and that Ada really needed God at a time like that. With Charles Baxter and Duane Larson I identified some of my own fears of "difficult patients," patients who question your value system and try to get you to go against it.

It is this very process of empathic connection, however, that leads to the creation of "characters" that exist independently of the real people upon whom they are based. The question, I suppose, is, Do you stop at some point, before you get so wrapped up in the characters you create? Or is that entanglement something vital for the whole process of becoming able to hold their perspectives? Again, I hope that in the case of a real relationship, the continued interaction with the real person could help the

writer to weed out the “empathic” connections that were too fictional. In addition, the writer may consider less intensive writing projects that trade some depth of exploration for some better grounding in reality.

Perspective-Holding

With the caveats discussed above, the problems of re-creating characters from real people, this writing experience has convinced me that writing from the fictional points of view of the participants in a conflict does allow a space to be created, an opportunity to tolerate multiple, irreconcilable perspectives.

At this point, however, the question arises as to whether this sort of writing process can be practically applied to real conflicts. For one thing, a physician does not have six months to write a novella about every patient with whom she is in conflict. For another thing, who is to say that such writing works when one is actually involved in the dispute? Is this medicine strong enough to work on the potent mix of real invested feelings that arise in one’s own confrontations?

I can offer only circumstantial evidence to the affirmative. At the beginning of this semester, I accepted a position as a graduate student instructor of an undergraduate course where I am responsible for grading four essays submitted by fifty-two students. To my great consternation, one student has bitterly contested my grading of three of his four essays. I have felt bulldozed, intimidated, and manipulated by this person. I have cursed my job almost every day this semester, partly because of my interactions with this individual. Recently, something has shifted as I have realized that this is just a conflict between two irreconcilable perspectives, his and mine. I decided to write from his perspective:

That TA for my MCB class. I have tried so hard. She gives me a B every time. First she said I didn’t talk about the readings good enough. So then I talked

about the readings, and then she said it wasn't organized well enough. It was well-organized. She said I wrote a well-organized paper the first time. This one is no different. She just has it in for me. She just doesn't like me because I'm an uppity person of color. I can tell she hates me. She gave me this look last time in section. She wishes I would just disappear. If only she could see how hard I try, how badly I want an A. Nothing else really matters. This stuff about learning is all bullshit. I know all I want to know already. I just want to do well in school so I can do well afterward. I'm the first person in my family to go to college. I want to make something of myself. But I have to encounter racism at every turn. The professor is no help either. I talked to him about her, but he just shrugs his shoulders and says I should go talk to her. I already talked to her. Many times. She doesn't listen. She cuts me off. She cut me off in class, too. She treats me like a child. I'm older than she is. I have seen so much. I have watched people die. I have worked my way through school. She doesn't know anything about me.

It was hard to write that, to imagine what I might look like from his perspective. But there had to be some way to equalize us. I have had a tendency to pathologize him, to put him into the "poor, wretched, difficult patient" stereotype. It has been easier to pity him than anything else. There has always seemed to be so much pathos in what he says to me; in how, for example, he can only repeat his arguments over and over, hoping that I will just drop from exhaustion and let him have his way. But there is more to it than that. To him I must seem incredibly erratic, since my comments on his papers have been so different each time. To me it is easy to say that he should put the considerable energy he puts into trying to wear me out, into writing better papers. But if he could do that, perhaps he would redirect his energies. I have been convinced that he is incredibly stubborn, and that the reason his papers have not improved is that he does not want to change his ideas or style. From his perspective, I suppose, he does not want to give up his thoughts just for me, just to match my ideas of what constitutes

a good paper. If only I could see things his way, I would change his grade. This, I believe, is his reasoning. His way of thinking is precious to him, and he does not want to lose that for anything.

That perspective seems valid to me, at least partly. But I will not grade according to multiple standards. I continue to hold my own perspective, that the most important thing in grading is to be consistent and fair and to be true to what I think constitutes a good paper. I don't even really like the idea of assigning grades to papers, especially when I have to make the grades fit a curve around a B every time. But if I am going to give grades, and especially if I am going to be constrained to a curve, it is important to me to not be swayed by intimidating students. It is an interesting idea, to grade papers by each student's own standards, but it does not seem tenable to me at this time.

I have felt better ever since looking at it this way. My biggest fear is not too far from what seems to be his biggest fear: a loss of integrity. I will be true to my own perspective by not changing my grading policies, and I will try to continue to hold his perspective and mine in my interactions with him. Things would be a lot easier if I weren't so afraid of losing my own perspective. It seems to me that the knowledge that it is possible to hold both perspectives has helped ameliorate this fear.

OK, So Now What?

Now that I have extolled the virtues of creative writing in medical conflict resolution, I can offer a few recommendations. 1) Institute more creative writing programs in medical schools. 2) Perform empirical studies to assess the benefits of creative writing for conflict resolution in treatment decisions. 3) Create informal

writing groups for physicians. 4) Consider getting patients and their families involved in the creative process.

Creative Writing Programs in Medical Schools

Creative writing should be offered as an elective class at more medical schools. There are as many ways of running these as there are ways of doing creative writing, but one tried and true method is that of Guy Micco's Narrative and Medicine class discussed in Chapter Three. An informal approach has worked well for the Narrative and Medicine class, since such an environment encourages creativity, openness, and honesty. Guy recently asked us to write about why we should write. No one else really wanted their piece to be put into my thesis, so I'll just share mine:

Writing is something strange, a journey through parts of your brain you might not use otherwise, a borderland between conscious and unconscious, a way to sleep when you are awake. Something about communication, about communing with all beings who have a language, because if you can write it, it isn't just yours anymore. If you can write it, it is in some way universal.

Empirical Studies

Personally I am convinced that creative writing is so valuable to the physician that the implementation of additional creative writing classes in medical schools would be well worth the time, money, and effort. I realize, however, that it might be helpful to first do empirical research into the question as to whether creative writing actually helps physicians in conflict resolution and/or perspective-holding.

I am wary, though, of excessive investment into finding empirical evidence of the efficacy of creative writing. On the one hand, it would be far too easy to make such a study say whatever you wanted it to say. On the other hand, I am convinced that

there are forms of truth that are inaccessible to the empirical gaze. The effect of creative writing may well be one of those.

With these caveats in mind, I recommend “intervention studies” in which physicians and/or medical students participate in creative writing programs and undergo some sort of assessment of their perspective-holding and/or conflict resolution skills. A few more caveats, in a different vein: It would be very difficult to control for confounders if we are comparing these people with themselves before the program, the most obvious of which is the effect of the life/professional experience that would be accruing as the writing program went on. An alternative would be to compare the program participants with their peers; but then, of course, there is the problem of selection bias. One might consider the option of forcing everyone in a particular school or hospital into the study, with half randomly assigned to write and the other half assigned to serve as control. This would be fraught with major ethical problems, of course.

A milder option would be to recruit as many people as possible into the study and then randomly assign them to writing program or control. This is perhaps the best alternative, but even here there is the problem that people willing to participate in a study such as this might tend already to be writers and still opt to write on their own despite being assigned to the control group.

Physician Writing Groups

A lower-budget alternative or adjunct to medical school writing classes is informal physician writing groups. Such groups need not meet more than, say, two hours every other week, which is what the Narrative and Medicine group does. Thus, it is a fairly small time investment into what turns out to be largely a recreational

activity. Writing groups not only allow the sharing of perspectives, the breaking down of internal critics, and the catharsis of day-to-day difficulties, but they are also a lot of fun.

Patients and Families

Everyone involved in treatment decision-making conflicts could benefit from the cultivation of the perspective-holding skill. I would like to extend my recommendations not only to nursing and other health care staff but also to the patients and their families themselves. It is much harder to propose a systematic approach to patients and families than it is to propose one for health care workers, since patients and families exist as patients and families for much shorter and intense periods of time and come from a greater diversity of educational background than do health care personnel. Nevertheless, a number of options arise. One is in-hospital workshops for patients and their families that employ creative writing and other modes of expression. Another is for physicians, chaplains, social workers, or other personnel to bring the “workshop” to the families on an individual basis. Perhaps people could be asked to write from the perspective of the patient, another family member, or the physician. Responses could be rendered as anonymous as possible, with a third party reading the responses aloud to the group. Yet another option is to expand the second endeavor to include modes of expression with which the members of that family may be more familiar. Role-playing, oral storytelling, music, drawing, sculpture, and meditation are among the possibilities.

Beyond Perspective

In addition to the need for perspective-holding in the resolution of treatment decision-making conflicts, there exist many other needs as well. Adequate space and

time needs to be allocated for discussion in hospitals among health care providers, patients, and patients' families. Financial pressures that impinge upon treatment decision-making conflicts need to be addressed, but they must be addressed in such a way that does not, as it does now, tend to coerce patients, families, and physicians into curtailing treatment before it may be emotionally or even medically appropriate.

At any rate, the crying need for both internal (e.g. perspective-holding) and external (e.g. time and space) conflict resolution tools gives us the opportunity to hold these multiply perceived needs as we would hold any other perspectives.

Notes

¹ Thich Nhat Hanh, Being Peace, Parallax Press, 1987. Reprinted in Levine, Stephen. Healing into Life and Death. New York: Doubleday, 1987, pages 86-87.

² Donald Herbert Cowart changed his first name to "Dax" in 1982.

³ Concern for Dying, Inc. Dax's Case. Unicorn Media, Inc., 1985.

⁴ Prendergast, Thomas J., and John M. Luce. "Increasing Incidence of Withholding and Withdrawal of Life Support from the Critically Ill." American Journal of Respiratory Critical Care Medicine 155 (1997): 15-20.

⁵ Prendergast, T. J. "Resolving Conflicts Surrounding End-of-Life Care." New Horizons 5.1 (1997): 62-71.

⁶ SUPPORT Principal Investigators. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." JAMA 274.20 (1995): 1591-1598.

⁷ Anstey, Mark. Negotiating Conflict: Insights and Skills for Negotiators and Peacemakers. Kenwyn, South Africa: Juta and Co, Ltd., 1991. I have modified this approach somewhat to tailor it more closely to treatment decision situations.

⁸ Clouser, K. Danner. "Humanities in Medical Education: Some Contributions." The Journal of Medicine and Philosophy 15 (1990): 289-301. Page 290.

⁹ Freed, Peter. Personal communication, April 1998.

¹⁰ Good, Byron J. Medicine, Rationality, and Experience. Cambridge, England: Cambridge University Press, 1994. Page 5.

¹¹ D'Amico, Robert. Historicism and Knowledge. New York: Routledge, 1989. Page x. Quoted in Good, page 6.

¹² Cf. Good, Chapters 1 and 4.

¹³ This section is based on Dax's Case and on Burton, Keith. "A Chronicle: Dax's Case as it Happened." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 1-12.

¹⁴ White, Robert B. Please Let Me Die: The Wish of a Blind Severely Maimed Burn Patient. Department of Educational Television, University of Texas Medical Branch, 1974).

¹⁵ In a recent article, Dax tells us that his decision to consent to surgery actually resulted from repeated conversations with a medical student, who helped him to get Duane Larson to promise that postoperative pain control would be adequate. Cowart, Dax, and Robert Burt. "Confronting Death: Who Chooses, Who Controls? A Dialogue between Dax Cowart and Robert Burt." Hastings Center Report 28.1 (1998): 14-24.

¹⁶ Cowart, Dax, and Robert Burt. "Confronting Death: Who Chooses, Who Controls? A Dialogue between Dax Cowart and Robert Burt." Hastings Center Report 28.1 (1998): 14-24.

¹⁷ Engelhardt, H. Tristram Jr. "Freedom vs. Best Interest: A Conflict at the Roots of Health Care." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 79-96. Page 87.

¹⁸ Engelhardt, pages 87-88.

¹⁹ Engelhardt, page 88.

²⁰ Childress, James F. and Campbell, Courtney C. "Who is a Doctor to Decide Whether a Person Lives or Dies? Reflections on Dax's Case." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 23-42. Page 29.

²¹ Winslade, William J. "Taken to the Limits: Pain, Identity, and Self-Transformation." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 115-130. Page 121.

²² Childress and Campbell.

²³ Quoted in Childress and Campbell, page 32.

²⁴ Quoted in Childress and Campbell, page 34.

²⁵ Childress and Campbell, page 25.

²⁶ White did not, however, actually oppose the cessation of treatment.

²⁷ Quoted in Childress and Campbell, page 32.

²⁸ Childress and Campbell, page 37.

²⁹ Childress and Campbell, page 35.

³⁰ Childress and Campbell; Engelhardt.

³¹ Childress and Campbell, page 36.

³² Engelhardt, page 90.

³³ Engelhardt, page 91.

³⁴ Cowart and Burt.

³⁵ May, William F. "Dealing with Catastrophe." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 131-150. Page 132.

³⁶ May, page 140.

³⁷ Johannesen, Stanley. "On Why We Should Not Agree with Dax." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 169-186. Page 172.

³⁸ Johannesen, page 175.

³⁹ Johannesen, page 179.

⁴⁰ May, page 132.

⁴¹ May, page 139.

⁴² May, page 133.

⁴³ May, page 133.

⁴⁴ Kliever, Lonnie D. "Dax and Job: The Refusal of Redemptive Suffering." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 187-211. Page 191.

⁴⁵ Kliever, page 197.

⁴⁶ Kliever, page 207.

⁴⁷ Childress and Campbell.

⁴⁸ Childress and Campbell, page 38.

⁴⁹ Cowart and Burt, pages 14-15.

⁵⁰ All quotes from conflict participants, unless otherwise indicated, are taken from Dax's Case.

⁵¹ Winslade, page 120.

⁵² White, Robert B. "A Memoir: Dax's Case Twelve Years Later." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 13-22. Page 18.

⁵³ Winslade, page 121.

⁵⁴ Childress and Campbell, page 38.

⁵⁵ White, 1986, page 17.

⁵⁶ Burt, cited in Childress and Campbell page 39.

⁵⁷ Winslade, page 121.

⁵⁸ Zaner, Richard M. "Failed or Ongoing Dialogues? Dax's Case." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 43-62. Page 57.

⁵⁹ Zaner, page 53.

⁶⁰ Cowart and Burt, page 15.

⁶¹ Zaner, page 53.

⁶² Zaner, page 55.

⁶³ Zaner, page 55.

⁶⁴ Gadow, Sally. "Remembered in the Body: Pain and Moral Uncertainty." Dax's Case: Essays in Medical Ethics and Human Meaning. Ed. Lonnie D. Kliever. Dallas, TX: Southern Methodist University Press, 1986. 151-168. Page 153.

⁶⁵ Gadow, page 154.

⁶⁶ Gadow, page 155.

⁶⁷ May, page 146.

⁶⁸ Gadow, page 156.

⁶⁹ Zaner, page 50.

⁷⁰ Zaner, page 51.

⁷¹ Whorf, Benjamin Lee. "Science and Linguistics." Language, Thought, and Reality: Selected Writings of Benjamin Lee Whorf. Ed. John B. Carroll. Cambridge, MA: The M.I.T. Press, 1940. 207-219. Page 213.

⁷² Good, page 90.

⁷³ I have edited out the paraverbal content of the transcript. I have also deleted an interjection by the woman's friend. The text in brackets is the interviewer's question.

⁷⁴ Good, page 94.

⁷⁵ Good, page 94.

⁷⁶ Good, page 101.

⁷⁷ White, 1986, page 17.

⁷⁸ White, 1986, page 19.

⁷⁹ White, 1986, pages 13-14.

⁸⁰ It would even be quite straightforward to separate Charles Baxter and Duane Larson's perspectives, but I have refrained from doing so for the sake of simplicity.

⁸¹ This writing is loosely based on Dax's Case and on Please Let Me Die. Anything not directly attributable to these documentaries is fiction.

⁸² Ray, Amy. "World Falls." Nomads, Indians, Saints. Indigo Girls. New York: CBS Records, Inc., 1990.